A study of social support and delay of treatment among African-American patients diagnosed with Hodgkin's and Non-Hodgkin's Lymphoma

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ABSTRACT

SOCIAL WORK

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A STUDY OF SOCIAL SUPPORT AND DELAY OF TREATMENT AMONG
AFRICAN-AMERICAN PATIENTS DIAGNOSED WITH HODGKIN’S AND
NON-HODGKIN’S LYMPHOMA

Advisor: Dr. Margaret Count-Spriggs

Dissertation dated December 2006

This study examines the influence social support has on delay of treatment among
African-American lymphoma patients. One hundred nineteen (119) social work
assessments were collected from medical records utilizing nonprobability sampling.
Data were extracted from the social work assessments of lymphoma patients considered
for or having had bone marrow transplantation. The measurement tool was designed
based on survey information from the Supportive Care Needs Survey, Social Support
Behaviors Scale and the Social Support Survey Instrument. The findings of the study
indicated that, overall, social support did not significantly influence delay of treatment.
However, there were statistically significant relationships among social worker support
and delay, gender and delay, and type of lymphoma diagnosis and delay for bone marrow
transplantation. A large percentage of the patient population who may have been
considered for bone marrow transplantation did not receive social work assessments and
could have experienced delay associated with limited social support. Further research
should be conducted on why this population did not receive social work assessments and comparisons should be made to the population that did in order to examine group differences.
A STUDY OF SOCIAL SUPPORT AND DELAY OF TREATMENT AMONG AFRICAN-AMERICAN PATIENTS DIAGNOSED WITH HODGKIN’S AND NON-HODGKIN’S LYMPHOMA

A DISSERTATION

SUBMITTED TO THE FACULTY OF CLARK ATLANTA UNIVERSITY

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

BY

RONI M. GLOVER

WHITNEY M. YOUNG, JR., SCHOOL OF SOCIAL WORK

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CHAPTER I

INTRODUCTION

Receiving a diagnosis of cancer can be shocking. Cancer survivors report that after having heard the diagnosis, not much else during the consultation is heard. The diagnosed person may often enter into a state of denial or begin to have fatalistic thoughts. Experiencing stress when given a diagnosis of cancer is a common and understandable reaction. Patients immediately begin to process thoughts on what may happen to their bodies, how their families will cope with the cancer experience, what the future will bring for their children, and harbor fears of dying (Harpham, 2003).

A psychological, spiritual, and intellectual evolution must occur before decision-making about treatment can begin. Some patients may process quicker than others and prepare to make treatment decisions promptly. For others, deciding to take the next step toward treatment decision-making may be too difficult, which may lead to a significant delay in care.

Delay in care can be costly in many ways and allowing a potentially aggressive disease to rapidly progress without treatment may result in undesirable health outcomes. The African-American community must be cautioned. Following heart disease, the second leading cause of death for African-Americans is cancer. Joiner (2004) examined issues concerning African-Americans and cancer mortality and stated that in the early
1990’s, 60 percent of Caucasians and only 44 percent of African-Americans met the five-year survival rate for cancer. Factors that may jeopardize the health of the African-American community and that have been identified as contributors to racial disparity in cancer are unequal access to quality medical care, lower socioeconomic status, diets that are high in fat and low in fiber, and overexposure to toxic wastes and air pollution in urban areas.

Social work assessments have been collected, for the past ten years, at a local hospital, on lymphoma patients whose treatment recommendations included bone marrow transplantation. These patients would have been diagnosed with one of three particular types of lymphoma usually treated with bone marrow transplantation, namely, relapsed follicular non-Hodgkin’s lymphoma, relapsed Hodgkin’s lymphoma, and relapsed diffuse large B-cell non-Hodgkin’s lymphoma. There are other types of lymphomas that may be treated with bone marrow transplantation and those will be included in this investigation. This study will take advantage of a unique opportunity to investigate the role social support plays in motivating patients to seek needed treatment without unsafe postponements; to explore which of the three types of social support – emotional, informational, and instrumental – may play a larger role in encouraging compliance; to address the issue of disparity in cancer incidence and mortality of the African-American community; and to add to the knowledge of bone marrow transplantation patients and their social support needs.

Social workers, who practice in the field of oncology, are dedicated to providing supportive care to cancer patients with a variety of needs. Though research on cancer has been conducted for decades, and the challenges of understanding and treating cancer are
still critical, cancer statistics are daunting for the African-American community, as well as statistics on other serious chronic illnesses. Health disparity research is prevalent and efforts to address and resolve urgent health issues of late-stage diagnoses and medical noncompliance continue. Social workers are charged with providing multifaceted services to their patients on the clinical, administrative, educational, and advocacy/liaison levels. Social workers at many hospitals pay especially close attention to bone marrow transplantation patients because of the additional care required in treatment that may result in severe complications, and they aim to facilitate healing environments for cancer patients, through the identification and attainment of various types of social support already confirmed, by study findings, to be beneficial to health outcomes.

Limited research is available on African-Americans diagnosed with lymphoma and considered for bone marrow transplantation. This study aims to provide further understanding of what the particular needs are of African-American bone marrow transplantation patients in relationship to social support. In addition, the study will explore the support needs of bone marrow transplantation candidates and/or recipients. Determining effective social work interventions to address current challenges and supportive needs of this population may be extended to other identified urgent care needs of the African-American community.

During 1996 and 2000, the cancer incidence rates or number of new cases for African-Americans were the highest among the racial groups, with 696.8 African-American males per 100,000 cases per year and 406.3 African-American females per 100,000 cases per year. Cancer death rates are also the highest among the African-American community, with 356.2 males per 100,000 cases per year and 198.6
females per 100,000 cases per year. Differences in exposure, access to screening, and quality care are factors that may contribute to incidence and mortality variants (National Cancer Institute, 2005).

In 2005, approximately 1.4 million new cancer cases and 570,000 deaths due to cancer were expected in the United States. African-American men and women have 40 percent and 20 percent higher death rates from all cancers than Caucasian men and women. African-American women have lower incidence rates while African-American men have a 24 percent higher incidence than Caucasians. Minority populations are more likely to be diagnosed with advanced stage disease than are Caucasians (A Cancer Journal for Clinicians, 2005).

When African-Americans receive the diagnosis of cancer, they are more likely to present with cancer at a distant stage rather than localized stage. Cancer at the more localized stage is easier to treat. For almost every type of cancer, five year survival is lower among African-Americans than in Caucasians. Joiner (2004) reported that African-Americans experience similar disease outcomes as Caucasians when they have equal access to quality cancer treatment.

Obtaining quality health care can be a challenging endeavor for African-Americans. In particular, for stem cell transplantation, physicians are the major decision-makers on which patients make good transplantation candidates. Selection criteria for all transplantations and the availability of matching donors for allogeneic transplantation can compromise health outcomes for African-Americans, if they are not deemed good candidates. Not having adequate social support, or possessing a history of smoking or substance abuse are other possible criteria that can deselect a patient with any
serious chronic illness from receiving technologically advanced or special medical
treatments associated with high risks for complications. Freeman (2006) is concerned
that kidney transplants and surgery for early-stage cancer of the lungs, colon, and breast
are not appropriately recommended or provided to African-Americans as readily as these
treatments are accessible to Caucasians.

African-Americans make up 12 percent of the U.S. population but the incidence
and mortality rates for many chronic illnesses among African-Americans are alarmingly
disproportionate. Technology and research have made significant advancements in
medicine but these potential technological benefits have not adequately reached the
African-American community.

African-Americans still rely on the ancient African teaching of “God force is
our life force” (Chissell, 1993, p. xxvi). Health care professionals must be conscious
of these beliefs and values and charged with providing culturally sensitive care to
African-American patients. The push from major national organizations for researchers
to conduct health disparity studies indicates that many of the already identified barriers to
treatment remain unaddressed and knowledge on how to remove the barriers must be
obtained.

African-Americans diagnosed with cancer may delay seeking recommended
treatment that, unfortunately, significantly impacts quality of life, but offers a good
prognosis. Having little trust in receiving appropriate medical care and fearing the cost
of treatment for serious illnesses may cause delay or noncompliance. The reasons for
their delay may or may not be rational but surely cannot be ignored.
Having access to supportive social interactions facilitates emotional stability and encouragement to pursue necessary medical care. Cancer patients possessing positive social support systems are motivated to comply with treatment recommendations. Health care professionals are becoming more aware of the study results that advocate and support the beneficial influence of positive social support systems, formal and informal, on patient compliance. Research findings have indicated that social support improves overall well-being. These studies, however, generally utilized middle-class, Caucasian people for research subjects. Not much is known about African-American social support experiences. Research has traditionally been designed and conducted with the assumptions that most people share similar beliefs and values in the United States (Hamilton, 2004).

Statement of the Problem

African-American men and women who have been diagnosed with cancer are presenting for detection and treatment at later stages of the disease, which cancer statistics indicate, significantly affects disease outcome. The identification of social factors that influence the timely initiation of recommended treatment will be examined.

Purpose of the Study

The purpose of the study is to examine the influence social support, specifically emotional, instrumental, and informational, has on delay in the treatment of lymphoma patients considered for bone marrow transplantation. Data extracted from the medical records of African-American patients who have been diagnosed with relapsed
lymphomas and considered for bone marrow or stem cell transplantation at metropolitan Atlanta, Georgia hospitals will be used in this study.

Research Question
The research question for the study is as follows:

Does having access to emotional, informational, and/or instrumental support decrease the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment?

Hypothesis
The null hypothesis for the study is as follows:

There is no statistically significant relationship between emotional, informational, and/or instrumental support and the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment.

Significance of the Study
This study purports to shed some light on the problems related to disease outcome of African-American patients diagnosed with cancer or other serious chronic illnesses and investigate the influence social support has on health outcome.

The perplexing issue is that while diagnosing and recommending treatment for serious chronic illnesses among people from diverse cultures, health care teams must be aware of the many potential treatment barriers in order to make medical services as accessible as possible.
This may be difficult to accomplish without the expertise of social workers. Social work in health care must be recognized as providing primary and holistic services that transcend settings, supporting diversity and helping to strengthen the dyad of individual and community well-being (Lowe, 1997).
CHAPTER II
REVIEW OF LITERATURE

This chapter is a review of the current literature related to this study. The intent is to develop a better understanding of how to promote more timely access to cancer care among African-Americans. This chapter is divided into seven sections. The sections are an overview of cancer; national and Georgia trends for lymphoma; clinical description of lymphoma, including description of relapsed Hodgkin’s, diffuse large B-cell, and follicular lymphomas; treatment delay; social support; social work and oncology; and theoretical framework.

Cancer

Prior steps to substantially reduce the burden of cancer among African-Americans have been insufficient. There are over 35 million African-Americans, descendants of persons from Africa who were involuntarily relocated to the United States and the Caribbean, during the African diaspora of the 17th to 19th centuries. If diagnosed with cancer, members of this population can expect to have poorer 5-year survival than other Americans (Underwood, 2003).

In a health behaviors survey of 1,253 African-Americans in several Alabama churches, the majority of respondents indicated they believe in destiny. With serious chronic health issues devastating the African-American community, the study findings
addressed the importance of developing health education and motivational interventions specifically for African-Americans. African-American health behaviors should be further researched in order to identify more appropriate and effective interventions (Green, et al., 2003).

In a report by the Chairman on the National Cancer Institute’s President’s Cancer Panel, a moral doctrine was advanced by patients and professionals in attendance at a series of panel sessions held in 2000 and 2001: no person in America with cancer should go untreated, experience insurance-related diagnosis or treatment delays that jeopardize survival, or be bankrupted by a cancer diagnosis (NCI, 2000-2001, p. i).

The American Cancer Society (ACS) is a voluntary health organization with national and international involvement that focuses on the prevention of cancer through research, education, advocacy, and patient services. The ACS celebrates more than two million volunteers, is recognized as the largest source of private, nonprofit cancer research funds (several billions) in the United States; and its advocacy efforts include the improvement of access to health care services for all Americans, as well as, protecting the rights of cancer survivors (American Cancer Society, 2005).

In 1995, the ACS established the Behavioral Research Center (BRC) with the aim of expanding research and focusing on supporting oncological, psychosocial and behavioral research. The BRC investigates the cancer experience from the aspects of prevention, screening, treatment, survivorship, and end-of-life concerns, paying special attention to those who may experience disparities. The BRC has three basic functions:

1. To conduct original psychosocial and behavioral research on cancer;
2. To provide consultation to other parts of the ACS; and
3. To carry out research that will provide the transfer of behavioral, psychological, and policy-knowledge and theory to improve cancer control practices (ACS, 2004, Research Program & Funding page).

Several BRC research projects exists that all appear to have similar goals of describing unmet needs of cancer survivors and focusing on psychosocial adjustment, quality of life, and survivorship concerns. These major American institutions are recognizing, through the initiatives they have set forth, serious issues of access to quality care among certain groups in this nation (ACS, 2005).

National Trends for Lymphoma

In the United States, lymphoma represents five percent of all cancers. An estimated $5 billion per year is spent on treatment and close to $120 million per year is spent on lymphoma research. The two types of lymphoma are referred to as non-Hodgkin’s (NHL) and Hodgkin’s lymphoma (HL). Annually, approximately 8,000 new cases of HL will occur and 1,400 deaths are predicted. Overall mortality has more rapidly decreased for HL than for other cancers, due to radiation and chemotherapy treatment effectiveness. The disease is more common in men than women and, in people ages 15 through 34 and older than 60 (NCI, 2005).

In the United States, the incidence rate from 1995-1999 for HL among African-American men was 2.7 per 100,000 compared to 3.4 per 100,000 for Caucasian men. For African-American women, the incidence rate was 13.3 per 100,000 compared to 19.3 per 100,000 for Caucasian women. During the same time span, the mortality rates were 8.5 and 5.1 for African-American men and women compared to 11.8 and 7.9
for Caucasian men and women. Much closer attention should be given to the presence of lymphoma in the African-American community. Comparison rates are alarming for the African-American community, which is just 12 percent of the total United States population (NCI, 2005).

The incidence for NHL has been rapidly increasing, approximately 73 percent between 1973 and 1991. The current U. S. rate is 15.1 cases per 100,000 people (Kallab, 2002).

This rate has risen per 100,000 persons from 11.1 in 1975 to 19.0 in 2000. Even considering statistical findings that HIV infection increases the risk of NHL, this does not adequately explain the overall increase of incidence rates of NHL. During the past decades, this increase for NHL exceeds the increased incidence for all other types of cancer except melanoma and lung cancer. While the etiology for melanoma and lung cancer is known, the etiology for NHL is not (Groves, et al., 2000).

It was estimated that 53,400 new cases of non-Hodgkin’s lymphoma (NHL) were diagnosed and 23,400 patients would die from NHL in 2003. The etiology of NHL has been associated with the use of hair-coloring products, pesticides, cigarette smoking, alcohol consumption, and blood transfusion. Further research is needed to confirm these associations (Zhang, 2004).

Exposure to hazardous occupational conditions among African-American men has been found to be disproportionate and that these men may have been exposed to chromium, an established human carcinogen that has been linked with close to a four-fold increase in the risk of NHL. This study on race-specific occupational risk factors, which utilized questionnaires administered by professional interviewers, included
959 subjects who worked in jobs with high risk exposure to chromium (chromate industry), wood dust (saw mills), and pesticides. African-American men also had increased risk for HL due to wood dust exposure but there was not the same risk for Caucasian men (Briggs, 2003).

African-American to Caucasian NHL incidence ratios for 1995 to 1999 were 19.9 per 100,000 to 24.5 for males and 11.2 per 100,000 to 16.5 for females. The mortality ratios for African-American to Caucasian were 7.8 per 100,000 to 11.2 for males and 4.7 per 100,000 to 7.5 for females (Ghafoor, et al., 2006).

The five-year relative survival rates for NHL from 1995 to 2000, were 51 percent survival for African-Americans and 60 percent survival for Caucasians. African-Americans have less likelihood of surviving five years after diagnosis than Caucasians (ACS, 2005).

Georgia Trends for Lymphoma

In the State Cancer Profiles for Georgia, the five year rate changes in mortality for African-Americans with NHL (1998-2002) were rising at 2.8 compared to the falling rates for breast, prostate, and lung cancer. In Atlanta, Georgia, the five year rate changes in African-American mortality for the same years were rising at 5.7. There were no local incidence and mortality statistics available for follicular, Hodgkin’s, and diffuse large B-cell lymphomas (State Cancer Profiles, 2006).

Clinical Features of Lymphoma

There are two groups of cancers (HL and NHL) that occur in the lymphatic system. This system, which protects the body from infection, is made of vessels that
branch into the tissues of the body. The vessels contain a watery fluid consisting of lymph and lymphocytes, which are infection-fighting cells. Lymph nodes are small organs that are located throughout the lymphatic system and they can be found in the groin, chest, neck, underarms, and abdomen (NCI, 2005).

For both types of lymphoma, cells in the lymphatic system divide too quickly and grow without appropriate control. The lymphatic tissue is located throughout the body, which allows for HL to present anywhere within the body. This disease is known to systematically spread, moving from one group of lymph nodes to another. HL is responsible for less than 1 percent of all cancer cases in the United States. There are different types of HL. The etiology is unknown and health care professionals find it difficult to predict who will or will not develop the disease. Clinicians and researchers do know that the disease is not contagious nor is it caused by shock or trauma. HL can be cured and/or controlled for many years (NCI, 2005).

NHL is the sixth most common cancer. NHL starts in the lymphatic system and spreads to other organs. The prognosis depends on the type of NHL, stage of the disease, and treatment. There are many different types of NHLs, which are categorized by two prognoses. If the NHL is indolent, then the prognosis is good and the patient has a survival rate of approximately ten years. If the NHL is aggressive, which is occurring more frequently in HIV-positive patients, the survival rate is approximately five years. Thirty-six percent of patients with aggressive NHL can expect to be cured (NCI, 2005).

In a study examining the impact of HIV infection on NHL, African-Americans with HIV/AIDS were found to have lower incidence rate of NHL but with the same disease combination among this population, the death rates have significantly increased.
Particular focus on HIV/AIDS and the African-American community is becoming more important. Diffuse large B-cell lymphoma is another type of lymphoma seen in people with HIV/AIDS. Special effort should be taken to bring awareness about the complications of these diseases (Hooper, et al., 2001).

A fine needle aspiration of fluid from the cancer site and/or a biopsy which is the removal of a sample of tissue followed by microscopic examination to see whether cancer cells are present, are utilized to help ascertain a diagnosis. Blood tests, scans, x-rays, and bone marrow samples are also collected (NCI, 2005).

The process of staging the disease is the determination of the extent to which the cancer has spread from its original site to other parts of the body. If there are additional medical problems caused by the cancer, further assessment will also occur at this time. Information is provided to the patient about how quickly treatment should start, and best recommendations on the treatment choices are provided. It is important to note that staging procedures may cause treatment delay (Harpham, 2003).

The stage of lymphoma indicates the number of groups of affected lymph nodes, where they are located in the body, and the identification of other organs that may be affected such as the bone marrow:

Stage 1 – The lymphoma is in one group of lymph nodes in one specific area of the body

Stage 2 – The lymphoma is in more than one group of lymph nodes, but all the affected nodes are contained within either the area above the diaphragm and below the diaphragm of the body

Stage 3 – The lymphoma is in lymph nodes above and below the diaphragm

Stage 4 – The lymphoma has spread beyond lymph nodes to other parts of the body (CancerBACUP, 2005).
Treatment

There are several methods of treatment for cancer for which the National Comprehensive Cancer Network (NCCN) has standardized. Surgery, which is the removal of a tumor by excision, is a common treatment method. Medicines such as anticancer drugs, hormone-blocking/supplementing drugs, and drugs that support the immune system are utilized. Steroids are often used to reduce feelings of sickness. There are a number of chemotherapeutic drugs that are often used in combination with supportive treatments. Biological therapy such as immunotherapy aims to strengthen the immune system to help fight cancer. Biological therapy employs such agents as interferons, interleukins, colony stimulating factors, tumor necrosis factors and monoclonal antibodies. Monoclonal antibody therapy is another treatment that uses the drug known as rituximab. This treatment is usually given with chemotherapy as part of a common regimen called CHOP-R, which uses the following combination of drugs: doxorubicin, cyclophosomide, vincristine, prednisolone with rituximab. Treatment with high-energy radiation is an important cancer therapy. Radiotherapy is the use of high-energy rays to destroy cancer cells while doing as little harm as possible to the healthy cells. It may also be given in addition to chemotherapy. A combination of all treatment methods is utilized depending on the diagnosis and staging (NCCN, 2005).

Bone marrow transplantation and stem cell transplantation are two important treatment methods considered for the cancers discussed in this study. Bone marrow is the soft, spongy tissue found in the center of large bones that produces white blood cells, red blood cells, and platelets. Bone marrow transplantation is a treatment in which bone
marrow that has been affected by a disease or by treatment for a disease is replaced with healthy bone marrow (NCI, 2005).

Out of thousands of people searching for a bone marrow transplantation match, a growing percentage of those are African-Americans, for whom finding a match can be extremely difficult (Reyes, 2005).

Laver et al. (2000) researched bone marrow donation and assessment of barriers among African-Americans. Surveys were administered to 589 participants to assess their attitudes towards donation. The study results showed that, in searching the National Marrow Donor Program registry, Caucasians have about an 80 percent chance of receiving an unrelated donor while African-Americans have less than a 30 percent chance. An awareness that transplantation saves lives and how donations can be made must be effectively promoted throughout the community.

Stem cell transplantations facilitate the use of more aggressive anticancer therapies. Blood is drawn from a vein in the patient’s arm by which the patient’s own stem cells are collected and utilized to rescue the bone marrow destroyed by chemotherapy and/or radiation therapy. Autologous and allogeneic stem cell transplantations are two types of stem cell treatments. Allogeneic transplantations rely on stem cell donors. In autologous transplantation, the patient’s own stem cells are used for anticancer treatment (Harpham, 2003).

Transplant centers assist with the documentation needed to authorize coverage of transplantation, which can costs well over $100,000. Working with insurance providers can be difficult. Financial support for transplants can be provided with the assistance of special organizations and fundraisers (Stewart, 2000).
Stockler-Goldstein et al. (2000) reported that the total cost of posttransplant care ranged from $80,000 to over $140,000. When treatment is not successful, transplantation-related deaths can be attributed to the following conditions: multiorgan failure, interstitial pneumonitis, hepatic failure, inadequate pulmonary function, multiple prior chemotherapy regimens, prior chest irradiation, and gastrointestinal bleeding.

Participation in a clinical trial is a viable treatment choice for cancer patients. A clinical trial is a form of research involving cancer patients that is intended to test new drugs and to uncover more efficient, beneficial treatment methods. There are situations where standard cancer therapy is not reliable and clinical trials may offer better treatment and follow-up opportunities as well as offering treatment at no costs to the patient (NCI, 2005).

Most treatment regimens are aimed at killing the cancer cells or tumors that inhabit the patient’s body, but these therapies can exact an unwelcome impact on the body’s normal organs unrelated to the cancer. The negative consequences of treatment are referred to as side effects or complications to treatment. Many types of complications can occur with some of the more common side effects being the following: anemia, fatigue, infection, fever, mouth sores, nausea/vomiting, hair loss, pain, depression, and death. Side effects can impact overall treatment outcome by interfering with therapeutic regimens (CancerConsultants.com, 2006).

Harpham (2003), a physician and cancer survivor, explained how a person may be considered cured of cancer: The most desirable cured state would be no detectable sign of cancer and life expectancy would remain the same as before the cancer originated. A one year remission may be considered a cure and, after a five year remission, the
likelihood of a cancer recurrence is low. Unfortunately, there is a greater chance of developing the same type of cancer with some lymphomas that are considered incurable.

Not only will patients require information on symptoms, diagnoses, side effects, coping strategies, and cures, a prognosis is also expected. A prognosis is a prediction of the recovery and outcome of a serious disease state (NCI, 2005).

**Relapsed Hodgkin’s Lymphoma**

Relapsed Hodgkin’s lymphoma (relapsed HL) is the recurrence of the disease in prior and/or new locations in the body. Relapse may occur within the first 2-3 years after the original treatment. The major risk factor for relapsed HL is resistance to conventional treatment. Chemotherapy, radiation, bone marrow and stem cell transplantation are treatments used for relapsed HL. When treatments must be repeated due to relapse, subsequent rounds of therapy are determined by where in the body the disease has returned, stage of relapsed HL, and prior treatment approaches (University of Maryland Medical Center, 2005).

Relapsed HL has a cure rate that ranges from 10 to 50%. When relapse occurs, there is a decrease in the chance for long-term survival. Cure rates decrease if relapse occurs within the first year after initial treatment. The later the relapse after initial treatment, the better the cure rate will be (Merck, 2006).

Follow up examinations may occur every two to three months for two years, every four to six months for the next three years, then annually after five years. Patients relapsing within one year may benefit from high-dose therapy until maximum response is attained (emedicine.com, 2002 ).
Relapsed Diffuse Large B-Cell Lymphoma

Diffuse large B-cell lymphoma (DLBL) is the most common lymphoma and is a rapidly-growing, aggressive NHL. This cancer type accounts for more than 30 percent of all lymphomas in the United States and affects approximately five individuals out of 100,000 each year. DLBL is a little more common in men than women and Caucasians than other races/ethnicities. It can occur within an age range of 10-88 years. The median age range at diagnosis is from 57-64 years and found most often in patients in their 70s. Mortality rates are significantly increasing in each race/sex group, with these increasing rates highest in areas where either HIV is epidemic or patients experience posttransplant diseases. The projected 5-year survival rates appear to be higher for Caucasians than for African-Americans (Kallab, 2002).

DLBL is a high-grade (rapid growing) lymphoma, which needs prompt treatment. DLBL can be fatal but with the appropriate treatment, the cure rate is approximately 50 percent. DLBL is a cancer which affects the B-lymphocytes. B-cells and T-cells are two main types of lymphocytes. Lymphocytes originate in the bone marrow or lymph nodes, where the B-cells mature and may develop abnormally. The T-cells leave before maturation and finish the development process in the thymus gland (Lymphoma Information Network, 2005).

DLBL can arise from other kinds of lymphoma or emerge due to genetics. Symptoms of DLBL are referred to as B symptoms, with one of the first being a painless swelling in the neck, groin, or armpit. The swelling is caused by enlarged lymph nodes. The lymphoma can spread throughout various organs of the body. Tiredness, appetite loss, and night sweats are additional symptoms that may be experienced. Chemotherapy
is the main treatment for DLBL. The stage of lymphoma, age and general health of the patient are considered when determining the type of chemotherapy to use. Outpatient treatment for 4-6 months is standard. High-dose chemotherapy with bone marrow or stem cell infusions has been effective in the treatment of DLBL. Radiation therapy can also be included. Side effects can be severe and the cancer specialists are very careful about prescribing this type of treatment to patients over the age of 45. However, especially fit patients, up to age 65, may be able to handle high-dose treatment (CancerBACUP, 2005).

Between 26 percent and 73 percent of patients with DLBL will be disease free for 5 years after diagnosis. If the patient is disease free for four or more years, the disease will seldom return (UpToDate Patient Information, 2005).

Relapsed Follicular Non-Hodgkin’s Lymphoma

Follicular lymphoma (FL) is one of the more common NHLs in the United States. Patients typically present with the disease in multiple parts of the body. FL is a B-cell lymphoma. The average age at diagnosis is 60 years old and the disease has progressed to the later stages. Risk factors for FL may be environmental, including exposure to chemicals, such as pesticides and hair dyes (Lymphoma Information Network, 2005).

Adult patients with early stage disease may be treated with local radiation. When treatment is necessary, chemotherapy, combined chemotherapy, whole body irradiation, or bone marrow transplantation may be recommended. For all other stages, close follow up is needed. The patient is followed for the development of systemic symptoms such as fever or weight loss. The overall survival rate of patients is 72-77% at five years. The
median survival time is 10 years. These lymphomas have a better prognosis than higher grade lymphomas (Lymphoma Information Network, 2005).

**Treatment Delay**

After a person receives a diagnosis of cancer, and has begun to process how the diagnosis and treatment will impact quality of life in very specific ways, conscious or subconscious treatment decision-making begins. Treatment begins promptly for some patients, while others may experience delay. Reportedly, 30 to 50 percent of cancer patients will not begin treatment, specifically, chemotherapy (Hudson, 1998).

Timely diagnosis and treatment at an early stage of disease is significant when pursuing cancer cures. Delay in seeking cancer treatment is closely related to advanced stage of disease at diagnosis (Bradley, 1998).

Rolland (1994) provides a time line that groups the phases of illness, beginning with the crisis phase of prediagnosis or symptomatic period and diagnosis, through the chronic phase of illness and ending with the terminal phase of death. He addresses the important psychosocial factors associated with the chronology of serious diseases so that the patient, family, and clinician can be prepared for the critical tasks necessary for each phase. One critical task occurs during the span between diagnosis and initial treatment, which is an extremely stressful period. The decision has to be made on whether or not treatment will be sought.

In a review of treatment delay definitions, total delay occurs from beginning of symptoms to the start of professionally recommended care. In 6 to 16 percent of research
cases, delay from physician visit to first treatment appointment typically exceeded three months (Richards, et al., 1999).

After diagnosis, staging, and receipt of the treatment recommendation, increased compliance can result if physicians provide information on how much time a patient may take before starting the first treatment. The aim is to allow the patient adequate time to process information about the diagnosis and treatment, without increasing cancer risk (Harpham, 2003).

A systematic review of 87 worldwide studies was conducted on influence of delay on survival in breast cancer. Two hypotheses were tested: 1) longer delays are linked with lower survival; and 2) longer delays are linked with more advanced stage. The most frequently reported delay times were from 3 to 6 months and the most frequently reported outcome measure was a 5 year survival period. Delay and tumor size was statistically significant. According to the investigators, lower survival is linked to delays of three to six months. The results supported the hypotheses (Richards, 1999).

Richards et al. (1999) conducted another study with approximately three thousand breast cancer patients who answered questions in an examination on the impact of delay on survival. Patients who presented with breast cancer in a London hospital from 1975 to 1990, were followed-up for the study. The two delay intervals researched were first between symptom onset and first visit to the hospital, and the second interval between symptom onset and first treatment which was considered total delay. Delay intervals used in the study were less than three months, three to six months, and more than six months. The results indicated that survival was worse among women with longer delays
and that, specifically, delays of 12 to 26 weeks were strongly associated with poor survival rates and more advanced stage of illness.

In a questionnaire-based study investigating the differences in delay and psychological distress among 252 male and female cancer patients in Norway, the diagnostic delay was more distressing for females than males. The three different periods of delay studied were before consulting the general practitioner to report symptoms, before attending the local hospital in response to the general practitioner’s referral, and before attendance at the oncological unit. The delay before consulting the general practitioner was from one to four weeks, with women experiencing a shorter delay than men among, in particular, the non-Hodgkin’s lymphoma patients. Delay before the referral response was from one week to three months and the delay was shorter among the higher educated and those less than 50 years of age. Patients were admitted to the oncology unit within the first month. The delay time intervals used for analysis in this study were less than one week, from one to four weeks, from one to three months and more than three months (Risberg, et al., 1996).

Saavedra (2004) examined the health behavior trends (delays and refusals in treatment) of American Indian, Hispanic, and non-Hispanic white breast cancer patients residing in New Mexico. A retrospective study was conducted examining the medical charts of 434 patients. A qualitative component was included in the study. The results indicated the delays experienced in diagnosis, treatment and/or refusal of treatment was 11.7 percent. More delays / refusals were experienced by American Indian women than the other ethnicities represented in the study.
Examining noncompliance studies may provide indicators of why treatment delay occurs. Missing just one appointment can be considered noncompliant. Results from health behavior studies revealed various reasons for noncompliance: not remembering appointment dates and times, having transportation problems, and experiencing anxiety about the diagnosis, treatment, and medical care costs (Hudson, 1998).

Oncologists were surveyed about patient noncompliance and half of these clinicians admitted experiencing difficulties with patients failing to make their initial appointments. The researcher believes the number of oncologists with compliance issues is higher than what was reported and surmised there were attempts to avoid negative reflection on the clinician (Hudson, 1998).

In a qualitative study investigating treatment plan decisions among cancer patients, 10 patients, aged 61 to 76 were interviewed. Complying with participation and complying without participation were factors examined:

1. Complying with participation was characterized by feelings of self-confidence and self-competence and by open dialogues between the participants, significant others and the physician.

2. Complying without participation was characterized by participants’ feelings of uncertainty and distress, and of being rushed into submitting to decisions without having time to reflect on the information provided or the opportunity to influence the treatment and care process.

3. There is an implicit imbalance of power in the relationship between patients and health care professionals.

4. Each person is profoundly affected by all aspects of a relationship in which the other party has superior communication skills that are used to influence him or her to accept certain conditions, especially in circumstances where he or she has received a potentially life-threatening diagnosis, such as cancer (Ramfelt and Lutzen, 2005, p. 143-144).
DiMatteo (1994) explains that approximately 38 percent of patients neglect short-term treatment and approximately 43 percent are noncompliant with long-term treatment. He is convinced that if the patients agree with the treatment recommendations and possess the mandatory resources, then compliance occurs and that it is the provider’s responsibility to educate the patient and instill belief that the treatment recommendation is correct. The physician must effectively communicate with and understand the patient well enough to make the treatment alliance a successful one. Patient concerns also include the amount of time away from work, childcare responsibilities, incorporating pill-taking, and other treatment procedures into a daily schedule.

If there is any kind of substantive travel involved in the pursuit of treatment, and limited support is available, traveling can be a barrier to treatment, causing delay. Research was conducted examining 118 patients’ perspectives on traveling for cancer treatment. The analysis uncovered the disagreeable experience of waiting, the idea of traveling as being stressful and the actual traveling and being away from home as tiring and presenting many conflicts (Fitch, et al., 2003).

Medical treatment is often delayed because of costs. Depending on the severity of the illness, cost of cancer treatment can be shockingly exorbitant for patients who may be underinsured, uninsured, or even insured. Medical care affordability is problematic and Greenwald (1986) made the following observations about managed care, medical costs, and care delay:

- Those treated in the HMO or making copayments encountered significantly longer time lags between diagnosis and the commencement of treatment than those receiving fully insured fee-for-service care;
• Predicting time from diagnosis to treatment, includes positive and statistically significant coefficients on the variables of HMO membership and copayment;

• These significant coefficients indicate that both those who belonged to the HMO and those who copaid waited longer between receiving diagnosis and beginning actual treatment than those in fully insured, fee-for-service situations (Greenwald, 1986, p. 651).

Misdiagnosis caused delay of 12 to 18 months in the diagnosis of melanomas, which was reported in a study on professional delay in the diagnosis of 83 patients with acral melanoma. Twenty-seven melanomas were clinically misdiagnosed by physicians and the delay in diagnosis was associated with advanced stage of disease and lower survival rate (Metzger, et al., 1998).

The dynamics of physician delay have not been well investigated. In a study on diagnostic delay in breast cancer, unimpressive physical findings was reported as a common cause of physician delay. Researchers found that the results of physician delay in terms of overall outcome were not statistically significant. Eight percent of the 606 subjects who experienced physician delay of greater than three months had larger cancers but did not exhibit significant differences in pathology, treatment, or outcome (Tarttler, et al., 1999).

Goodson and Moore (2002) researched the causes of physician delay by examining records in a practice that regularly utilizes screening mammography. The cases of 435 patients were investigated. Forty-four patients received incorrect diagnoses because of misread mammograms and pathologic findings, poorly performed fine-needle aspirations that missed the cancer, and the major cause of physician delay in breast
cancer diagnosis was, reportedly, providing benign diagnosis without biopsy when there actually was malignancy.

Sandovsky (2002) received similar results in his study on reducing physician delay in breast cancer diagnosis. He reported that misreading mammograms as benign was the most prevalent cause of physician delay and the investigator suggested physician use of practice guidelines to avoid this kind of delay.

Data collected and analyzed on over 2000 patients with breast and colorectal cancer in Germany indicated breast cancer patients who lived further away from cancer centers received faster treatment at hospitals. There was no difference in treatment for colorectal cancer patients living in rural and urban areas. There was variation in delay between general practices. Practices with more female general practitioners were associated with less delay (Robertson, et al., 2004).

In a study on patient and provider characteristics, the investigators reported, “There is considerable variation in treatment and outcome not explained by traditional prognostic factors” (Hodgson, et al., 2001, p. 501). Identified variations in this study were: 1) inadequate physician knowledge of practice guidelines; 2) treatment decisions based on unmeasured clinical factors; and 3) patient preferences.

The Selker et al. (1989) Delay Tool was utilized to analyze 201 medical records and identify unnecessary administrative hospital delays. There are nine categories in the Delay Tool: test scheduling, test results, surgery, consultation, patient, physician, education, discharge, and facility/bed unavailability. The significant findings provided the following recommendations: “The micro recommendations addressed specific issues related to the unavailability of outside resources, discharge planning and physician

A review on equitable access to cancer services was conducted and identified patient, provider, and system barriers to services. Patient barriers are associated with old age, ethnicity, and low socioeconomic class. The review of system barriers identified managed care organizations as providing high levels of screening to healthy people but more research is required to examine interventions with diverse populations. The findings indicated “providers are often ill-prepared to communicate the complexities of cancer care to their diverse patient populations” (Mandelblatt, et al., 2000, p. 2378).

Miller and Bovbjerg (2002) examined patient safety in large, capitated medical groups. Shortcomings in diagnosis, abnormal tests follow-up, scope of practice and referral patterns, and continuity of care were targeted patient safety problems. The researchers reported that medical care could be safer. Their qualitative study included background information obtained from interviews with insurance company managers, malpractice law experts, patient safety associations and consulting firms. Data on types of legal claims from 1985 to 1999 was provided by the Physician Insurance Association of America (PIAA). Delay in diagnosis and misdiagnosis were considered the most common source of avoidable injury. Unpublished PIAA data that was obtained revealed close to two-thirds of categorized physician errors: failure to do something or delay in doing something. The specific categories are identified: 1) errors in diagnosis (40.8 percent); 2) failure to supervise or monitor cases (8.8 percent); 3) activities not performed (4.1 percent); 4) failure to recognize a complication of treatment (4 percent);
5) failure or delay in referral to a specialist (3.8 percent); and 6) delay in performance (2.6 percent).

Miller and Bovbijer (2002) identified organizations’ present methods of changing processes to prevent injuries. Five categories were provided: 1) identify events/problems; 2) analyze and track incidents; 3) decide on new standards and how to intervene to change systems; 4) intervene to support new standards; and 5) monitor performance. Internal and external factors to promote patient safety were identified. External factors are litigation, accreditation and public regulation, competition, payment method, professionalism, and consumerism. The internal factors are size of group, physician leadership and governance structures, past successful process change and intellectual capital, extent of reliance on capitation, information system assets, financial capital, and organizational integration and affiliation. The researchers offer four policies that may assist in providing patient safety: 1) increase consumer demand by raising the visibility of safety; 2) increase consumer demand by setting new performance and performance reporting standards; 3) set minimum standards for information systems that can improve safety; and 4) increase demand for systematic care throughout the organization. The researchers reported that:

The most important obstacle to error reduction and patient safety was medical socialization that makes errors seem unacceptable, which serves to provide evidence of failures of character, and that can rarely be admitted or discussed among physicians. This socialization leaves physicians emotionally isolated in their responses to errors and any lessons learned are obtained privately (Miller & Bovbijer, 2002, p. 435).
Delay, Gender, and Age

Reportedly, men and women respond differently to illness. Risberg et al. (1996) conducted a study examining distress and delay and it was found that women reported experiencing more distress than males but both men and women reported experiencing the most distress when treatment delay occurred before hospital admittance. There was a positive correlation between length of total delay and distress.

There are a number of factors to consider in assessing how men will respond after receiving a diagnosis of prostate cancer. The identification of stressors, strength of coping skills, and the availability of an adequate social support system influences the management of a cancer diagnosis and treatment demands. Men are taught to respond differently to illness during their childhood than women. Beliefs and practices become entrenched. Many prostate patients must decide among several treatment options which may cause significant emotional struggle. Unfortunately, men too often neglect their health problems and do not seek medical care (Curtis, et al., 2003).

More information on health behavior among men is needed. Present medical and behavioral research on men’s health has been under-informed on the daily experiences of men and their perceptions of health and masculinity as personal, cultural, and social constructs (Watson, 2000).

A survey of 222 breast cancer patients who were all over the age of 55 was conducted in an examination on patient and physician interaction. In this study, treatment delay was considered 60 days from symptom onset to first treatment. Age was shown to be associated with treatment delays. Results showed that physicians spent more time with their younger patients, providing information and support, and were not as
responsive to older patients. Maly et al. (2004) reported that, in the United States, the population of those over the age of 55 is steadily increasing and this population is more likely than those younger to encounter disparity in breast cancer treatment.

Reportedly, older women have a less than desired amount of breast cancer knowledge and encounter treatment disparity, which places them at greater risks for treatment delays. Patient-physician interaction may steer the inclination towards or away from treatment delays and disparities (Maly, et al., 2004).

**African-Americans, Barriers to Treatment, and Delay**

Dressier and Binden (2000) report that because of limited theory connecting biological factors with the cultural and individual, researching cultural diversity and health behaviors is unaccommodating.

According to the Intercultural Cancer Council (2006), 31 percent of African-Americans live at or below the poverty level and, residing in poor neighborhoods renders African-American people to be five times more likely to present with advanced disease at diagnosis and not receive adequate treatment for the disease.

The results of a review of literature on underserved African-American communities and strategies for cancer prevention identified barriers to care:

1. Inadequate access to and availability of services;
2. Competing priorities;
3. Lack of knowledge of cancer prevention and screening recommendations;
4. Culturally inappropriate or insensitive cancer control materials;
5. Mistrust of the health care system;
In the publication, Medical Letter on the CDC & FDA (2004), investigators reported on the status of delay of diagnosis and treatment among African-American breast cancer patients. As reported by the CDC and FDA, the chances of survival are likely to be decreased after a treatment delay of 3 or more months. After the patient-physician consultation, treatment was initiated within 2 months.

African-American women are experiencing longer delays of 3 or more months due to what appears to be socioeconomic status (including health insurance status); marital status; and health behavior, history and available medical resources. The reasons for the delays must be further researched.

A cultural analysis and a series of semistructured interviews were conducted among 750 low-income African-American and Caucasian women on cultural differences in breast cancer mortality. Based on the premise that annual mammography, primary care utilization, and prompt treatment facilitate more promising stage of disease and with no significant differences of these factors among the two groups of women, there was no difference in stage of disease at diagnosis. African-American women maintain cultural beliefs that more white than black women have breast cancer and that breast cancer results in rapid death. These beliefs interfere with African-American women’s pursuit of timely diagnosis and treatment (Barg, 2000).

A difference in the duration of adjuvant chemotherapy among African-American women and Caucasian women was examined in a study including 136 early stage, breast cancer patients, whose white blood cell (WBC) counts were followed throughout treatment. The researchers reported the WBC for African-American women was much
lower than Caucasian women. The results indicated that African-American women needed longer durations of treatment than others (Hershman, et al., 2003).

There are few studies assessing healthcare barriers and African-American, with the majority of the research focusing on populations of prostate patients such as Smith’s (1996) study. African-American men with higher socioeconomic status were found to perceive fewer healthcare barriers and more promptly sought medical treatment than African-American males with less socioeconomic status.

Another study examining prostate cancer among African-American men received results that may be useful in the investigation of treatment delay. Assessing fear of a cancer diagnosis among African-American men, 60 percent of the subjects indicated serious concern about experiencing impotence and incontinence after treatment. (Parchment, 2004).

African-American men experienced more delay from time of diagnosis to treatment than Caucasian men, due to a practice referred to as ‘watchful waiting,’ which is non-aggressive therapy and is utilized instead of more assertive treatment regimens. In 2002, approximately 200,000 prostate cancers were diagnosed and an estimated 75 percent of these cancers were localized or had not spread to other parts of the body (Parchment, 2004).

In a study investigating African-American men’s health seeking behavior, Leininger’s Culture Care Diversity and Universality Theory and the Health Belief Model were used to examine social dimensions that influence motivation such as education, economics, religion and politics as well as the barriers to help-seeking behavior. A major identified barrier is African-American men’s mistrust of the health care system and
intervention that increases trust may be needed. Results of the study also found that significant others strongly influence African-American men’s health-seeking behavior. Specific cultural motivators such as targeted outreach and special health centers for this population can be established through social policy (Plowden, 2003).


With the exception of Native-American men, African-American men have the lowest life expectancy of all groups. When a man feels his masculinity may be threatened, he will ignore his illnesses and refuse medical treatments. African-American men receive inadequate medical care, even when it is pursued. Another health-impacting environmental force of hazardous waste sites that were studied, 75 percent were placed in African-American communities (Sabo & Gordon, 1995).

**Treatment Delay Summary**

Treatment response at an early stage of disease is important to positive health outcomes. From 30-50 percent of cancer patients will never begin chemotherapy. The most crucial phase of illness is between diagnosis and treatment. In 6-16 percent of study cases, after the diagnostic consultation, the first treatment exceeded three months. Lower survival is associated with 3-6 months delay. Health care professionals can provide patients with information on the safe amount of time they may need for decision-making, being clear on what is considered treatment delay. Longer delays are
linked to lower survival and advanced stage. Higher educated patients, cancer patients younger than age 50, and women experience shorter delay. Older age has been associated with treatment delay and disparity.

There is a positive correlation between distress and total delay. As revealed in compliance studies, people have lots of reasons for noncompliance such as anxiety about treatment, forgetting about appointments, and experiencing fear of medical costs. Oncologists have reported concerns about noncompliance. Transportation can be a significant barrier. Health care costs and type of insurance can be problematic factors for many patients. Fully insured fee-for-service patients are able to initiate treatment quicker than HMO/copay patients who, in turn, receive care quicker than patients with public insurance.

More research is needed on cultural diversity and health care. African-American men with higher socioeconomic status perceive fewer health care barriers but may have concerns about the physical risks of treatment. Significant others influence the health behavior of African-American men. African-American men, unfortunately, often receive inadequate medical care even when they pursue care and are sometimes subjected to watchful waiting.

Social Support

Extensive research has been conducted on social support since the late 1800’s, when researchers began to assess concerns on the breakdown of social ties and suicide and on the dynamics of community life and mental health status. These studies were
referred to as social integration research. Lower levels of social integration were associated with negative health risks. There are five theoretical perspectives on social support: supportive actions, appraisal, social cognition, symbolic interactionism, and relationships. These perspectives are described by their intellectual tradition, aspect of support emphasized, type of support measures emphasized, support operates, and the emphasis of stress buffering or main effects of support. Drawing consensus on a universal definition of social support has been a difficult endeavor for social scientists. Until agreement occurs, investigators must choose the definition or definitions that best fit the research at hand. For the purpose of this study, social support is any process through which social relationships might promote health and well-being (Cohen, et al., 2000).

In African cultural tradition, the social support dynamic was manifested in the African-American community by the spirit of collective responsibility and this phenomenon has survived through the Middle Passage; the slavery period; the Progressive Era, with its utilization of the Black Codes; and the Great Depression to the present. Collective responsibility emphasizes the importance of helping others and caring for the sick, and safeguards the constructs of informal support, mutual aid, and group survival necessary only because professional health care has not been appropriately accessible to the African-American community (Carlton-LaNey, et al., 2001).

It is common for the cancer patient to worry while waiting for the initial treatment appointment. Thinking about the side effects of the treatment, which can be severe, as
well as how the medical experience will significantly disrupt normal home and work life, is exceedingly stressful (NCCN, 2005).

Baum (2004) discussed the importance of addressing three patient needs that will relieve distress. Patients have a need for various types of social support, to not have to suffer from disease symptoms, and to be provided a cure or a prolonged life.

Weiss (1974) expanded the functions of social support as it relates to social relational provisions. The six functions offered are reliable alliance, social integration, guidance, opportunity for nurturance, reassurance of worth, and attachment/intimacy.

Hopper (2003) utilized Laireiter and Bauman’s taxonomy of social support (social integration, social network, supportive climate, received and perceived support) to review definitions of social support. The researcher examined a number of studies which investigated the concepts of social integration and social network. Social integration includes the factors of marital status, contacts with friends and relatives, participation in formal and informal organizations and church membership. Social networks consist of spouse/partner, other relatives (extended family), friends, neighbors, coworkers, formal and informal caregivers and other health and welfare professionals.

An extensive literature review and analysis on social support theory and related research was conducted. The author made the observation that all of the definitions of social support imply that support is of a positive nature. The numerous definitions were placed into five categories of social support: type of support provided, recipient’s perceptions, intentions of the provider of support, reciprocity, and social networks. Most social support research investigates the recipient’s perceptions of support and the majority of results indicate that social support does influence positive health-related
outcomes. It is important to note that support, even positive support, can be perceived as negative by the recipient. For some people in need of support, requesting and receiving support may be difficult. People provide support for many reasons. The more common reasons are due to dealings of empathy, obligation, or that similar support may be needed by the provider in the future. When operationalizing and measuring social support, researchers tend to examine only a fraction of the social support concept. The author encourages future researchers to focus on social support interventions that influence optimal health outcomes (Hupcey, 1998).

Considerable research has been done on social support and cancer, using the more prevalent types of cancer such as the breast, colon, lung, and prostate cancers for investigation. Many of the following social support studies may identify cancers or other chronic illnesses studied other than lymphoma, for which there is limited research involving psychosocial associations.

Waxler-Morrison (1991) found that the clinical stage of disease is significantly linked with survival, when social context at the time of diagnosis and the chances of surviving breast cancer four years later was examined. The association between the number of supportive personal and work relationships was found to be statistically important to survival.

McCabe’s (1991) study results supported the hypothesis that patients who have the perceptions that they lack interpersonal support experience recurrent disease quicker than those whose perceptions are of possessing positive social support. This research focused on the association between the body’s immune system and the central nervous
system, which includes cognition and behavior, and the impact that these two major systems have on disease outcome.

A questionnaire-based study investigated the effects of social support on health among 263 black South African patients, between the ages of 16 and 89, who were diagnosed with diabetes. The researchers reported in their findings that the more social support received, the better the general health and well-being of the patient (Westaway, et al., 2005).

**Types of Social Support**

There are three major types of social support interactions: 1) the communication of care and concern referred to as emotional support 2) the information provided to increase knowledge and to assist with decision-making referred to as informational support and 3) the provision of tangible goods referred to as instrumental support (House & Kahn, 1985).

These particular types of supports are also referred to as functional support, when different types of supportive functions are provided through relationships and these functions may be helpful with resolving many types of problems. Functional support (emotional, informational, instrumental, companionship and validation) measures perceived support (available if needed) and received support (recently provided). Studying functional support helps to enhance understanding of support needs of different populations (Cohen, et al., 2000).

In an investigation on social support, networks, cohesion and health, reportedly, health status is related to the degree to which individuals are part of a social system.
Emotional and instrumental support are significantly related to health outcomes and social networks and mortality risks are closely associated (Berkman, 2000).

Berkman (2000) also discussed Boissevain’s Social Network Model that explains how relationships with those of whom we are not intimately tied are just as important as our relationships with very close relatives and friends. This explanation expounds on the three major types of support: emotional, informational, and instrumental. Social networks can be examined by considering marital status, contacts with friends and relatives, religious affiliation, and membership in employment and voluntary organizations. The effects of social isolation on high risk chronic diseases places a person at a much higher risk of death than if the person was socially connected. Social workers may be able to effect positive change and reinstate humanitarianism back into the health care system by effecting biopsychosocial interventions and by advocating better integration between the health care system and the community through improved health policies.

In one of the largest European surveys about women patients’ perceptions of their cancer treatment, results from over 30,000 respondents residing in 15 countries indicated that women do not have sufficient information about what to expect from cancer treatment and that most of the women were informed of their diagnosis in a consultation with a specialist physician. The patient’s spouse, followed by children, family, and friends were the most reported sources of support. The most negatively affected relationships were with employers. Single patients reported feelings of isolation throughout all the phases of illness and experienced higher rates of depression (Veronesi, 1999).
Emotional Support

A number of studies have shown that various psychosocial interventions have positive outcomes for cancer patients. The outcomes were idealized as feelings of well-being and cancer regression. Results of a study on emotional coping involving breast cancer patients who received psychosocial intervention were evaluated. The results showed that coping improved with intervention after a 4-month delay as well as with immediate intervention (Carlsson, 1994).

Researchers studied changes in social activity and relationship satisfaction and examined how those changes impacted immune functioning, specifically, the tumor necrosis factor responses among 44 breast cancer patients. Measurements occurred at the time of cancer diagnosis, initial surgery, and 12 months later. The findings indicated that the higher the rate of social interaction experienced by the patient, the more stimulated the tumor necrosis factor responses, which strengthened immune functioning (Marucha, et al., 2005).

Research results on coping and marital adjustment among prostate patients and their spouses revealed that, although the patients resorted to avoidance and denial behavior, the spouses positively responded to treatment demands. The majority of the men believed their marital relationships improved during the course of illness and treatment, despite reporting negative sexual changes among the couples due to impotence (Lavery & Clarke, 1999).

A longitudinal study was conducted with 630 married subjects to examine occupational quality and whether it influences health-risk behavior. The mediating variables used were social integration, marital integration, and psychological control.
For women, social integration more strongly affected health-risk behaviors than marital integration and psychological control. For men, marital integration more strongly benefitted health behaviors (Wickrama, et al., 1997).

Breast cancer patients were followed for one year post-surgery in an investigation on social support and adjustment to cancer. Four standardized inventories were utilized throughout the illness phases, from diagnosis to ongoing recovery. The study results showed that women needed continuous emotional support from their spouses throughout all phases, increasing support was needed apart from spousal support, and women worried about their spouses and children during the illness phases (Hoskins, et al., 1996).

Living with others, especially children, provided motivation to accept aggressive cancer treatment. Parents with cancer, typically, do not want to cause major disruptions in the lives of their children (Yellen & Cella, 1995).

Women in need of social support during cancer care may experience guilt for not caring for themselves well enough to avoid the cancer and neglecting to protect their loved ones from the distress that accompanies the cancer experience. Accepting care and support from others may exact challenges to the care receiver. Sulik's (2005) qualitative study of women's unequal participation in care-giving and care-receiving resulted in the suggestion that women redefine their concepts of care.

Adult cancer patients, their spouses, and children responded to an assessment of psychological maladjustment during the diagnostic phase of illness. The severity of the illness indicated the level of distress experienced by the patients and their family. Risks for psychological maladjustment among the children were determined by sex of the
patient, sex of the child, and age. Adolescent girls whose mothers were the identified
cancer patients experienced the most distress (Compas, et al., 1994).

Lesbian breast cancer patients exhibited fewer difficulties with body image,
receiving social support from partners and friends, and their perception of the health care
system than heterosexual patients. The study compared the cancer experiences of lesbian
and heterosexual breast cancer patients (Fobair, et al., 2000).

In a study on social support networks, adults, aged 60 to 91, who identified
themselves as lesbian, gay, or bisexual, reported receiving their emotional support from
domestic partners and relatives and felt more positive about their overall health than
those living alone. The receipt of support from those aware of their sexual orientation
was preferred (Grossman, et al., 2000).

Lesbians, diagnosed with cancer, tend to have feelings of discomfort with
provider communication and treatment interventions. They report experiencing distress
at having to disclose their sexual orientation, for fear of possible discriminatory
treatment. Securing emotional support was also identified as difficult (Matthews, 1998).

Formal support groups are frequently utilized to provide identified needs of the
patient. Cancer patients are brought together in a group to discuss cancer-related issues
in the hopes of fostering support and encouraging patients to use their individual
resources (Weiss, 2003).

Support groups, which are, typically, free services, provide emotional and
informational support to those with similar issues. Professional social workers often
facilitate these groups. The groups may decide how often to meet. Various types of
groups are formed such as face-to-face, online or telephone. There are organizations that
demonstrate great creativity, their goals being to encourage commitment to the groups, bonding, relaxation, and enjoyment (Landay, 1998).

Informational Support

Finding successful methods to initiate and maintain patient involvement with prescribed care is important. Providing customized materials, patient instructions, or helpful information, specifically for enhancing retention, facilitates patients’ understanding their medical conditions and helps the physician provide treatment (Prounis, 2005).

Mettler (1993) conducted a questionnaire-based investigation on the relationships between social support, informational support, and cancer treatment adherence among 46 patients receiving chemotherapy. Findings revealed the patients were most influenced by their doctors; were satisfied with the support and information received, which was received most from nurses; that most of these patients admitted to experiencing great fear about their chemotherapy treatments; most experienced moderate side effects to the drug treatments; and that emotional despair was experienced due to hair loss.

“Only 35 percent of patients receive instructions from their physicians on how to take medication” (Prounis, 2005, p. 140-141). Believed to be unintentional, the physician-patient visit, which is critical, is not managed well enough to ensure the patient’s complete understanding to comply with treatment recommendations.

Research has shown that women prefer to have complete information (written or verbal) when diagnosed with invasive breast cancer. Psychosocial support is preferred as
most women respond with shock when hearing about their diagnosis (De Morgan, et al., 2002).

Being involved with family members or friends who have experienced cancer promotes quicker responses to symptoms and less delay. Peer relationships can be effective at providing desired information that promotes improved health-seeking behavior (Bradley, 1998).

Plass and Koch (2001) researched participation in formal social support among 132 cancer patients, using a number of measurement tools. Patients who received psychosocial support reported wanting to obtain help with distress and coping with the illness and patients who did not pursue psychosocial support believed the informal support from family, friends, and physician was enough.

Negative perceptions of the patient-provider relationship were examined in the Commonwealth Fund 2001 Health Care Quality Survey, which included 6722 participants. Of the study population, 14.1 percent African-Americans, 19.4 percent Hispanic-Americans, 20.2 percent Asian-Americans, and 9.4 percent Caucasians believed they were treated disrespectfully by the provider. The study findings revealed that owning these negative perceptions caused unfortunate outcomes such as delay of care, receipt of less than optimal care, and noncompliance (Blanchard & Lurie, 2004).

The National Council on Patient Information and Education Miscommunication reports that half of all patients forget what the physician verbally communicates to them and, after having left the consultation one hour later, an even higher percentage (60 percent) could not precisely repeat physician instructions. Doctor-patient encounter
programs were designed to empower patients to fully participate in their own treatment, which will, ultimately, improve patient outcomes (Prounis, 2005).

In an observation study examining new consultations between oncologists and bowel cancer patients in England, recorded dialogue was coded according to relevancy. A comparison analysis was conducted and the results indicated the patients’ active involvement through treatment decision-making revealed conflicting and unclear information about the treatment plan (Sandersa, 2004).

Results from a quantitative study on patient expectations and physician support found that of 105 participants, 5.9 percent of the patients’ expectations were met, meaning they received exactly what they wanted from their physicians. The majority of the patients expressed satisfaction with the cancer consultation and there was no significant link to expectations of emotional or informational support (Brown, et al., 1997).

A comparative study was conducted to investigate the impact that communication has on patient outcome and to determine which of three randomly sampled groups -- oncology physicians, oncology nurses or oncology social workers -- was most effective in communication practices with cancer patients. They were asked to hold discussions on complementary therapies with their patients and then complete the mailed surveys. Survey information covered how many discussions were initiated, their comfort levels, and whether there were noticeable improvements in the patient-professional relationship. Social workers initiated more discussions than the other professionals (Hann, 2003).

Support groups can be a source of empowerment for cancer patients as well as other informational sources such as the internet and patient advocacy. Patient support
group sessions; phone, email, or written patient reminders; and creative types of positive reinforcement are ways to assist in improving treatment adherence (Prounis, 2005).

Researchers are exploring various group support techniques such as the Supportive-Expressive Group Therapy which aims to move patient groups through illness phases, transitioning them from negative coping to creative living, assertiveness, and celebration of living. Inspiring treatment compliance and decreasing delay of initial treatment is the goal of this technique (Kissane, et al., 2004).

Men, aged 48 to 85 years old and diagnosed with prostate cancer, completed the Supportive Care Needs Survey and reported the need for assistance with psychological concerns involving daily living, issues of sexuality, and informational support. All 206 participants in the study were part of prostate cancer self-help groups. The younger men in the groups who lived in urban areas were found to require more psychological care than participants who were older and not living in urban areas (Steginga, et al., 2000).

Seeking knowledge about cancer and treatment from the Internet serves as a viable form of informational support. Listserves, web forums, and chat rooms are convenient and, if preferred, anonymous methods of garnering support. Many of these internet sites allow for discussions among survivors or cancer peers and are, sometimes, monitored by experts or healthcare providers. When sites are not monitored, there are risks that unsupported cancer survivors could become unnecessarily victimized by fear or distress. With advancing technology, teleconferencing, which facilitates live video and audio may become more accessible to interested persons (Sharp, 2000).

In a breast cancer study investigating the psychological benefits of Internet use for medical information among Caucasian, African-American, and Hispanic patients,
Internet use for medical reasons was associated with higher social support than use for other reasons or not using it at all (Fogel, 2003).

**Instrumental Support**

Health care research frequently looks for results to indicate or confirm health outcomes. Health outcome is defined by the World Health Organization (2005) as being able to afford health care services, having needed services available, and receiving culturally appropriate services.

Factors that leverage health outcomes are accessibility, availability, affordability, and adaptability. Maintaining a respectable degree of these factors is an ever increasing challenge for many people with serious illnesses (Facion, 1999).

Various reports indicate that approximately 45 million Americans are without health insurance and over 40 percent of African-American workers do not have coverage. Health care cost is rising and the black community suffers disproportionately (Malveaux, 2005).

Bhattacharya, Goldman, and Sood (2003) examined the quality of care received by HIV patients possessing public versus private health insurance. According to their findings, either type of insurance provides a safeguard from untimely mortality but that private insurance is a preferred safeguard over public.

The majority of cancer patients receiving treatment experience some level of fatigue as a side effect of the treatment regimen. Approximately, a third of the 379 respondents to telephone interviews on how fatigue impacts the lives of cancer patients,
indicated they were employed and 75 percent of these patients reported having to change their employment status due to the impact of fatigue (Curt, et al., 2000).

Some cancer patients experience employment discrimination which was revealed in an investigation involving 422 patients who completed self-report surveys. The type of occupation is an important predictor of a patient continuing employment once a diagnosis is received (Rothstein, et al., 1995).

Participation in clinical trials is an excellent instrumental support to explore. A major benefit of clinical trials involving African-Americans is opportunity to explore the design of medications specifically for African-Americans. BiDil is a drug developed to treat heart failure, which was an outcome of the African-American Heart Failure Trial. This trial, cosponsored by the Association of Black Cardiologists, was the first designed specifically for black patients (Witmyer, 2005).

Special networks have been established such as the Lymphoma Support Network (LSN) that offer various instrumental as well as informational support. Peer support programs match cancer survivors with volunteers with similar disease experiences who provide emotional and informational support. The LSN may provide financial aid to assist with hardship concerns or needs not covered by insurance. For patients who may experience employment discrimination, patient advocacy and legal resource programs are available (Leukemia and Lymphoma Organization, 2006).

Women aged 55-84 who lived alone tend to use the health care system for prevention and screening more than women living with a spouse, who were more likely to be diagnosed with advanced disease. In the examination of health, sociodemographic,
and psychosocial factors that predict stage at diagnosis, a significant predictor of disease stage was living arrangement (Moritz & Satariano, 1993).

**Social Support, Gender, and Age**

Current psychoneuroimmunological research supports the notion that being able to express emotions is beneficial to human health. Women tend to be more comfortable with developing close relationships and cultivating social networks than men. Men are more comfortable with activity-focused male-to-male relationships, tend to seek emotional support from women, and that social support may be more influential in men’s health than women’s (Hegelson & Cohen, 1996).

Women prefer one-to-one communication when receiving information and would rather have family, friends, or cancer survivors to provide health information. Formal support interventions that may be especially beneficial to women include buddy systems with cancer peers, group projects such as an inspirational choir composed of cancer survivors, facilitation of natural support systems, and feminist pedagogical approaches (Hurdle, 2001).

Women perceive their psychological adjustment following a diagnostic meeting with their physicians to be linked to the interpersonal skills of the physicians. The importance of patient-physician communication is emphasized (Mager & Andrykowski, 2002).

Markovic et al. (2004) focused on the principle of patient autonomy which explained that after the patient receives the medical knowledge about the disease, treatment, and prognosis from the physician, the patient is expected to make an
autonomous decision about the treatment path. The patient is able to weigh her treatment options while taking into account her own health beliefs. In this study, women tended to accept the advice of the primary care physician, if the patient-physician relationship was considered a positive, trusting one. Women assumed a passive role and relied on the medical professionals to make the decisions on treatment modalities, believing the clinicians were more capable and had a better understanding of the cancer and required treatment.

Results of a study on the early psychological adjustment in breast cancer patients showed there is a relationship between social support and successful adjustment within the year following breast cancer diagnosis. A total of 87 subjects were assessed, through the utilization of questionnaires, before the diagnosis, followed up 8 weeks after receiving treatment, and then again after 9 months. Psychosocial intervention should occur for women at risk for psychological maladjustment following a cancer diagnosis due to their experience of emotional trauma, insomnia, fatalism, appetite loss, multiple fears, and suicidal ideation (Nosarti, 2002).

The anticipation of a breast cancer diagnosis brings about emotional distress. Self-report questionnaires were used in a study conducted to determine what happens when patients receive a new diagnosis. They may experience feelings of disbelief, sadness, depression, anger, and become overwhelmed with thoughts of helplessness and hopelessness. They may have difficulty hearing or saying the word ‘cancer’ (Drageset & Lindstrom, 2005).

Patient assessment for designing age appropriate interventions should include social support. As the average age of the U.S. population increases, cancer incidence
may increase. There are three factors that, reportedly, link advanced age and cancer development: time span of cancer progression, normal age-related changes that may resemble cancer, preconditions for cancer progression (Repetto & Balducci, 2002).

**Social Support and Bone Marrow Transplantation**

Bone marrow transplantation is used to treat aggressive cancers. While this treatment method may save lives, it can significantly reduce the quality of a patient’s life. Current research is attempting to address this issue and have found that social support received from family and spouses help with recovery from long-term complications (Case, 2004).

One of the most aggressive treatments for cancer is autologous bone marrow transplantation. A study aimed to increase the body of knowledge on psychosocial impact on bone marrow transplantation. Forty-five participants received group support intervention and the healing process, which was assessed among five domains, was found to be beneficial. The domains were physical, psychological/emotional, vocational, social, and family/spousal intimacy (Feigin, 1999).

Risk factors for poor quality of life outcomes (physical, sexual, occupational) of patients receiving allogeneic and autologous bone marrow transplants were greater age at transplant, lower educational level, and more advanced stage of disease. Questionnaires were administered to 200 bone marrow transplant recipients to gather information on the range of quality of life outcome. The majority reported having compromised quality of life compared to their premorbid status (Andrykowski, et al., 1995).
Bone marrow transplant patients were interviewed one week prior to transplant, and three, six, and twelve months after receiving transplants. Researchers assessed the psychosocial functioning of patients and close family members during a one-year span of time. Correlations between the patients’ biopsychosocial functioning and family members’ distress was most significant at the three month post-transplant period. All 28 of the patients and their family members experienced high anxiety (61%) prior to the transplant. Less than half of the patients died during the one-year study (Keogh, et al., 1998).

Psychological and social factors of depression, BMT-related stress, chronic stress and resources in everyday life, pain-related coping behavior, and social support which were exhibited pre-BMT were significant predictors of increased vulnerability for the treatment-related side effects of moderate to severe mouth pain and anxious mood. In a longitudinal study, utilizing a self-rating scale, 63 patients were assessed daily (Schulz-Kindermann, 2002).

Researchers interviewed 112 bone marrow transplantation candidates utilizing an F.I.T. assessment tool. The tool focuses on family functioning, individual psychological maturity, and the capacity to understand the transplant process. The relationship between psychosocial factors and survival among the BMT candidates were examined. Each candidate received on F.I.T. score. The lowest scores near three indicated poorer prognosis or survival while the higher scores near nine indicating the propensity of strong survival (Hoffman, 1999).

A research team aimed to determine a patient’s emotional status before receiving a transplant utilizing a scale that screens for psychosocial issues in bone marrow
transplantation patients. The interests in patient management of care and care planning inspired this study. The ability to predict psychosocial problems during BMT, based on the scores from the scale, was associated with pre-BMT results (Molassiotis, 1999).

In the researchers’ review of literature on social support, helpful social support is essential during in-patient hospitalization and the post transplantation period. Prior to undergoing autologous blood stem cell transplantation, ninety-nine patients were surveyed with a scale which focused on social support and illness. The scale indicated positive social support and negative social support. Utilizing Cox regression analysis, negative social support, identified by experiences such as criticizing, victimizing, and avoiding interactions, showed significant relationship to poor survival following autologous stem cell transplantation. However, there was no association between positive social support and survival (Frick, et al, 2005).

**Cultural Concerns and Social Support among African-Americans**

Joiner (2004) explicitly outlines the historical and present state of health care for African-Americans in the U. S.:

African-Americans overcome insurmountable obstacles to defeat the racist Jim Crow system. Now, the fight for equal rights has turned to quality health care. African-Americans lead the nation in heart disease, obesity, cancers, stroke, diabetes, and kidney disease. The death rate for blacks is 30 percent higher than for whites. There are many factors that contribute to health disparities, including diet, access to care, quality of care and the lack of minority health care providers. All these factors can be traced to a system that has historically devalued black life (Joiner, 2004, p. 18).

Historical social maltreatment such as the Tuskegee Experiment, a 40-year syphilis study, funded by the government, which left African-American men untreated, has led African-Americans to distrust traditional health care services. Research studies
have indicated that, in general, African-American men have inferior health status, with 28 percent without health insurance and 40 percent dying prematurely. Seeking the kind of health they need is challenging. These percentages are inclusive of all educational levels and socioeconomic status. Joiner (2004) further discusses provider bias:

The 1999 Kaiser Family Foundation report found that 69 percent of physicians believed that the health care system rarely or never treats people unfairly based on an individual’s race/ethnicity. An Institute of Medicine report revealed that many doctors don’t consciously discriminate against patients. However, who gets what kind of care is often decided based on preconceived negative stereotypes about certain groups. The report found that provider bias, prejudice and stereotyping may contribute to health care disparities. Even those who were well-meaning demonstrated negative racial attitudes. The report cited a study in which doctors working in a clinical setting rated African-Americans, despite their income or education, as lazy, less intelligent, less educated, less likely to comply with medical advice and more likely to abuse drugs and alcohol (Joiner, 2004, p. 18-19).

The National Cancer Institute has defined health disparity as discrepancies in the incidence, prevalence, mortality, and burden of cancer that exist among specific population groups in the United States. The groups can be identified by race, ethnicity, social class, disability, income, age, or sexual orientation (NCI, 2005).

According to former President Clinton, by 2010, health disparities will be eliminated. It is 2006, less than four years away from the goal. African-Americans, to date, have little reason to trust that, in the very near future, genuine concern about quality of their health care and equal access in the U.S. health care system will be adequately corrected (Dept. of Health and Human Services Minority Resources, 2006).

Study results on trust in the health care environment indicate patient trust predicts health-seeking behaviors, namely, preventive health and adherence to treatment recommendations. According to Thom (2004), trust is, first, a person’s
acknowledgement of being in a vulnerable situation and, second, feeling secure that an identified person will act in the vulnerable person’s best interest. To measure trust in the health care system, physician attributes involving trust factors were identified by patients. The ability to establish good rapport; to understand and empathize; to provide honest, complete information about the patient’s illness and health; and to actually serve in the patient’s best interests were important identified physician attributes that could inspire patient trust, which is essential for high quality health care. He estimates that patient trust is closely associated with patient adherence and this may explain hesitancy to pursue medical care, from prevention to surgery, among African-Americans, who may experience high levels of medical mistrust.

A qualitative study on social support and elderly African-American cancer patients, determined that the types of social support used by this patient population has not been prioritized in current research. Hamilton et al. (2004) thinks middle-class Caucasians have typically been study subjects in research on types of social support experiences and that when African-American cancer patients are included in studies, the findings inappropriately indicate that these patients lack support. The subjects indicated the following types of social support were preferred:

- Emotional support: the presence of others, encouraging words, distracting activities, protecting, monitoring

- Instrumental support: offers of prayers, assistance to continue religious practices, assistance to maintain social roles, assistance to live at home

- Informational support: church-sponsored support groups, family, friends, getting information on what to expect, how to manage symptoms, help to interpret information, validation of information received (Hamilton, et al., 2004, p. 792).
Research results on perceived racism and social support among 64 African-American college students revealed that social support helped to control blood pressure reactivity during experiences of perceived racism (Clark, 2003).

In a questionnaire-based investigation on health behavior involving 216 African-American men, discrimination experiences were positively related to high levels of medical mistrust and that psychosocial, historical, socioenvironmental and healthcare factors must be examined to understand the health behaviors of African-American men (Powell, 2005).

Data from Medicare claims for over 90,000 men diagnosed with prostate cancer were used to examine treatment changes during a time span of 10 years. Results indicated Caucasian men received routine follow-up treatment twice more than African-American men (Zeliadt, 2004).

Fourteen African-American prostate cancer survivors were interviewed during a study on cultural beliefs and attitudes about complementary and alternative practices and products. Prayer was very important in coping with the stressors that were associated with prostate cancer (Jones, 2005).

There was support found for a study hypothesis that African-American men would be more likely than Caucasian men to place their lives in God’s care and not concentrate on the future as much as the present. The researcher investigated factors that contribute to health attitudes and behavioral outcomes by administering time perspective and religious problem-solving instruments (Flourney, 2002).
The structural and political conditions that create inequities in health are typically ignored and, instead, the focus is placed on the behaviors of African-Americans that result in negative outcomes (Barg, 2000).

In a qualitative study on coping strategies of 196 African-American women, the findings provided multiple behavioral strategies which explains African-American responses to rendered inequities:

- **Internal coping** – resting on faith (relying on prayer and spirituality), standing on shoulders (drawing strength from African-American ancestors), valuing oneself (sustaining a positive self-image)
- **External coping** – leaning on shoulders (relying on social support)
- **Specific coping** – role flexing (altering their outward behavior or presentation), avoiding (diminishing contact with certain people and situations), standing up and fighting back (directly challenging the source of the problem) (Shorter-Gooden, 2004, p. 406).

In a qualitative study on social support intervention among African-American women, three focus groups of 18 were conducted with lower income, socially isolated, and pregnant subjects. Stressors and types of intervention to address those stressors were investigated and were identified as typical basic needs. They reported coping through their relationships with God, their mothers, and some with their male partners. The expectations were for their identified support systems to be there for them, indulge and listen to them. The social support interventions developed through this study, were four 30-60 minute sessions provided throughout the pregnancy, which consisted of skill-building for self-esteem and accessing support and providing a support coordinator assigned to acknowledge and value the subject (DeJoseph, et al., 1996).
Henderson (2003) compiled information on support networks that 43 African-American breast cancer support group participants used. In the data collected, the majority of the women were married, possessed a high school education or less, and had incomes of $30,000 to $59,999. The majority reported God as their most important source of support and reported using the following a great deal: talking to someone to find out more about the situation, talking to someone who could do something concrete about the problem, talking to someone about how they were feeling, asking a respected relative or friend for advice, accepting sympathy and understanding from someone, and getting professional help.

African-Americans tend to believe that when cancer is diagnosed, death is certain. This belief is a basic feature of the concept of cancer fatalism, which is considered a barrier to treatment. Powerful research on fatalism and spirituality has been conducted by Powe (2003) and her colleagues.

Spirituality among African-Americans significantly enhances coping with racial stress and influences positive health outcomes. This concurs with the findings of the above studies (Bowen-Reid & Harrell, 2002).

A review of literature was conducted on spiritual beliefs that influence the treatment decisions of African-Americans because information on and understanding of such cultural dynamics can be beneficial for health care providers. The belief that God is ultimately responsible for all aspects of human health and that the physician is ‘God’s instrument’ provides a source of support, comfort, and a productive way to influence healing. Results indicated that African-Americans are more likely than Caucasians to place great importance on healing through prayer, that the will of God is most important
in their recovery, and that they have relied on this higher degree of spirituality since the historical times involving oppression (Johnson, 2005).

**Social Support Measurement Instruments**

In this study, social support is defined as any process through which social relationships might promote health and well-being (Cohen, et al., 2000). Three models were considered in order to construct an index to measure social support factors, focusing on the evidence of the existence of social support during the time span between diagnosis and initial treatment.

**Supportive Care Needs Survey**

The Supportive Care Needs Survey was designed by Bonevski, et al. (2000), to measure the needs of cancer patients and to also assess health services and treatment delivery. The 59 items in the survey are grouped into five categories: psychological needs, health system needs, physical and daily living needs, patient care and support and sexuality. In this questionnaire, the respondents are able to educate and offer explanations on whether their needs were satisfied and whether the amount of help needed was low, moderate, or high (CMHSR Measures Collection, 2006).

**Social Support Behaviors Scale**

The Social Support Behaviors Scale was designed in 1987 by Vaux, Riedel, and Stewart and intended to measure five dimensions of available social support from family and friends: emotional, socializing, practical assistance, financial assistance, and advice/guidance. Subjects completing the scale are asked to consider how likely family
members and/or friends would provide assistance in 45 different ways listed in the instrument. The scale’s focus is on perceived social support and covers the factors important to emotional, informational, and instrumental support (Vaux, et al., 1987).

Medical Outcomes Study: Social Support Survey Instrument

The Medical Outcomes Study: Social Support Survey Instrument was developed for patients with chronic conditions who participated in a two-year study on medical outcomes. The self-administered instrument is brief and measures how often (none of the time, little of the time, some of the time, most of the time, and all of the time) various kinds of support may be available to the patient. The survey measures five social support dimensions: emotional/informational support, tangible support, affectionate support, positive social interaction and additional items. The statements under each dimension are intended to gather information indicating support available to the patient (Rand, 2006).

Summary of Social Support

Female cancer patients worry about their spouses and children and experience self-blame and guilt about their illnesses. Cancer patients can become extremely upset, worry about the side effects of treatment, and how their lives will be disrupted. People need a variety of types of social support.

There is no consensus on the definition of social support. The most studied area of social support is perceived and received care. Social support and health outcomes are significantly related. Some say the number of supportive relationships is related to survival but other researchers believe the quality of or perception of supportive
relationships is more significant. The most negatively affected social relationships among cancer patients are with employers.

Family or friends with past experiences with cancer elicit quicker responses to symptoms and less delay among those in receipt of their support. Religiosity and spirituality influence health outcomes. Spouses of prostate cancer patients experience the same distress as the patient but positively responded to treatment demands, which allowed them provide effective intervention with their husbands. Living with others provides motivation to get treatment. Studies on living alone had conflicting results. Having to divulge their sexual orientation the health care professionals is discomforting for patients who are gay, and population primarily received emotional support from domestic partners, family and friends.

Close to 50 percent of U.S. population do not have health insurance. Clinical trial participation can be a viable treatment option. Bone marrow transplantation patients experience significant quality of life challenges. High levels of pretransplant anxiety among patient and family is a predictor of increased risk for posttransplant complications. There is limited research on social support, lymphoma and bone marrow transplantation patients.

Negative stereotypes of certain groups are still present in the health care system. African-American people have historically depended on support from extended family, which is a distinguishing characteristic among this population. African-American cancer patients have their own translations of emotional, information, instrumental support, as well as, internal and external coping and extended family and church/spirituality are important support systems in the African-American community. There is a gap in
research on social support during all stages of illness and on the political conditions responsible for health disparity.

Social Work and Oncology

Social Work Profession and Mission

The National Comprehensive Cancer Network (NCCN) provides detailed medical treatment guidelines for cancer specialists. This network also presents a version written specifically for cancer patients. Information on patient distress is included in the treatment guidelines. The Association of Oncology Social Work, established in 1984, is an international organization with over 900 social workers. This organization provided the distress guidelines for NCCN and was organized to provide comprehensive services to patients and families throughout all phases of the cancer experience. Services are provided in a variety of settings including cancer centers, hospitals, home health and hospice programs, community-based agencies, and private practice settings. The association’s mission is to facilitate quality psychosocial care of cancer survivors and their support systems by focusing on education, networking, advocacy, research, and resource development (Association of Oncology Social Work, 2006).

The National Association of Social Workers, as well as the National Association of Black Social Workers, each has components within their programs to address health and cancer issues. These organizations provide training, research, and advocacy support for social workers who provide services to cancer patients.
Psychosocial Intervention

After the patient receives a cancer diagnosis, information about support services is traditionally provided. The hospital or clinic may offer resources such as support groups; financial, nutritional, and pastoral services; and patient and family counseling. The patient is responsible for contacting the support services they feel would assist in their overall medical care unless the hospital or clinic takes the initiative to set up these services for the patient (Winship Cancer Institute, 2006).

Interviewing patients to identify their primary support persons should be conducted by social workers, who would then strongly encourage the patient and the health care team to include these significant others for positive support throughout the cancer care experience (Davis, 2004).

An investigation was conducted on the effectiveness of structured telephone interviews by social workers for the purpose of prescreening patients before their first cancer treatments at a major cancer center. Substantive information on the patient’s support systems was gathered and patient rapport was promptly established by the social workers. The researchers were able to gather enough pertinent information about the patients to identify assistance that could be provided before or the patients’ initial visit (Korcz, 1998).

A study evaluating hospital social work, specifically examining patient acceptance of consultation by a social worker, was conducted. Of the 273 cancer patients, 78 percent considered consultation by the social workers beneficial. Ninety-six percent of these patients felt that consultations should be offered to all cancer patients, as many patients were unaware of hospital social workers. Patient topics of interests in the
consultations were on medical rehabilitation, social law, coping strategies, and individual psychosocial issues (Bonninghaus, et al., 1999).

The results of a literature review on usage of psychosocial oncology services revealed that only 15 to 25 percent of cancer patients may use the services. Many patients are concerned with instrumental support. Methods on increasing access to and usage of social work services among all groups of people should be further explored (Cwikel, 1999).

Beder (1995) examined, in a quantitative-descriptive study, the diverse demographic features and the relationship between social support perceptions and breast cancer adjustment among African-American women. As a professor of social work, the researcher was most interested in exploring the implications for social work intervention. Women, aged 65 or younger, who were diagnosed for the first time, had mastectomies, were socioeconomically disadvantaged, and covered by Medicaid or Medicare were recruited from hospitals in New York City. Fifty women were 3 months postmastectomy and fifty were 12 months postmastectomy. The Psychosocial Adjustment to Illness Scale, the Interpersonal Support Evaluation List, and the Social Work Involvement Scale were utilized in the study. Higher perceptions of social support caused positive adjustment to the illness. Social work utilization in the hospitals was low and, ironically, did not have as a significant role as expected in this study.

Community Intervention

In this 21st century, the social work profession has competition from other health care professions for the crucial roles of traditional medical social work such as
psychosocial therapy, intake and discharge planning, and community liaison work. The changing healthcare system is adapting to the managed care protocol that influences the duration of hospital stays, medical costs, and how the provision of social work services should be handled (Sulman, 2001).

Rizzo examined utilization reviews and focused on social work roles in health care settings. The findings indicate that because of decreased lengths of stay and increased tension over how health care budgets should be utilized, hospital-based social work, which is not considered income generating, may suffer casualties to hospital downsizing (Rizzo, 2000).

Zebrack (2000) explains how social workers must respond to such dilemmas: “Caught in conflicts that challenge them to reconcile simultaneous commitments to client service/empowerment and institutional conformity, social workers must establish a more powerful position to negotiate institutional and public policies that uphold the primacy of a core social work ethic” (Zebrack, 2000, p. 89).

One way oncology social workers can hold more powerful negotiating positions is by staying current with important research. Participating in, as well as staying current with, intervention research may be crucial to gathering changing information on patient needs which include groups of people - minorities, non-traditional, non-middle-class groups - not sufficiently represented in research (Cwikel, 1999).

Berkman (2000) stated in her work entitled, Social Support, Social Networks, Social Cohesion and Health, that social work has made important contributions in the area of physical and mental health. Social workers provide creative and effective solutions to complex health problems involving social relationships.
The attempts to improve health care access and participation among people of color have not been easy tasks for social workers. Wells (1977) discussed the state of health care and social work in the United States. Throughout the past centuries, people of color have struggled to get and keep all provisions covered within their human rights. The social workers’ struggles are the same in the delivery of services in health care. There must entail a holistic response to all factors that contribute to the lack of optimal health. Social workers must teach patients how to use the health care system in ways that benefit them or to change a system that does not work for them.

Not all patients are able to receive hospital care and the number of people receiving outpatient cancer care has increased. These patients return to their communities, more than likely, in need of support services. In response to changing client needs, social work professionals, with cancer care knowledge and experience, are in advantageous positions to act as liaisons with community agencies and to develop new community resources (Clark, 2000).

Theoretical Framework

In her career as a social worker, Jane Isaacs Lowe (1997) has focused on and conducted research on community-oriented practice. Lowe designed the Social-Health Model to provide a forum for enhancing the education of social workers in health care practice and believes that health is not only a function of human biology and physiology but, significantly, involves the social and physical environment. A community is a group of people with common interests and social workers must examine the issues of community and public health and claim leadership roles in the health care arena, with the
specific goal of improving health via the home, work, and social environments of the individual.

The Social-Health Model facilitates the examination of links between health, illness, and the social functioning of individuals, groups, and communities. Health impacting social problems such as poverty, substance abuse, violence, and discrimination must have interventions designed to further prevention and health promotion, utilizing a community-oriented framework. The Social-Health Model creates a path for social workers to “identify themselves as primary care providers who possess expertise in” community practice, education, and research (Lowe, 1997, p. 217).

Improving the health of African-Americans, who are experiencing disturbing incidence and mortality rates in major chronic illnesses, will necessitate a community-oriented approach. The significant economic, environmental, and political problems that result in health disparity indicate that the personal lifestyles and behaviors of African-Americans are not the only concerns in need of examination and resolution. The Social-Health Model demonstrates the importance of psychosocial interventions in primary care and requires the promotion of support from all community shareholders (Lowe, 1997).

The Social Cognitive Theory has been a platform on which many theories have been supported and will provide the basis of the framework for this study. Bandura (1994) theorized that a person’s behavior is determined by a combination of cognitive, behavioral, and environmental factors. According to this theory, which is frequently utilized in health care research, a patient, equipped with social learning experiences, possesses a core set of determinants for health behavior. These determinants include
knowledge of health risks and benefits; perceived self-efficacy; outcome expectations; health goals; and perceived facilitators.

The Social Cognitive Theory stresses the importance of integrating significant causal factors and core determinants in order to understand how human beings forge decisions. A lymphoma patient may seek to understand a given diagnosis, staging of the disease, and treatment recommendations. The comprehension gained may provide an increased capability to make prompt, appropriate health decisions, which would then allow the patient to proceed on an evaluative journey that processes all expected benefits and losses. The patient is, thereby, better equipped to determine short term and long term health plans based on personal needs and/or desires. Throughout this journey, perceptions about the social support network are processed and supportive social interactions are utilized to cope with and/or overcome the illness.

This research sought to examine the influence that a variety of supportive social interactions may have on health behavior during the time span between the diagnostic consultation and the patient’s first cancer treatment. The Social Cognitive Theory provides a conceptual framework for investigating connections between psychosocial and behavioral determinants and outcomes.

Research studies, utilizing the Social Cognitive Theory, have been conducted on countless health topics, especially with adherence studies: children’s dietary behavior, exercise management interventions among the elderly, patients receiving cardiovascular treatment, health education for HIV infection, and quality of life outcomes through intervention with cancer patients. This framework is useful in explaining and predicting behaviors and examining behavior change.
The Social Cognitive Theory has been criticized for providing a "static view of behavior change," (Gebhardt & Maes, 2001, p. 528-536) in that, once self-efficacy is established by an individual, an assumption is made that the expected behavior change will definitely occur. The theory has also been criticized for examining behavior on an individual level rather than group levels but the constructs of collective efficacy and social change are clearly explained within the theory.

Barbara Powe (1997) designed the Powe Fatalism Model to provide a framework for examining cancer fatalism which is the belief that a cancer illness is beyond the scope of human control and that a diagnosis of cancer means certain death. Cancer fatalism is an identified barrier to cancer screening and treatment, which may cause significant treatment delay among cancer patients. African-American cancer patients, with their extraordinary history of slavery in this country, possess lived experiences of racism and poverty and these experiences along with possible feelings of hopelessness and despair have been identified as evidence of fatalism.

Finding meaning in life through a higher being, exercising prayer and faith, and attending church are associated with having spirituality. Powe (1997) and her colleagues believe that "hope may be the common denominator that binds the concept of fatalism and spirituality" and this coping mechanism may assist in positively modifying health-seeking behaviors (Powe, 1997, p. 142).

The social work profession will continue to support, enhance, and develop community-oriented services dedicated to improving overall health and well-being. Particular attention must be given to those with special needs such as African-American patients considered for bone marrow transplantation who may not have access to quality
care, who may be hesitant to pursue care due to feelings of anxiety and medical
mistrust, or may pursue care but are deemed poor candidates for the transplant due to
lack of adequate support systems (single mother without childcare assistance). The
Social-Health Model assumes the importance of facilitating support throughout all
possible levels of functioning – the individual, economic, political, environmental, and
other levels.

There is synergy with the Social-Health and Social Cognitive models, in that,
both assume the importance of examining integrating causal factors for increased
comprehension of concerns and for providing a framework for the creation of appropriate
interventions to address multidimensional issues that concurrently impact individuals and
communities.

Powe’s Fatalism Model provides excellent opportunities to understand concepts
of religion, spirituality, and health that have traditionally been overlooked in research
which has included African-American participants.
CHAPTER III

METHODOLOGY

Chapter III describes the methods and procedures used in the investigation on the influence of social support on treatment delay among African-American patients diagnosed with lymphoma. The chapter is divided into the following sections: research design; description of the site; sample and population; instrumentation; treatment of the data; and limitations of the study.

Research Design

The descriptive and explanatory research design was used in this study. This study was designed to collect data in order to describe and explain the influence that the presence of supportive social interactions may have on the timely initiation of treatment among African-American lymphoma patients who are considered for bone marrow transplantation at Emory University Healthcare and the Winship Cancer Institute.

Description of the Site

This research study was conducted in Atlanta, Georgia, a large urban metropolitan area. This research was part of an IRB approved, ongoing study on treatment outcomes for patients with non-Hodgkin’s lymphoma at Emory University Healthcare and the Winship Cancer Institute. Existing data for this study was obtained
from the Emory University Healthcare databases containing medical information on oncology patients at the Winship Cancer Institute, Crawford Long Hospital, Emory Clinic and Emory Hospital. A data manager has direct access to data that was requested and made available to the investigator for this study.

Sample and Population

The target population for this research will be composed of lymphoma patients considered for bone marrow transplantation, with special emphasis on African-American patients. These patients have been diagnosed with relapsed lymphomas, with the three major diagnoses being relapsed follicular lymphoma, relapsed Hodgkin’s lymphoma and relapsed diffuse large B-cell lymphoma. These diagnoses, depending on the stage of the disease, requires transplantation as standard treatment. The Emory University Healthcare databases house patient data including extensive social work assessments only on lymphoma cancer patients considered for transplantation. Demographic data and the bone marrow transplantation social work assessments on 119 patients were collected, utilizing nonprobability sampling. Bone marrow transplantation social work assessments are those records that contain the following patient information: demographic, marital status, insurance, employment status, diagnosis and treatment, family of origin, support and caregiver, compliance status, financial concerns, hobbies and interests, coping skills, religious affiliation, history of psychiatric treatment, substance use, legal history, veteran’s status, lodging and transportation plan, advance directives, resources given to the patient, assessment, and recommendation and plan.
Oncology patients provided consent to medical information storage in the databases of the Emory University Healthcare. All patient identifying information used for research is protected. The Health Information and Portability Accountability Act of 1996 (HIPAA) identifiers are masked. Masked information consists of patient name, patient ID, patient address, patient phone number, patient social security number, patient corporate identifier, and medical record number.

Instrumentation

This study examined the influence of social support (emotional, informational, and instrumental) on the time span between diagnosis and initial treatment among lymphoma patients considered for bone marrow transplantation. The hypothesis for this study was that there was a statistically significant relationship between emotional, informational, and/or instrumental support and the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment.

The research study utilized an inventory tool, the Patient Support Index, which is a compilation of informational items obtained from established social support measurement instruments. The inventory was designed to collect data pertinent for this study. Data was read from the social work assessments and hematology notes (dates were collected for the New Patient Consult and the following appointment) and recorded on to the Patient Support Index in order to show evidence of support that may have been received by the patient.

Section I of the inventory consists of eight items (1 through 8) concerning age, gender, race/ethnicity, diagnosis, stage of disease, date of diagnosis, date of initial
treatment, and the time from diagnosis to initial treatment. These items will provide information for the presentation of a patient demographic profile and determines the amount of treatment delay.

Sections II (Emotional Support), III (Informational Support), and IV (Instrumental Support) consists of the last thirteen items which will measure to what extent emotional, informational, and instrumental support exists among the patients who may or may not have experienced treatment delay.

Measures for Demographic and Patient Information

Demographic and patient information used in this study were defined based on guidelines by the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) and guidelines established by the IRB approved lymphoma study with Emory University School of Medicine and Winship Cancer Institute. This information was operationalized as follows: age (date of birth to date of diagnosis); gender (male or female); race/ethnicity (black, white, Hispanic, Asian/Pacific Islander, other); diagnosis (documented diagnosis); and stage of disease (documented pathologic stage).

Measures for Social Support

Social support is defined in this study as any process through which social relationships might promote health and well-being (Cohen, et al., 2000). Functional or available support, a dimension of social support, is further delineated to emotional support (availability of people who can allow discussions of feelings and express care and acceptance towards an individual having problems), informational support (provision of information that may be useful for solving problems), and instrumental support
(provision of tangible assistance such as child care or home care). All of the social support variables allow for the theoretical benefits attributed to each of the three functional supports examined.

The social support variables used in this study were operationalized as follows: spouse/partner (married, domestic partner, single, separated, widowed, divorced, unknown); children (adult children, children less than 18 y.o., none); other support (extended family-kin and non-kin, friends, organizations); church/spiritual (church attendance, personal prayer, visits with clergy, none); clinician (physician, nurse, social worker, none); formal peer support (cancer peer interaction, no cancer peer interaction); formal group support (support group attendance, no support group attendance); cancer resources (online resources, resource center, printed materials, other, none); employment status (employed, self-employed, homemaker, retired, disabled, unemployed, unknown); basic needs (place to live, access to food/prepared meals, available transportation, childcare assistance); health insurance (private, public, none); living arrangement (live with others, live alone); and clinical trials (participating in a clinical trial for lymphoma, not participating in a clinical trial for lymphoma).

**Measure for Initial Treatment Delay**

The examination of the link between duration of symptoms and survival among approximately 3000 women provides a useful study model for measuring delay. The 16-year study’s hypothesis stated that, among the subjects, those with duration of symptoms 12 weeks or longer would result in worse survival rates than the subjects with less delay. Existing data was extracted from the hospital’s database and delay intervals,
specifically, the interval between onset of symptoms and first treatment (total delay) was examined, while noting any influence on survival. Statistical analysis was conducted using the chi-squared test (assessed delay with cut-off of 12 weeks and 26 weeks) and log rank test (assessed influence on survival of delay) and multivariate analysis using the stepwise Cox regression model (assessed survival from diagnosis). The results showed that the relationship between longer delay and worse survival was statistically significant. The reported survival rates were: 1) 51 percent for delay less than 12 weeks; 2) 44 percent for delay 12-26 weeks; and 3) 40 percent for delay greater than 26 weeks (Richards, et al., 1999).

The measure used in this study for initial treatment delay is as follows: time from diagnosis to initial treatment (number of weeks elapsed, less than 12 weeks, 12 to 26 weeks, more than 26 weeks).

Treatment of the Data

Statistical treatment of the data employed descriptive statistics, including measures of central tendency, frequency distribution, and cross tabulation. Statistical analysis were performed by using the Statistical Package for Social Sciences. The Chi squared test was used to assess delay (Richards, 1999) and logistic regression analysis was used to test the hypothesis and determine if social support explains differences in treatment delay (Mertler & Vannatta, 2001).
Limitations of the Study

This study was dependent on the accuracy and completeness of the medical data previously collected by the hospital social workers. The existing data may not include information on all of the study measures.
CHAPTER IV
PRESENTATION OF FINDINGS

The purpose of this chapter was to present the findings of the study in order to describe and explain the influence that the presence of supportive social interactions may have on the timely initiation of treatment among lymphoma patients who are considered for bone marrow transplantation. This chapter presents the findings of the study. The findings are organized into two sections: demographic and clinical data; and research question and hypothesis.

Demographic and Clinical Data

This section provides a profile of the study population. Descriptive statistics were used to analyze the following: age group, gender, ethnicity, marital status, children, employment status, diagnosis and stage of disease.

A target population for the research was composed of lymphoma patients considered for bone marrow transplantation and had at least one consultation with a social work clinician, at which time information was provided for a complete social work assessment.

These patients provided consent to medical information storage in the Emory University Healthcare databases. The bone marrow transplantation social work assessments and additional social work notes regarding the lymphoma patients are
electronically stored within the hematology notes section in the Emory University Healthcare databases.

Table 1

Demographic and Clinical Characteristics of the Study Population

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18 – 30</td>
<td>13</td>
<td>10.9</td>
</tr>
<tr>
<td>31 – 50</td>
<td>42</td>
<td>35.3</td>
</tr>
<tr>
<td>51 – 70</td>
<td>63</td>
<td>52.9</td>
</tr>
<tr>
<td>Over 70</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>68</td>
<td>57.1</td>
</tr>
<tr>
<td>Female</td>
<td>51</td>
<td>42.9</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>27</td>
<td>22.7</td>
</tr>
<tr>
<td>White</td>
<td>78</td>
<td>65.5</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5</td>
<td>4.2</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>6.7</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>76</td>
<td>63.9</td>
</tr>
<tr>
<td>Never married</td>
<td>21</td>
<td>17.6</td>
</tr>
<tr>
<td>Widowed</td>
<td>4</td>
<td>3.4</td>
</tr>
<tr>
<td>Divorced</td>
<td>13</td>
<td>10.9</td>
</tr>
<tr>
<td>Separated</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>Domestic partner</td>
<td>3</td>
<td>2.5</td>
</tr>
<tr>
<td><strong>Children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>18</td>
<td>15.1</td>
</tr>
<tr>
<td>Under 18 years</td>
<td>35</td>
<td>29.4</td>
</tr>
<tr>
<td>Over 18 years</td>
<td>66</td>
<td>55.5</td>
</tr>
</tbody>
</table>
Table 1 (continued)

Demographic and Clinical Characteristics of the Study Population

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>51</td>
<td>42.9</td>
</tr>
<tr>
<td>Unemployed</td>
<td>26</td>
<td>21.8</td>
</tr>
<tr>
<td>Self-employed</td>
<td>3</td>
<td>2.5</td>
</tr>
<tr>
<td>Retired</td>
<td>16</td>
<td>13.4</td>
</tr>
<tr>
<td>Homemaker</td>
<td>3</td>
<td>2.5</td>
</tr>
<tr>
<td>Disabled</td>
<td>20</td>
<td>16.8</td>
</tr>
<tr>
<td>Health Insurance Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5</td>
<td>4.2</td>
</tr>
<tr>
<td>Public Insurance</td>
<td>28</td>
<td>23.5</td>
</tr>
<tr>
<td>Private Insurance</td>
<td>86</td>
<td>72.3</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hodgkin’s</td>
<td>32</td>
<td>26.9</td>
</tr>
<tr>
<td>Follicular</td>
<td>12</td>
<td>10.1</td>
</tr>
<tr>
<td>Diffuse Large B-Cell</td>
<td>51</td>
<td>42.9</td>
</tr>
<tr>
<td>Other NHL</td>
<td>24</td>
<td>20.2</td>
</tr>
<tr>
<td>Stage of Disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage I</td>
<td>5</td>
<td>4.2</td>
</tr>
<tr>
<td>Stage II</td>
<td>23</td>
<td>19.3</td>
</tr>
<tr>
<td>Stage III</td>
<td>23</td>
<td>19.3</td>
</tr>
<tr>
<td>Stage IV</td>
<td>32</td>
<td>26.9</td>
</tr>
<tr>
<td>Unknown</td>
<td>36</td>
<td>30.3</td>
</tr>
<tr>
<td>Major Emotional Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>99</td>
<td>83.2</td>
</tr>
<tr>
<td>Extended family</td>
<td>10</td>
<td>8.4</td>
</tr>
<tr>
<td>Friends</td>
<td>8</td>
<td>6.7</td>
</tr>
<tr>
<td>Church/Spiritual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal prayer</td>
<td>56</td>
<td>47.1</td>
</tr>
<tr>
<td>Church attendance</td>
<td>41</td>
<td>34.5</td>
</tr>
<tr>
<td>Visit with clergy</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>None</td>
<td>20</td>
<td>16.8</td>
</tr>
</tbody>
</table>
Table 1 (continued)

Demographic and Clinical Characteristics of the Study Population

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinician Support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td>94</td>
<td>79.0</td>
</tr>
<tr>
<td>Social Worker</td>
<td>10</td>
<td>8.4</td>
</tr>
<tr>
<td>Physician</td>
<td>15</td>
<td>12.6</td>
</tr>
<tr>
<td>Living Arrangement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Live alone</td>
<td>12</td>
<td>10.1</td>
</tr>
<tr>
<td>Live with others</td>
<td>107</td>
<td>89.0</td>
</tr>
</tbody>
</table>

As indicated in Table 1, the typical patient in this study was a 51 to 70 years old, married white male with adult children. This typical patient was employed, had private health insurance, lived with others, received the diagnosis of relapsed diffuse large B-cell lymphoma, and was either in stage IV of the disease or stage was unknown. The major source of emotional support was received from family members, personal prayer was most important, and clinician support was, more than likely, received from nurses. The following tables include frequency distributions the results of statistical analysis of demographic and clinical variables.

Research Question and Hypothesis

There was one research question and one null hypothesis in the study. This section provides an analysis of the research question and a testing of the null hypothesis.
Research Question: Does having access to emotional, informational, and/or instrumental support decrease the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment?

Null hypothesis: There is no statistically significant relationship between emotional, informational, and/or instrumental support and the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment.

In this study, social support has been defined as any process through which social relationships might promote health and well-being. Emotional, informational, and instrumental support are components of functional support which measures perceived (available if needed) and received support (recently provided) (Cohen, et al., 2000).

In this study, treatment delay (total delay) was defined as the time interval that occurs from the beginning of symptoms to the start of professionally recommended care. Treatment delay can best be explained utilizing the following three intervals: 1) less than 12 weeks for acceptable time elapse; 2) 12 to 26 weeks for significant delay; and 3) more than 26 weeks for advanced delay.

Table 2 is a frequency distribution of the time since diagnosis to initial treatment among 119 lymphoma patients considered for bone marrow transplantation. Table 2 indicates the type of delay experienced by these patients.
Table 2

Time since diagnosis to initial treatment

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 12 weeks</td>
<td>108</td>
<td>90.8</td>
</tr>
<tr>
<td>12-26 weeks</td>
<td>9</td>
<td>7.6</td>
</tr>
<tr>
<td>&gt; 26 weeks</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>Total</td>
<td>119</td>
<td>100.0</td>
</tr>
</tbody>
</table>

As shown in Table 2, lymphoma patients who experienced less than 12 weeks delay was 90.8%. Lymphoma patients who experienced 12 to 26 weeks delay was 7.6% and 1.7% experienced more than 26 weeks delay.

Table 3 is a cross tabulation of ethnicity and time since diagnosis or delay among 119 lymphoma patients considered for bone marrow transplantation. Table 3 indicates the type of delay experienced by the five ethnic groups.
Table 3
Ethnicity by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>24</td>
<td>20.2</td>
<td>3</td>
<td>2.5</td>
<td>27</td>
</tr>
<tr>
<td>White</td>
<td>71</td>
<td>59.7</td>
<td>7</td>
<td>5.9</td>
<td>78</td>
</tr>
<tr>
<td>Hispanic</td>
<td>5</td>
<td>4.2</td>
<td>0</td>
<td>0.0</td>
<td>5</td>
</tr>
<tr>
<td>Asian</td>
<td>1</td>
<td>.8</td>
<td>0</td>
<td>0.0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>5.9</td>
<td>1</td>
<td>.8</td>
<td>8</td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
<td>119</td>
</tr>
</tbody>
</table>

\( \chi^2 = .831 \quad \text{df} = 4 \quad p = .934 \)

As shown in Table 3, close to six percent (5.9%) of lymphoma patients who experienced more than 12 weeks delay were white while (2.5%) were black. There were no Hispanic or Asian patients who experienced more than 12 weeks delay.

The chi-square test was conducted to determine if there was a statistically significant relationship between ethnicity and delay. Chi-square results indicate there is no statistically significant relationship between ethnicity and delay at the .05 probability level.

Table 4 is a cross tabulation of marital status and delay among 119 lymphoma patients considered for bone marrow transplantation. Table 4 indicates marital status and the type of delay experienced by these lymphoma patients.
### Table 4

Marital Status by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>69</td>
<td>58.0</td>
<td>7</td>
<td>5.9</td>
<td>76</td>
<td>63.9</td>
<td></td>
</tr>
<tr>
<td>Never married</td>
<td>18</td>
<td>15.1</td>
<td>3</td>
<td>17.6</td>
<td>21</td>
<td>17.6</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>4</td>
<td>3.4</td>
<td>0</td>
<td>0.0</td>
<td>4</td>
<td>3.4</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>12</td>
<td>10.1</td>
<td>1</td>
<td>.8</td>
<td>13</td>
<td>10.9</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>2</td>
<td>1.7</td>
<td>0</td>
<td>0.0</td>
<td>2</td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td>Domestic partner</td>
<td>3</td>
<td>2.5</td>
<td>0</td>
<td>0.0</td>
<td>3</td>
<td>2.5</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
<td>119</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

\[ \chi^2 = 1.590 \quad df = 5 \quad p = .902 \]

As shown in Table 4, close to six percent (5.9%) of married lymphoma patients experience more than 12 weeks delay. Lymphoma patients who were never married and experienced more than 12 weeks delay was (17.6%) and patients who indicated they were divorced and experienced more than 12 weeks delay was (.8%). Those patients who indicated they were widowed, separated, or reported having domestic partners had no results of delay more than 12 weeks.

The chi-square test was conducted to determine if there was a statistically significant relationship between marital status and delay. Chi-square results indicate there is no statistically significant relationship between marital status and delay at the .05 probability level.
In the study, having children may be a source of emotional support or positive motivation for the patient. This type of support can best be explained utilizing the following measures: 1) no children; 2) children under age 18; and 3) children over age 18.

Table 5 is a cross tabulation of children as a source of support and delay among 119 lymphoma patients considered for bone marrow transplantation. Table 5 indicates the type of delay experienced by lymphoma patients with or without children.

Table 5
Children by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>16</td>
<td>13.4</td>
<td>2</td>
<td>1.7</td>
<td>18</td>
</tr>
<tr>
<td>Under 18 years</td>
<td>33</td>
<td>27.7</td>
<td>2</td>
<td>1.7</td>
<td>35</td>
</tr>
<tr>
<td>Over 18 years</td>
<td>59</td>
<td>49.6</td>
<td>7</td>
<td>5.9</td>
<td>66</td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
<td>119</td>
</tr>
</tbody>
</table>

χ² = .741        df = 2        p = .691

As shown in Table 5, (5.9%) of lymphoma patients with children over 18 years of age experienced more than 12 weeks delay. Those patients who indicated they had no children or had children under the age of 18 years of age had the same results of (1.7%) for delay more than 12 weeks.
The chi-square test was conducted to determine if there was a statistically significant relationship between children as a source of social support and delay. Chi-square results indicate there is no statistically significant relationship between children as a source of support and delay at the .05 probability level.

Table 6 is a cross tabulation of the major source of emotional support and delay among 119 lymphoma patients considered for bone marrow transplantation. Table 6 indicates the type of delay experienced by lymphoma patients with regard to 1) family, 2) extended family, and 3) friends. This result served as indication of the first selection of emotional support reported by the patient to the social worker.

### Table 6

Major source of emotional support by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
</tr>
<tr>
<td></td>
<td>#</td>
</tr>
<tr>
<td>Emotional Support</td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>91</td>
</tr>
<tr>
<td>Extended family</td>
<td>8</td>
</tr>
<tr>
<td>Friends</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>106</td>
</tr>
</tbody>
</table>

Note: 2 missing responses

\[ \chi^2 = 1.612 \]
\[ df = 2 \]
\[ p = .447 \]
As shown in Table 6, (77.8%) of lymphoma patients who experienced less than 12 weeks delay indicated family as their major source of support. Patients who indicated having extended family as their major source of support and having experienced less than 12 weeks delay was (6.8%). The majority of the patients who experienced more than 12 weeks delay and indicated family as their major source of support was (6.8%).

The chi-square test was conducted to determine if there was a statistically significant relationship between major source of emotional support and delay. Chi-square results indicate there is no statistically significant relationship between major source of emotional support and delay at the .05 probability level.

Table 7 is a cross tabulation of the second major source of emotional support and delay among 119 lymphoma patients considered for bone marrow transplantation. Table 7 indicates the type of delay experienced by lymphoma patients with regard to 1) family, 2) extended family, and 3) friends. This result served as indication of the second or 'next-in-line' selection of emotional support reported by the patient to the social worker.
Table 7
Second major source of emotional support by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>%</td>
<td>More than 12 weeks</td>
<td>%</td>
<td>Total</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Family</td>
<td>6</td>
<td>7.1</td>
<td>2</td>
<td>2.4</td>
<td>8</td>
<td>9.5</td>
<td></td>
</tr>
<tr>
<td>Extended family</td>
<td>21</td>
<td>25.0</td>
<td>3</td>
<td>3.6</td>
<td>24</td>
<td>28.6</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>46</td>
<td>54.8</td>
<td>2</td>
<td>2.4</td>
<td>48</td>
<td>57.1</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2.4</td>
<td>2</td>
<td>2.4</td>
<td>4</td>
<td>4.8</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>75</td>
<td>89.3</td>
<td>9</td>
<td>10.7</td>
<td>84</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

Note: 35 missing responses

\[ \chi^2 = 10.391 \quad df = 3 \quad p = .016 \]

As shown in Table 7, (54.8%) of lymphoma patients who experienced less than 12 weeks delay indicated friends as their second major source of support. Patients who indicated having extended family as their second major source of support and having experienced less than 12 weeks delay was (25.0%). The majority of the patients who experienced more than 12 weeks delay and indicated extended family as their second major source of support was (3.6%).

The chi-square test was conducted to determine if there was a statistically significant relationship between the second major source of emotional support and delay. Chi-square results indicate there is a statistically significant relationship between the second major source of emotional support and delay at the .05 probability level.
Church/spiritual support can best be explained utilizing the following measures: 1) personal prayer; 2) church attendance; and 3) visits with the clergy. Table 8 is a cross tabulation of church/spiritual support as a source of emotional support and delay among 119 lymphoma patients considered for bone marrow transplantation.

Table 8
Support from church/spiritual by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th>Less than 12 weeks</th>
<th>More than 12 weeks</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Church/Spiritual</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td></td>
<td>18</td>
<td>15.1</td>
<td>2</td>
</tr>
<tr>
<td>Personal prayer</td>
<td></td>
<td>51</td>
<td>42.9</td>
<td>5</td>
</tr>
<tr>
<td>Church attendance</td>
<td></td>
<td>37</td>
<td>31.1</td>
<td>4</td>
</tr>
<tr>
<td>Visit with clergy</td>
<td></td>
<td>2</td>
<td>1.7</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>108</td>
<td>90.8</td>
<td>11</td>
</tr>
</tbody>
</table>

$\chi^2 = .237 \quad \text{df} = 3 \quad p = .971$

As shown in Table 8, (42.9%) of lymphoma patients who experienced less than 12 weeks delay indicated personal prayer as a source of support. Patients who indicated church attendance as a source of support and having experienced less than 12 weeks delay was (31.1%). The majority of the patients who experienced more than 12 weeks delay and indicated personal prayer as a source of support was (4.2%).
The chi-square test was conducted to determine if there was a statistically significant relationship between the church/spiritual support as a source of emotional support and delay. Chi-square results indicate there is no statistically significant relationship between church/spiritual support and delay at the .05 probability level.

Table 9 is a cross tabulation of clinician support as a source of informational support and delay among 119 lymphoma patients considered for bone marrow transplantation. Informational support can best be explained utilizing the following measures for clinician support: 1) nurse; 2) social worker; and 3) physician.

Table 9

Support from clinician by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th>Less than 12 weeks</th>
<th>More than 12 weeks</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Clinician</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurse</td>
<td></td>
<td>86</td>
<td>72.3</td>
<td>8</td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
<td>9</td>
<td>7.6</td>
<td>1</td>
</tr>
<tr>
<td>Physician</td>
<td></td>
<td>13</td>
<td>10.9</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>108</td>
<td>90.8</td>
<td>11</td>
</tr>
</tbody>
</table>

\[ \chi^2 = .366 \quad df = 2 \quad p = .833 \]

Table 9 indicates that (72.3%) of lymphoma patients who experienced less than 12 weeks delay received informational support from a nurse. Patients who indicated
having received support from a social worker and having experienced less than 12 weeks delay was (7.6%). Patients who experienced more than 12 weeks delay and indicated having received support from a physician was (10.9%).

The chi-square test was conducted to determine if there was a statistically significant relationship between clinician support as a source of informational support and delay. Chi-square results indicate there is no statistically significant relationship between clinician support and delay at the .05 probability level.

Table 10 is a cross tabulation of formal peer support as a source of informational support and delay among 119 lymphoma patients considered for bone marrow transplantation. Formal peer support can best be indicated utilizing the following measures: 1) No (no support); and 2) Yes (received support).

Table 10
Formal Peer Support by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th>Less than 12 weeks</th>
<th>More than 12 weeks</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
</tr>
<tr>
<td>Formal peer support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td></td>
<td>107</td>
<td>89.9</td>
<td>10</td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td>1</td>
<td>.8</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>108</td>
<td>90.8</td>
<td>11</td>
</tr>
</tbody>
</table>

$\chi^2 = 4.028 \quad df = 1 \quad p = .045$
Table 10 indicates that (.8%) of lymphoma patients who experienced less than 12 weeks delay received formal peer support. Patients who indicated having received support from a formal peer and having experienced more than 12 weeks delay was (.8%).

The chi-square test was conducted to determine if there was a statistically significant relationship between formal peer support as a source of informational support and delay. Chi-square results indicate there is a statistically significant relationship between formal peer support and delay at the .05 probability level.

Table 11 is a cross tabulation of formal group support as a source of informational support and delay among 119 lymphoma patients considered for bone marrow transplantation. Formal group support can best be indicated utilizing the following measures: 1) No (no support); and 2) Yes (received support).

Table 11

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Group support</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>101</td>
<td>84.9</td>
<td>10</td>
<td>8.4</td>
</tr>
<tr>
<td>Yes</td>
<td>7</td>
<td>5.9</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
</tr>
</tbody>
</table>

$\chi^2 = .108 \quad df = 1 \quad p = .742$
Table 11 indicates that (5.9%) of lymphoma patients who experienced less than 12 weeks delay received formal group support. Patients who indicated having received support from group participation and having experienced more than 12 weeks delay was (.8%).

The chi-square test was conducted to determine if there was a statistically significant relationship between formal group support as a source of informational support and delay. Chi-square results indicate there is no statistically significant relationship between formal group support and delay at the .05 probability level.

Table 12 is a cross tabulation of employment status as a source of instrumental support and delay among 119 lymphoma patients considered for bone marrow transplantation. Employment status can best be explained utilizing the following measures: 1) employed; 2) unemployed; 3) self-employed; 4) retired; 5) homemaker; and 6) disabled.
Table 12

Employment status by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Employed</td>
<td>46</td>
<td>38.7</td>
<td>5</td>
<td>4.2</td>
</tr>
<tr>
<td>Unemployed</td>
<td>23</td>
<td>19.3</td>
<td>3</td>
<td>2.5</td>
</tr>
<tr>
<td>Self-employed</td>
<td>3</td>
<td>2.5</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Retired</td>
<td>15</td>
<td>12.6</td>
<td>1</td>
<td>.8</td>
</tr>
<tr>
<td>Homemaker</td>
<td>3</td>
<td>2.5</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Disabled</td>
<td>18</td>
<td>15.1</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
</tr>
</tbody>
</table>

\( \chi^2 = .978 \)  \( \text{df} = 5 \)  \( p = .964 \)

Table 12 indicates that (38.7%) of lymphoma patients who experienced less than 12 weeks delay were employed and (19.3%) were unemployed. Patients who indicated having employment but experienced more than 12 weeks delay was (4.2%) and those unemployed was (2.5%).

The chi-square test was conducted to determine if there was a statistically significant relationship between employment status as a source of instrumental support and delay. Chi-square results indicate there is no statistically significant relationship between employment status and delay at the .05 probability level.

Table 13 is a cross tabulation of health insurance status as a source of instrumental support and delay among 119 lymphoma patients considered for bone
marrow transplantation. Health insurance status can best be explained utilizing the following measures: 1) none; 2) public insurance; and 3) private insurance.

Table 13
Health insurance status by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>Health insurance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>3.4</td>
<td>1</td>
<td>.8</td>
<td>5</td>
<td>4.2</td>
</tr>
<tr>
<td>Public insurance</td>
<td>25</td>
<td>21.0</td>
<td>3</td>
<td>2.5</td>
<td>28</td>
<td>23.5</td>
</tr>
<tr>
<td>Private insurance</td>
<td>79</td>
<td>66.4</td>
<td>7</td>
<td>5.9</td>
<td>86</td>
<td>72.3</td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
<td>119</td>
<td>100.0</td>
</tr>
</tbody>
</table>

\[ \chi^2 = .887 \quad df = 2 \quad p = .642 \]

Table 13 indicates that a majority (66.4%) of lymphoma patients who experienced less than 12 weeks delay had private insurance. Patients who indicated having no insurance and experienced more than 12 weeks delay was (.8%).

The chi-square test was conducted to determine if there was a statistically significant relationship between health insurance status as a source of instrumental support and delay. Chi-square results indicate there is no statistically significant relationship between health insurance status and delay at the .05 probability level.
Table 14 is a cross tabulation of living arrangement as a source of instrumental support and delay among 119 lymphoma patients considered for bone marrow transplantation. Living arrangement can best be explained utilizing the following measures: 1) live alone; and 2) live with others.

Table 14
Living arrangement by Delay

<table>
<thead>
<tr>
<th>Variable</th>
<th>Time since diagnosis to treatment</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Less than 12 weeks</td>
<td>More than 12 weeks</td>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Living arrangement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Live alone</td>
<td>10</td>
<td>8.4</td>
<td>2</td>
<td>1.7</td>
<td>12</td>
<td>10.1</td>
<td></td>
</tr>
<tr>
<td>Live with others</td>
<td>98</td>
<td>82.4</td>
<td>9</td>
<td>7.6</td>
<td>107</td>
<td>89.9</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>108</td>
<td>90.8</td>
<td>11</td>
<td>9.2</td>
<td>119</td>
<td>100.0</td>
<td></td>
</tr>
</tbody>
</table>

$\chi^2 = .877$  df = 1  p = .349

Table 14 indicates that a majority (82.4%) of lymphoma patients who experienced less than 12 weeks delay lived with others. Patients who indicated living alone and experienced more than 12 weeks delay was (1.7%).

The chi-square test was conducted to determine if there was a statistically significant relationship between living arrangement as a source of instrumental support and delay. Chi-square results indicate there is no statistically significant relationship between living arrangement and delay at the .05 probability level.
Results of Hypothesis Testing

Binary forward logistic regression was conducted to determine which independent variables (age, gender, ethnicity, employment status, insurance status, marital status, and children) were predictors of treatment delay greater than 60 days and treatment delay greater than 90 days. Separate logistic regressions were run on each dependent variable for treatment delay. The average number of days from initial diagnosis to initial treatment was 52 days ($M = 52.05$, $S = 134.73$). The median number of days from initial diagnosis to initial treatment was 32 days.

Hypothesis 1a: Demographic characteristics (age, gender, ethnicity, employment status, insurance status, marital status, and children) predict delay of treatment greater than 60 days.

Logistic regressions were conducted to determine which independent variables (age, gender, ethnicity, employment status, insurance status, marital status, and children) were predictors of treatment delay greater than 60 days. Data screening led to the elimination of six outliers. Regression results indicated the overall model fit of one predictor (gender) was statistically reliable in distinguishing between the presence or absence of treatment delay greater than 60 days ($-2 \text{Log Likelihood}=123.183$, $\chi^2(1)=4.264$, p<.05). The model correctly classified 77.3% of the cases. Regression coefficients are presented in Table 15.

Wald statistics indicated that gender significantly predicted the presence of treatment delay greater than 60 days. Odds ratios for this variable indicated change in the likelihood of having treatment delay greater than 60 days when the predictors increase by 1.
A cross-tabulation measurement revealed that a higher percentage of males (29.4%) experienced treatment delay greater than 60 days than females (13.7%). The phi (Φ) statistical measurement indicated a weak relationship (Φ = -.185) between the two variables.

Table 15
Regression coefficients for treatment delay greater than 60 days – demo

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>Wald</th>
<th>df</th>
<th>P</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (1)</td>
<td>.963</td>
<td>3.921</td>
<td>1</td>
<td>.048</td>
<td>2.619</td>
</tr>
</tbody>
</table>

Hypothesis 1b: Demographic characteristics (age, gender, ethnicity, employment status, insurance status, marital status, and children) predict delay of treatment greater than 90 days.

Logistic regressions were conducted to determine which independent variables (age, gender, ethnicity, employment status, insurance status, marital status, and children) were predictors of treatment delay greater than 90 days. Data screening led to the elimination of seven outliers. Regression results indicated that none of the predictors fit the overall model. Regression coefficients of variables not in the equation are presented in Table 16.
Table 16
Regression coefficients of variables not in the equation for delay greater than 90 days – demo

<table>
<thead>
<tr>
<th>Gender</th>
<th>Score</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group (1)</td>
<td>1.339</td>
<td>1</td>
<td>.247</td>
</tr>
<tr>
<td>Age group (2)</td>
<td>.106</td>
<td>1</td>
<td>.745</td>
</tr>
<tr>
<td>Age group (3)</td>
<td>.218</td>
<td>1</td>
<td>.640</td>
</tr>
<tr>
<td>Gender (1)</td>
<td>.737</td>
<td>1</td>
<td>.391</td>
</tr>
<tr>
<td>Ethnicity (1)</td>
<td>.333</td>
<td>1</td>
<td>.564</td>
</tr>
<tr>
<td>Ethnicity (2)</td>
<td>.149</td>
<td>1</td>
<td>.700</td>
</tr>
<tr>
<td>Ethnicity (3)</td>
<td>.479</td>
<td>1</td>
<td>.489</td>
</tr>
<tr>
<td>Ethnicity (4)</td>
<td>.093</td>
<td>1</td>
<td>.761</td>
</tr>
<tr>
<td>Employment Status (1)</td>
<td>.227</td>
<td>1</td>
<td>.633</td>
</tr>
<tr>
<td>Employment Status (2)</td>
<td>.425</td>
<td>1</td>
<td>.515</td>
</tr>
<tr>
<td>Employment Status (3)</td>
<td>.282</td>
<td>1</td>
<td>.595</td>
</tr>
<tr>
<td>Employment Status (4)</td>
<td>.111</td>
<td>1</td>
<td>.739</td>
</tr>
<tr>
<td>Employment Status (5)</td>
<td>.282</td>
<td>1</td>
<td>.595</td>
</tr>
<tr>
<td>Insurance Status(1)</td>
<td>.912</td>
<td>1</td>
<td>.340</td>
</tr>
<tr>
<td>Insurance Status(2)</td>
<td>.254</td>
<td>1</td>
<td>.614</td>
</tr>
<tr>
<td>Marital Status (1)</td>
<td>.071</td>
<td>1</td>
<td>.790</td>
</tr>
<tr>
<td>Marital Status (2)</td>
<td>1.146</td>
<td>1</td>
<td>.284</td>
</tr>
</tbody>
</table>
Hypothesis 1c: Social Support (having a major source of support, receiving support from church/spiritual, receiving support from a clinician, having formal peer support, and having formal group support) predicts delay of treatment greater than 60 days.

Logistic regressions were conducted to determine which independent variables (having a major source of support, receiving support from church/spiritual, receiving support from a clinician, having formal peer support, and having formal group support) were predictors of treatment delay greater than 60 days. Data screening led to the elimination of four outliers. Regression results indicated the overall model fit of one predictor (receiving support from a clinician) was statistically reliable in distinguishing between the presence or absence of treatment delay greater than 60 days.
(-2 Log Likelihood = 115.556, $\chi^2(1) = 11.891$, $p<.01$). The model correctly classified 79.8% of the cases. Regression coefficients are presented in Table 17.

*Wald* statistics indicated that receiving support from a clinician significantly predicted the presence of treatment delay greater than 60 days. Odds ratios for this variable indicated change in the likelihood of having delay greater than 60 days when the predictors decrease by 1.

A cross-tabulation measurement revealed patients who received support from a social worker had lower percentages of delay (10%) than patients who received support from a nurse (18.1%) or a physician (60.0%). The phi ($\Phi$) statistical measurement indicated a moderate relationship ($\Phi = .342$) between the two variables.

Table 17

| Regression coefficients of treatment delay greater than 60 days – social support |
|-------------------------------|-----|-----|-----|-----|
|                              | $B$ | *Wald* | $df$ | $P$ | Odds Ratio |
| Clinician support (1)        | -1.916 | 10.502 | 1 | .001 | .147 |
| Clinician support (2)        | -2.603 | 4.977 | 1 | .027 | .074 |

Hypothesis 1d: Social Support (having a major source of support, receiving support from church-spiritual, receiving support from a clinician, having formal peer support, and having formal
group support) predicts delay of treatment greater than 90 days.

Logistic regressions were conducted to determine which independent variables (having a major source of support, receiving support from church-spiritual, receiving support from a clinician, having formal peer support, and having formal group support) were predictors of treatment delay greater than 90 days. Data screening led to the elimination of four outliers. Regression results indicated the overall model fit of one predictor (having formal peer support) was statistically reliable in distinguishing between the presence or absence of treatment delay greater than 90 days (-2 Log Likelihood = 66.231 $\chi^2(1) = 2.435$, $p = .119$). The model correctly classified 91.6% of the cases. Regression coefficients are presented in Table 18.

Wald statistics indicated that having formal peer support did not significantly predict the presence of treatment delay greater than 90 days. Odds ratios for this variable indicated change in the likelihood of having delay greater than 90 days when the predictors decrease by 1.

Table 18
Regression coefficients for treatment delay greater than 90 days – social support

<table>
<thead>
<tr>
<th></th>
<th>$B$</th>
<th>$Wald$</th>
<th>$df$</th>
<th>$P$</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer support (1)</td>
<td>-2.485</td>
<td>2.912</td>
<td>1</td>
<td>.088</td>
<td>.083</td>
</tr>
</tbody>
</table>
Hypothesis 1e: Demographic characteristics (age, gender, ethnicity, employment status, insurance status, marital status, and children) predict delay of BMT greater than 24 weeks.

Logistic regressions were conducted to determine which independent variables (age, gender, ethnicity, employment status, insurance status, marital status, and children) were predictors of BMT delay greater than 24 weeks. Data screening led to the elimination of seven outliers. Regression results indicated that none of the predictors fit the overall model. Regression coefficients of variables not in the equation are presented in Table 19.

Table 19
Regression coefficients of variables not in the equation for delay of BMT greater than 24 weeks – demo

<table>
<thead>
<tr>
<th></th>
<th>Score</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group (1)</td>
<td>.000</td>
<td>1</td>
<td>.985</td>
</tr>
<tr>
<td>Age group (2)</td>
<td>5.024</td>
<td>1</td>
<td>.025</td>
</tr>
<tr>
<td>Age group (3)</td>
<td>4.330</td>
<td>1</td>
<td>.037</td>
</tr>
<tr>
<td>Gender (1)</td>
<td>.111</td>
<td>1</td>
<td>.739</td>
</tr>
<tr>
<td>Ethnicity (1)</td>
<td>1.687</td>
<td>1</td>
<td>.194</td>
</tr>
<tr>
<td>Ethnicity (2)</td>
<td>.116</td>
<td>1</td>
<td>.734</td>
</tr>
<tr>
<td>Ethnicity (3)</td>
<td>1.179</td>
<td>1</td>
<td>.278</td>
</tr>
</tbody>
</table>
Table 19 (continued)

<table>
<thead>
<tr>
<th></th>
<th>Score</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity (4)</td>
<td>.285</td>
<td>1</td>
<td>.594</td>
</tr>
<tr>
<td>Employment Status (1)</td>
<td>.916</td>
<td>1</td>
<td>.339</td>
</tr>
<tr>
<td>Employment Status (2)</td>
<td>2.162</td>
<td>1</td>
<td>.141</td>
</tr>
<tr>
<td>Employment Status (3)</td>
<td>.576</td>
<td>1</td>
<td>.448</td>
</tr>
<tr>
<td>Employment Status (4)</td>
<td>.026</td>
<td>1</td>
<td>.873</td>
</tr>
<tr>
<td>Employment Status (5)</td>
<td>.576</td>
<td>1</td>
<td>.448</td>
</tr>
<tr>
<td>Insurance Status(1)</td>
<td>1.916</td>
<td>1</td>
<td>.166</td>
</tr>
<tr>
<td>Insurance Status(2)</td>
<td>.440</td>
<td>1</td>
<td>.507</td>
</tr>
<tr>
<td>Marital Status (1)</td>
<td>3.365</td>
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<td>.067</td>
</tr>
<tr>
<td>Marital Status (2)</td>
<td>1.351</td>
<td>1</td>
<td>.245</td>
</tr>
<tr>
<td>Marital Status (3)</td>
<td>.874</td>
<td>1</td>
<td>.350</td>
</tr>
<tr>
<td>Marital Status (4)</td>
<td>4.016</td>
<td>1</td>
<td>.045</td>
</tr>
<tr>
<td>Marital Status (5)</td>
<td>.936</td>
<td>1</td>
<td>.333</td>
</tr>
<tr>
<td>Child (1)</td>
<td>1.821</td>
<td>1</td>
<td>.177</td>
</tr>
<tr>
<td>Child (2)</td>
<td>.082</td>
<td>1</td>
<td>.774</td>
</tr>
</tbody>
</table>

Hypothesis 1f: Diagnosis and stage of disease (relapsed Hodkin’s, relapsed follicular, relapsed diffuse large B-cell, stages I, II, III, and IV) predicts delay of bone marrow transplantation treatment.
Logistic regressions were conducted to determine which independent variables (relapsed Hodkin’s, relapsed follicular, relapsed diffuse large B-cell, stages I, II, III, and IV) were predictors of delay for bone marrow transplantation treatment. Data screening led to the elimination of four outliers. Regression results indicated the overall model fit of three predictors (relapsed Hodgkin’s, relapsed follicular, relapsed diffuse large B-cell) were statistically reliable in distinguishing between the presence or absence of bone marrow transplantation treatment delay (-2 Log Likelihood= 87.301, \( \chi^2(1)= 8.545 \), \( p<.05 \)). The model correctly classified 78% of the cases. Regression coefficients are presented in Table 20.

\textit{Wald} statistics indicated that diagnosis (3) (relapsed diffuse large B-cell) significantly predicted treatment delay. Odds ratio for this variable indicated change in the likelihood of having bone marrow transplantation treatment delay when the predictor decreases by 1.

A cross-tabulation measurement revealed patients who were diagnosed with relapsed diffuse large B-cell lymphoma received bone marrow transplantation treatment within less than 24 weeks (89.2%). The phi (\( \Phi \)) statistical measurement indicated a moderate relationship (\( \Phi = .311 \)) between the variables.
<table>
<thead>
<tr>
<th>Hypothesis 1g:</th>
<th>Social Support (having a major source of support, receiving support from church-spiritual, receiving support from a health professional, having formal peer support arranged, and having formal group support arranged) predicts delay of BMT greater than 24 weeks.</th>
</tr>
</thead>
</table>

Data screening led to the elimination of five outliers. Regression results indicated that none of the predictors fit the overall model. Regression coefficients of variables not in the equation are presented in Table 21.
Table 21
Regression coefficients of variables not in the equation for delay greater than 90 days – social support

<table>
<thead>
<tr>
<th>Major Source of Support</th>
<th>Score</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Major Source of Support (1)</td>
<td>.576</td>
<td>1</td>
<td>.448</td>
</tr>
<tr>
<td>Major Source of Support (2)</td>
<td>2.728</td>
<td>1</td>
<td>.099</td>
</tr>
<tr>
<td>Major Source of Support (3)</td>
<td>6.567</td>
<td>1</td>
<td>.010</td>
</tr>
<tr>
<td>Church-Spiritual Support (1)</td>
<td>1.821</td>
<td>1</td>
<td>.177</td>
</tr>
<tr>
<td>Church-Spiritual Support (2)</td>
<td>.617</td>
<td>1</td>
<td>.432</td>
</tr>
<tr>
<td>Church-Spiritual Support (3)</td>
<td>2.934</td>
<td>1</td>
<td>.087</td>
</tr>
<tr>
<td>Health Professional Support (1)</td>
<td>3.094</td>
<td>1</td>
<td>.079</td>
</tr>
<tr>
<td>Health Professional Support (2)</td>
<td>4.016</td>
<td>1</td>
<td>.045</td>
</tr>
<tr>
<td>Formal Peer Support (1)</td>
<td>3.589</td>
<td>1</td>
<td>.058</td>
</tr>
<tr>
<td>Formal Group Support (1)</td>
<td>1.490</td>
<td>1</td>
<td>.222</td>
</tr>
</tbody>
</table>

Hypothesis 1h: Days of Delay predicts delay of bone marrow transplantation treatment greater than 60 days.

Logistic regressions were conducted to determine which independent variables were predictors of treatment delay greater than 60 days. Data screening led to the elimination of four outliers. Regression results indicated the overall model fit of one predictor was statistically reliable in distinguishing between the presence or absence of
treatment delay greater than 60 days (-2 Log Likelihood= 84.627, $\chi^2(1)= 11.220, p<.01$).

The model correctly classified 82.4% of the cases. Regression coefficients are presented in Table 22.

*Wald* statistics indicated that receiving bone marrow transplantation significantly predicted the presence of treatment delay greater than 60 days. Odds ratios for this variable indicated change in the likelihood of having delay greater than 60 days when the predictors decrease by 1.

Table 22

Regression coefficients for delay of BMT greater than 24 weeks – diagnosis

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>Wald</th>
<th>df</th>
<th>P</th>
<th>Odds Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delay &gt; 90 Days (1)</td>
<td>-3.150</td>
<td>7.746</td>
<td>1</td>
<td>.005</td>
<td>.043</td>
</tr>
</tbody>
</table>

Hypothesis 1i: Demographic and clinical characteristics (age, gender, ethnicity, employment status, health insurance status, marital status, children, diagnosis, and stage of disease) predict receipt of bone marrow transplantation.

Logistic regressions were conducted to determine which independent variables (age, gender, ethnicity, employment status, health insurance status, marital status, children, diagnosis, and stage of disease) were predictors of receipt of bone marrow transplantation. Data screening led to the elimination of 9 outliers. Regression results
indicated that none of the predictors fit the overall model. Regression coefficients of variables not in the equation are presented in Table 23.

Table 23

Regression coefficients of variables not in the equation for receipt of bone marrow transplantation

<table>
<thead>
<tr>
<th></th>
<th>Score</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age group (1)</td>
<td>.425</td>
<td>1</td>
<td>.514</td>
</tr>
<tr>
<td>Age group (2)</td>
<td>1.699</td>
<td>1</td>
<td>.192</td>
</tr>
<tr>
<td>Age group (3)</td>
<td>.888</td>
<td>1</td>
<td>.346</td>
</tr>
<tr>
<td>Gender (1)</td>
<td>.191</td>
<td>1</td>
<td>.662</td>
</tr>
<tr>
<td>Ethnicity (1)</td>
<td>1.866</td>
<td>1</td>
<td>.172</td>
</tr>
<tr>
<td>Ethnicity (2)</td>
<td>1.145</td>
<td>1</td>
<td>.285</td>
</tr>
<tr>
<td>Ethnicity (3)</td>
<td>.036</td>
<td>1</td>
<td>.849</td>
</tr>
<tr>
<td>Ethnicity (4)</td>
<td>.310</td>
<td>1</td>
<td>.577</td>
</tr>
<tr>
<td>Employment Status (1)</td>
<td>6.865</td>
<td>1</td>
<td>.009</td>
</tr>
<tr>
<td>Employment Status (2)</td>
<td>2.272</td>
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<td>.132</td>
</tr>
<tr>
<td>Employment Status (3)</td>
<td>.164</td>
<td>1</td>
<td>.685</td>
</tr>
<tr>
<td>Employment Status (4)</td>
<td>2.005</td>
<td>1</td>
<td>.157</td>
</tr>
<tr>
<td>Employment Status (5)</td>
<td>.164</td>
<td>1</td>
<td>.685</td>
</tr>
<tr>
<td>Insurance Status (1)</td>
<td>.036</td>
<td>1</td>
<td>.849</td>
</tr>
</tbody>
</table>
Table 23 (continued)

<table>
<thead>
<tr>
<th></th>
<th>Score</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insurance Status (2)</td>
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<td>1</td>
<td>.082</td>
</tr>
<tr>
<td>Marital Status (1)</td>
<td>1.681</td>
<td>1</td>
<td>.195</td>
</tr>
<tr>
<td>Marital Status (2)</td>
<td>.360</td>
<td>1</td>
<td>.548</td>
</tr>
<tr>
<td>Marital Status (3)</td>
<td>.005</td>
<td>1</td>
<td>.944</td>
</tr>
<tr>
<td>Marital Status (4)</td>
<td>1.809</td>
<td>1</td>
<td>.179</td>
</tr>
<tr>
<td>Marital Status (5)</td>
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<td>1</td>
<td>.429</td>
</tr>
<tr>
<td>Child (1)</td>
<td>.020</td>
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<td>.403</td>
</tr>
<tr>
<td>Child (2)</td>
<td>.701</td>
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<td>.679</td>
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<tr>
<td>Diagnosis (1)</td>
<td>.053</td>
<td>1</td>
<td>.819</td>
</tr>
<tr>
<td>Diagnosis (2)</td>
<td>.016</td>
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<td>.899</td>
</tr>
<tr>
<td>Diagnosis (3)</td>
<td>.763</td>
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<td>.382</td>
</tr>
<tr>
<td>Stage of disease (1)</td>
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<td>1</td>
<td>.849</td>
</tr>
<tr>
<td>Stage of disease (2)</td>
<td>.756</td>
<td>1</td>
<td>.385</td>
</tr>
<tr>
<td>Stage of disease (3)</td>
<td>1.742</td>
<td>1</td>
<td>.187</td>
</tr>
<tr>
<td>Stage of disease (4)</td>
<td>2.861</td>
<td>1</td>
<td>.091</td>
</tr>
</tbody>
</table>
CHAPTER V
CONCLUSIONS AND RECOMMENDATIONS

The research study was designed to answer the question concerning the influence social support (emotional, informational, and instrumental) has on the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment.

The conclusions and recommendations of the research findings are presented in this chapter. Recommendations are proposed for future discussions for social workers, health care practitioners and administrators, and policy makers. The research question is presented to summarize the significant findings of interest.

Research Question: Does having access to emotional, informational, and/or instrumental support decrease the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment?

In order to determine if social support was influential in treatment delay, the types of social support (emotional, informational, and instrumental) were identified and analyzed. Emotional support was indicated by the following factors: a major source of support of family, extended family, friends or others; marital status; church/spiritual; and children. Informational support was indicated by the following factors: clinician (nurse,
social worker, physician); formal peer services; and formal group services. Instrumental support was indicated by employment status, health insurance status, and living arrangement.

Of the 119 patients who received bone marrow transplantation social work assessments, a majority of patients (63.9%) were married, had adult children (55.5%), relied on personal prayer (47.1%), identified their family (83.2%) as their major source of emotional support. The results on informational support showed a majority (79%) received support from nurses, only (1.7%) received formal peer support, and (6.7%) received formal group support. The results on instrumental support showed a majority of patients (42.9%) were employed, (72.3%) had private insurance, and (89.9%) were living with other people. All patients had daily living needs (access to food, shelter, and transportation) that were met. Although some patients had gone through clinical trial evaluation, there was no clinical trial participation.

In order to determine if social support was influential in treatment delay, the amount of time between receiving a lymphoma diagnosis and receiving initial recommended treatment was analyzed. A majority of patients experienced typical delay, which was less than 12 weeks (90.8%). Those who experienced significant delay were (7.6%) for 12 to 26 weeks delay and (1.7%) for more than 26 weeks delay.

Additionally, the amount of time between receiving a lymphoma diagnosis and receiving a bone marrow transplantation was also analyzed. Of the 119 patients who received social work assessments, 91 (76.5%) actually received bone marrow transplantation.
The bone marrow transplantation social work assessments collected on 119 patients provided useful information on perceived and/or received social support needs of relapsed lymphoma patients considered for transplantation. All patients had prior histories of lymphoma disease, had received standard treatment, including, for some patients, prior bone marrow transplantation. They presented with a range of from no symptoms to a combination of the following symptoms: swollen lymph nodes or lumps, low energy or fatigue, pain, stomach pain, bruising, night sweats and itching. If there were no symptoms, diagnosis was discovered through CT or PET scans or tests given for other concerns.

The patients were typically seen at the clinic for a ‘New Patient Consult’ and given the diagnosis. Most were accompanied by a family member or friend. They were immediately assigned to a nurse care coordinator, who explained the mechanics of getting bone marrow transplantation; helped coordinate with different treatment services; to each new patient, provided a calendar for treatment appointments; and provided continual follow/up assistance.

Most patients admitted being shocked about their relapse diagnosis. Once the diagnosis for the relapsed lymphoma (date of diagnosis used in this analysis) was confirmed, most of the 119 patients received treatment with little to no delay (typical delay). Standard care consisted of prompt treatment that prepared the patient for transplantation. This treatment is referred to as ICE or R-ICE, which is a combination of chemotherapy drugs. Several cycles of this treatment may be administered. Stem cells are collected and stored. Some patients were treated on outpatient status and others were admitted for inpatient care.
The next scheduled appointment date (initial treatment date used in this analysis) occurs to provide a treatment plan to the patient, conduct the social work assessment, and administer continued care.

Social work assessments were most often requested by the oncologist. During the assessment, information is exchanged and collected. The social workers often provided psychosocial counseling at this session. One interesting question that the social worker typically asked was ‘What are your long term expectations?’ The most repeated answer was ‘to live a normal life again.’ The patient was encouraged to put together a caregiving team. Most were able to do so. A resource packet was given to each patient. The following information was included in the packet: a preparing for stem cell transplant checklist, fundraising information, an application for assistance through the Leukemia / Lymphoma Society, scheduling for Patient and Family Stem Cell Transplant Orientation, a flier on bone marrow transplantation support group, and a list of local community resources.

The patient was given post-transplantation suggestions for lodging plans due to standard care requirements to reside within 30 minutes of the transplant center for a month afterwards. Contact information for the Winn Dixie Hope Lodge and alternative lodging information was provided. During this period, the patient must also have a caregiver with them at all times. Many of the patients and their families traveled for treatment from locations outside of metro Atlanta. They were encouraged to fundraise to offset many of the costs.

The social work assessment session was complete when the social worker had explained his/her availability for continued support and provided the patient with contact
information. Social workers were contacted by a few patients and social work notes on these consultations were included in the hematology notes section of the Emory University Healthcare databases. The social worker continued to work with the multidisciplinary team throughout patient care.

Of the 119 lymphoma patients, (5.9%) of lymphoma patients who experienced more than 12 weeks delay were white while (2.5%) were black. There were no Hispanic or Asian patients who experienced more than 12 weeks delay. When the chi-square statistical test for significance was applied, the null hypothesis was not rejected ($p = .934$) indicating that there was no statistically significant relationship between ethnicity and delay at the .05 level of probability (See Table 3).

Close to six percent (5.9%) of married patients who experienced more than 12 weeks delay. Lymphoma patients who were never married and experienced more than 12 weeks delay was (17.6%) and patients who indicated they were divorced and experienced more than 12 weeks delay was (.8%). Those patients who indicated they were widowed, separated, or reported having domestic partners had no results of delay more than 12 weeks. When the chi-square statistical test for significance was applied, the null hypothesis was not rejected ($p = .902$) indicating that there was no statistically significant relationship between marital status and delay at the .05 level of probability (See Table 4).

Lymphoma patients with children over 18 years of age who experienced more than 12 weeks delay were (5.9%). Those patients who indicated they had no children or had children under the age of 18 years of age had the same results of (1.7%) for delay more than 12 weeks. When the chi-square statistical test for significance was applied, the null hypothesis was not rejected ($p = .691$) indicating that there was no statistically
significant relationship between having children as a source of support and delay at the .05 level of probability (See Table 5).

Lymphoma patients who experienced less than 12 weeks delay and indicated family as their major source of support were (77.8%). Patients who indicated having extended family as their major source of support and having experienced less than 12 weeks delay was (6.8%). The majority of the patients who experienced more than 12 weeks delay and indicated family as their major source of support were (6.8%). When the chi-square statistical test for significance was applied, the null hypothesis was not rejected ($p = .447$) indicating that there was no statistically significant relationship between major source of emotional support and delay at the .05 level of probability (See Table 6).

Lymphoma patients who experienced less than 12 weeks delay and indicated friends as their second major source of support were (54.8%). Patients who indicated having extended family as their second major source of support and having experienced less than 12 weeks delay was (25.0%). The majority of the patients who experienced more than 12 weeks delay and indicated extended family as their second major source of support was (3.6%). When the chi-square statistical test for significance was applied, the null hypothesis was rejected ($p = .016$) indicating that there is a statistically significant relationship between the second major source of emotional support and delay at the .05 level of probability (See Table 7).

Lymphoma patients who experienced less than 12 weeks delay and indicated personal prayer as a source of support were (42.9%). Patients who indicated church attendance as a source of support and having experienced less than 12 weeks delay was
(31.1%). The majority of the patients who experienced more than 12 weeks delay and indicated personal prayer as a source of support were (4.2%). When the chi-square statistical test for significance was applied, the null hypothesis was not rejected (p = .971) indicating that there was no statistically significant relationship between church/spiritual support and delay at the .05 level of probability (See Table 8).

Lymphoma patients who experienced less than 12 weeks delay and received informational support from a nurse were (72.3%). Patients who indicated having received support from a social worker and having experienced less than 12 weeks delay was (7.6%). Patients who experienced more than 12 weeks delay and indicated having received support from a physician was (10.9%). When the chi-square statistical test for significance was applied, the null hypothesis was not rejected (p = .833) indicating that there was no statistically significant relationship between clinician support and delay at the .05 level of probability (See Table 9).

Lymphoma patients who experienced less than 12 weeks delay and received formal peer support were (.8%). Patients who indicated having received support from a formal peer and having experienced more than 12 weeks delay was (.8%). When the chi-square statistical test for significance was applied, the null hypothesis was rejected (p = .045) indicating that there is a statistically significant relationship between formal peer support and delay at the .05 level of probability (See Table 10).

Lymphoma patients who experienced less than 12 weeks delay and received formal group support were (5.9%). Patients who indicated having received support from group participation and having experienced more than 12 weeks delay was (.8%). When the chi-square statistical test for significance was applied, the null hypothesis was not
rejected (p = .742) indicating that there was no statistically significant relationship between formal group support and delay at the .05 level of probability (See Table 11).

Lymphoma patients who experienced less than 12 weeks delay and were employed were (38.7%) and (19.3%) were unemployed. Patients who indicated having employment but experienced more than 12 weeks delay was (4.2%) and those unemployed was (2.5%). When the chi-square statistical test for significance was applied, the null hypothesis was not rejected (p = .964) indicating that there was no statistically significant relationship between employment status and delay at the .05 level of probability (See Table 12).

A majority of lymphoma patients who experienced less than 12 weeks delay and had private insurance were (66.4%). Patients who indicated having no insurance and experienced more than 12 weeks delay was (.8%). When the chi-square statistical test for significance was applied, the null hypothesis was not rejected (p = .642) indicating that there was no statistically significant relationship between health insurance status and delay at the .05 level of probability (See Table 13).

Lymphoma patients who experienced less than 12 weeks delay and lived with others were (82.4%). Patients who indicated living alone and experienced more than 12 weeks delay was (1.7%). When the chi-square statistical test for significance was applied, the null hypothesis was not rejected (p = .349) indicating that there was no statistically significant relationship between living arrangement and delay at the .05 level of probability (See Table 14).
As indicated in Table 15, a higher percentage of males (29.4%) experienced treatment delay greater than 60 days than females (13.7%). There was a weak relationship ($\Phi = -.185$) between the two variables.

As indicated in Table 17, patients who received support from a social worker had lower percentages of delay (10%) than patients who received support from a nurse (18.1%) or a physician (60.0%). There was a moderate relationship ($\Phi = .342$) between the variables.

As indicated in Table 20, patients who were diagnosed with relapsed diffuse large B-cell lymphoma received bone marrow transplantation treatment within less than 24 weeks (89.2%). There was a moderate relationship ($\Phi = .311$) between the variables.

In sum, with the information collected from the 119 social work assessments, the expectation was that most factors of social support would significantly influence delay of treatment. In the study, gender, clinician support, and delay in bone marrow transplantation indicated significance. The majority of the patients represented in the sample appeared to have strong social support systems in place, exemplary profiles for the selection criterion of technologically advanced treatment methods such as bone marrow transplantation. Aside from the 119 available social work assessments used in this study, there exists a list of over 200 lymphoma patients possibly in need of similar treatment who did not receive social work assessments. This list dates back to 1996 and social work assessments for bone marrow transplantation began to appear in 2002. Only 26 of these 200 patients were referred from 2002 to present. So the majority were patients prior to 2002 and, according to practices at that time, would not have received social work assessments. The collection of vital patient data, including demographic
information such as ethnicity, was incomplete. The researcher questions if this is the underserved group, possibly equipped with less than the required social support system, that this study might have examined. What happened to patients from this particular list? Did they receive treatment or are they experiencing patient, provider, or administrative delay?

Based on the literature review, social support does assist in neutralizing the effects of distress and lymphoma patients often experience some level of distress at diagnosis. The results of this study are consistent with emerging studies such as Frick's et al. (2005), who did not find any association between positive social support and survival among patients undergoing autologous peripheral blood stem cell transplantation but did obtain a relationship between negative or problematic social support and poor survival chances following transplantation.

In the overall results specific to this study, significant differences in ethnicity, social support, and treatment delay were not found. The patients represented in this sample, including African-American patients, received quality cancer care. To address health disparity concerns, the information gathered from this study on the social support needs of these lymphoma patients provides a meaningful profile for social support that will be helpful in securing quality care for African-America lymphoma and/or bone marrow transplantation patients.

Future studies should be conducted to continue to test social support and its impact on health outcomes. With this study, the work has been extended. Though not enough to make substantial conclusions, the study results were meaningful enough to
raise important questions about health-seeking behaviors and the expanding role the social work profession must claim in health care provision.

Recommendations

Research on social support and survival must continue with a focus on lymphoma, as the non-Hodgkin’s lymphoma incidence rate is rapidly increasing. Understanding the support needs of African-American cancer patients will help to continue to provide quality health care and address the issues of health disparity. Social workers are needed to play an even larger role in this endeavor. Patient education on how to care for self and family, should chronic illness occur, can be conducted on the individual and community level. As a result of the findings of this study, the researcher is recommending the following:

1. Social workers should utilize their skills as counselor, educator, and advocate, on the individual and community level, to help facilitate greater access to health care resources.

2. More research conducted by social workers should continue, in order to identify and locate the underserved population and provide data on the underserved population.

3. The number of social work staff in health care settings should increase.

4. Obtain social work assessments for all lymphoma patients.
APPENDIX A

Patient Support Index

Section I: Demographic and Patient Information

1. Age group: 1) ___ 18-30 2) ___ 31-50 3) ___ 51-70 4) ___ Over 70

2. Gender: 1) ___ Male 2) ___ Female

3. Ethnicity: 1) ___ Black 2) ___ White 3) ___ Hispanic 4) ___ Asian 5) ___ Other

4. Diagnosis: 1) ___ Relapsed Hodgkin’s 2) ___ Relapsed Follicular
   3) ___ Relapsed Diffuse Large B-Cell 4) ___ Other NHL

5. Stage of Disease: 1) ___ Stage I 2) ___ Stage II 3) ___ Stage III 4) ___ Stage IV
   5) ___ Unknown

5a: Date of Diagnosis _______  Date of Initial Treatment _______ (DD – IT = Delay)

6. Time Since Diagnosis to Initial Treatment: 1) ___ Less than 12 weeks 2) ___ 12 to 26 weeks
   3) ___ More than 26 weeks

Section II: Emotional Support

7. Marital Status: 1) ___ Married 2) ___ Never Married 3) ___ Widowed
   4) ___ Divorced 5) ___ Separated 6) ___ Domestic Partner

8. Children: 1) ___ None 2) ___ Under 18 Yrs 3) ___ Over 18 Yrs

9. Major source of support: 1) ___ Family 2) ___ Extended Family 3) ___ Friends
   4) ___ Other

10. Second major source of support: 1) ___ Family 2) ___ Extended Family 3) ___ Friends
    4) ___ Other

11. Third major source of support: 1) ___ Family 2) ___ Extended Family 3) ___ Friends
    4) ___ Other

125
APPENDIX A (continued)

12. I received the most support from church/spiritual:  1) _____ None  2) _____ Personal prayer
   3) _____ Church Attendance  4) _____ Visit with clergy

13. Which clinician gave me the most support:  1) _____ None  2) _____ Nurse
   3) _____ Social Worker  4) _____ Physician

14. Formal peer services were arranged:  1) _____ No  2) _____ Yes

15. Formal group services were arranged:  1) _____ No  2) _____ Yes

Section IV: Instrumental Support

16. Employment status:  1) _____ Employed  2) _____ Unemployed  3) _____ Self employed
   4) _____ Retired  5) _____ Homemaker  6) _____ Disabled

17. I need a place to live:  1) _____ No  2) _____ Yes

18. I need access to food/prepared meals:  1) _____ No  2) _____ Yes

19. I need available transportation:  1) _____ No  2) _____ Yes

20. I need childcare assistance:  1) _____ No  2) _____ Yes

21. Health Insurance status:  1) _____ None  2) _____ Public Insurance  3) _____ Private Insurance

22. Living arrangement:  1) _____ Live alone  2) _____ Live with others

23. Clinical Trial:  1) _____ No  2) _____ Yes
APPENDIX B

IRB LETTERS

January 20, 2006

Dr. Georgiana Bolden
Office of Sponsored Programs
Clark Atlanta University
(404) 880-6979

Re: Study of Social Support and Treatment Delay Among African-American Patients Diagnosed with Lymphoma

Principal Investigator: Roni Glover

Dear Dr. Bolden:

Roni Glover is a participant in the ongoing, IRB approved research project on “Assessing Treatment Outcomes for Patients with Non-Hodgkin’s Lymphoma” at Emory University’s Winship Cancer Institute. Ms. Glover is working directly with the principal investigator to examine social support and its influence on treatment delay among African-American patients with lymphoma. She has controlled access to existing patient data, which is located in the Emory Healthcare Data Center.

Sincerely,

Christopher Flowers, MD
Principal Investigator
Emory University School of Medicine
Winship Cancer Institute
crflowe@emory.edu
APPENDIX B (continued)

CLARK ATLANTA UNIVERSITY
Institutional Review Board
Office of Sponsored Programs

January 18, 2006

Mr. Roni Glover (rmarieg@aol.com)
School of Social Work
Clark Atlanta University
Atlanta, GA 30314

RE: Study of Social Support and Treatment Among African-American Patients
   Diagnosed with Hodgkin's/Non Hodgkin's Disease

Principal Investigator: Roni Glover

Human Subjects Code Number: HR2006-1-140-1

Dear Mr. Glover:

The Human Subjects Committee of the Institutional Review Board (IRB) has reviewed your
protocol referenced above and approved of it as exempt from full IRB review in accordance
with 45 CFR 46.106b.2. You may begin your study one week from the date of this notice.

Protocol Approval Code is HR2006-1-140-1/A

This approval is valid for one year from the date of this notice. This permit will therefore
expire on January 17, 2007. Thereafter, continued approval is contingent upon the annual
submission of a renewal form to this office. Any reaction or problems resulting from this
investigation should be reported immediately to the IRB, to the Department Chairperson and
any sponsoring agency.

If you have any questions, please contact Dr. Georgiana Bolden at the Office of Sponsored
Programs (404) 880-6979 or Dr. Paul I. Musey, (404) 880-6829.

Sincerely:

[Signature]

Paul I. Musey, Ph.D.
Chair
IRB: Human Subjects Committee

cc. Dr. Margaret Count-Spriggs (mspriggs@cau.edu)
    Office of Sponsored Programs (gholden@cau.edu)
APPENDIX C

SPSS PROGRAM ANALYSIS

RONI GLOVER
PATIENT SUPPORT INDEX
STUDY OF SOCIAL SUPPORT AND DELAY OF TREATMENT

'ITLE 'Study of Social Support and Delay of Treatment'.

SUBTITLE 'Patient Support Index - Roni Glover'
'Margaret Counts-Spriggs PhD'
'Christopher Flowers MD'
'Robert W Waymer PhD'.

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SUPORT5 16
SUPORT6 17
SUPORT7 18
PEER 19
GROUP 20
EMPLOY 21
PLACE 22
MEALS 23
TRANS 24
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INSURA 26
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### APPENDIX C (continued)

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GENDER 'Q2 Gender'
ETHNIC 'Q3 Ethnicity'
DIAGNOS 'Q4 Diagnosis'
STAGE 'Q5 Stage of Disease'
TIME 'Q6 Time since diagnosis to initial treatment'
MARITAL 'Q7 Marital Status'
CHILD 'Q8 Children'
SUPPORT1 'Q9 Major source of support'
SUPPORT2 'Q10 Second major source of support'
SUPPORT3 'Q11 Third major source of support'
SUPPORT4 'Q12 I received the most support from church-spiritual'
SUPPORT5 'Q12a I receive the second most support from church-spiritual'
SUPPORT6 'Q13 Which clinician gave me the most support'
SUPPORT7 'Q13a Which clinician gave me the second most support'
PEER 'Q14 Formal peer services were arranged'
GROUP 'Q15 Formal group services were arranged'
EMPLOY 'Q16 Employment status'
PLACE 'Q17 I have a place to live'
MEALS 'Q18 I have access to food-prepared meals'
TRANS 'Q19 I have available transportation'
CHILDCA 'Q20 I need childcare assistance'
INSURA 'Q21 Health Insurance status'
LIVING 'Q22 Living arrangement'
TRIAL 'Q23 Clinical Trial'.

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APPENDIX C (continued)

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<td>Employ</td>
<td>Employed</td>
<td>Unemployed</td>
<td>Self Employed</td>
</tr>
<tr>
<td></td>
<td>Retired</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Homemaker</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Disabled</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Place</td>
<td>None</td>
<td>'Yes'</td>
<td></td>
</tr>
<tr>
<td>Meals</td>
<td>None</td>
<td>'Yes'</td>
<td></td>
</tr>
<tr>
<td>Trans</td>
<td>None</td>
<td>'Yes'</td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX C (continued)

'No'
2 'Yes'/'
INSURA
1 'None'
2 'Public Insurance'
3 'Private Insurance'
LIVING

>Warning # 4492 in column 1. Text: LIVING
>The (ADD) VALUE LABELS command included a symbol other than a value where a
>value (either numeric or string) was expected. For compatibility with
>previous systems, a parenthesized value would have been acceptable. All
>value labels up to the next slash will be ignored.

1 'Live alone'
2 'Live with others'
TRIAL
1 'No'
2 'Yes'/'.

MISSING VALUES
    AGEGRP GENDER ETHNIC DIAGNOS STAGE TIME MARITAL CHILD
    SUPORT1 SUPORT2 SUPORT3 SUPORT4 SUPORT5 SUPORT6 SUPORT7
    PEER GROUP EMPLOY PLACE MEALS TRANS CHLDCA INSURA LIVING TRIAL (0).
BEGIN DATA
0013213211310023231242211321
>Warning # 1102
>An invalid numeric field has been found. The result has been set to the
>system-missing value.

    Command line: 14  Current case: 1  Current splitfile group: 1
    Field contents: '001'
    Record number: 1  Starting column: 1  Record length: 256
002222341121342320114221321
END DATA.

FREQUENCIES
/VARIABLES AGEGRP GENDER ETHNIC DIAGNOS STAGE TIME MARITAL CHILD
    SUPORT1 SUPORT2 SUPORT3 SUPORT4 SUPORT5 SUPORT6 SUPORT7
    PEER GROUP EMPLOY PLACE MEALS TRANS CHLDCA INSURA LIVING TRIAL
/STATISTICS=.
BEGIN DATA
00132132113110023231242211321
00222323411213423201142221321
0032123412113020201112221311
0043124413310010201162221221
0053123211313430201212221321
0063213411313430201112221321
0073124411213020401132221321
00821112122212010431122211121
0093122514314443431162221211
0103123421312330302212221321
0113113413212010201112221321
0121221514212030201162221221
013312441300202011222211121
0143251411310023201142221321
0153123121312320201142221321
016322341131430201112221321
01712132111302320112221221
0182222211213030201152221321
0192222411212020201162221221
0203222121313030201122221321
021313351433202011122221321
022322251133420201142221321
0232221211210010431122221321
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0263123311313020201122221321
0272121212130010201112221311
0283124411310020201112221321
0293113511210020201142221221
0303113421314030201112221321
0311134112313030201162221221
0323123511313023201142221321
0331221312113032201122221321
0343123311313230201112221321
0352114311310010201142221321
0363114311313023201112221321
0372124111210010201112221321
038322321131002320112221321
03942245113123320201142221321
0403122211313020201112221321
0412133512113030201112221311
04222441313020431112221321
0432211513213010201112221321
0443224521310020431162221321
04532322212301040112221211
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048222341121302020112221321
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0502111314231020201162221111
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053111351622103020112221221
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0573124511310020201162221221
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059322151131303020112221321
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0623211214313032201162221221
0633124511310010202112221321
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0651221412112320301112221121
0663114315323020201162221221
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0683154511210010401112221321
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070325321331303020112221321
071212331121434020112221321
072223511213030301162221321
073222151122141020112221321
074222321131002020112221321
075313331131002020112221321
076122141211202020112221321
077222121213103020112221321
0783213511310020201152221221
079311132131003220112221321
0803122511300203011522211321
081212341121231020112221321
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0833123411310023201142221221
084322141131233020112221321
0853253511313010201112221321
086211431222002030112221211
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08921212242132020112221121
090122151221202040112221321
091121341211002034112221121
APPENDIX C (continued)

0923123211313030201112221321
0933123111313430201212221321
0943144511313020201112221321
0952122511312020201162221221
096221133221403220112221221
097212131113020401112221321
098211131121302020111221321
0992121232131020201112221311
100322351131303020112221321
101222351131001020112221321
10232233123123020112221321
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1073253511310030301212221321
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1092121311300030431132211321
1103113516123020401112221221
11131131111123020114221321
112212221131010201112221321
1132254521312310201162221221
1142123314310030201162221321
1153123411310030201112221321
116123341211203201162221321
1172222111310020201112221321
11821224142123020112221321
119322351131303020112221321
END DATA.
Notes. - Diagram of a modification of the Social Cognitive Theory with social support elements.


- Cognitive, environmental, and behavioral factors are manifested by three types of social support: Instrumental, Informational, and Emotional Support

- Positive outcome: Available support enhances the patient's ability to seek medical treatment.

- Negative outcome: Limited support reduces the patient's ability to seek medical treatment.
Conceptual Model: The Influence of Social Support on Initial Treatment Delay in Lymphoma Patients Considered for Bone Marrow Transplant (BMT)
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