A THEORY OF CANCER SURVIVORSHIP BASED ON THE NEEDS OF A
POPULATION DIAGNOSED WITH CHRONIC LYMPHOCYTIC LEUKEMIA

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Dedication

This work is dedicated to my patients, thank you for opening your hearts and lives to me and for telling your stories. I hope that I have told your stories with hope and love.

A special dedication to:

My children Shelby, Sara and Beth. Sara, we miss you everyday. Wish you were here, I know you would be proud. To Gerald, Judy and Jim, thank you for always being there (my pack) with love and unconditional support. To Saif and Latoya, you both have been instrumental in this project. I thank you for your friendship and support, I couldn’t have done it without you. To Elvis, my dog and my faithful companion who spent all 6 ½ years at my feet waiting for me to finish so he could go back to bed.

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Abstract

Currently, there are an estimated 13 million Americans alive today with a history of cancer (American Cancer Society, 2013). By the year 2020, this number is expected to reach 20 million (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007). As new treatments are developed and survivors live longer, a new category of survivors living with chronic yet incurable cancers has emerged. There are an estimated 15,680 new cases of chronic lymphocytic leukemia diagnosed in 2013 (ACS, 2013). New technologies, along with advances in disease management has lead to an overall increase in 5 and 10 year survival rates in CLL with the average median survival rate of 10 years (Brenner, Gondos, & Pulte, 2008; Cortes, et al., 2010).

The purpose of this study was to formulate a theory that captured survivorship based on the needs of the population diagnosed with the most common form of leukemia, chronic lymphocytic leukemia. There were a total of 12 participants in this study. Utilizing a qualitative grounded theory methodology, the study consisted of semi-structured interviews to explore their concept of survivorship and the effect on their lives as a result of living with their disease.

Data results were grouped into six main themes (There’s a Cloud There, In the Beginning, Certainty of Illness, Lens of Life, Human Advocacy, and Cures for the Incurable). This study increases understanding and provides insight into what it is like to live with CLL. The study also assists in guiding healthcare professionals to develop appropriate strategies and to better educate and manage the multiple dimensions of these unique survivors.
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CHAPTER ONE
Introduction

Background

Cancer survivorship is a continually emerging area of interest in nursing today. This is primarily because people are living longer after a diagnosis of cancer. The American Cancer Society (ACS, 2013) reports an estimated 1.6 million new cases of cancer diagnosed in the United States in 2013. One third of all Americans will be diagnosed with cancer in their lifetime.

Currently, there are an estimated 13 million Americans alive today with a history of cancer (ACS, 2013). By the year 2020, this number is expected to reach 20 million (Erikson et al., 2007). This dramatic increase is due to multiple health care advances, an aging population, and increased survival. Improvements in early detection and treatment have resulted in more Americans surviving cancer (ACS, 2009). With increased survivorship, significant changes emerge in the health care needs of patients and their families as they learn to develop a “new normal” in living with cancer. Definitions of a cancer survivor have ranged from being cancer free for 5 years to completion of active treatment to time of diagnosis to recurrence or death (Pieters & Heilemann, 2011).

The National Coalition for Cancer Survivorship (NCCS) defines the cancer survivor as a person diagnosed with cancer from the time of diagnosis through the remaining years of his/her life, however, multiple organizations have differing views on the definition and the definition of survivor remains ill defined (Pieters & Heilemann, 2011). Other definitions of a cancer survivor have ranged from being cancer free for 5
years to completion of active treatment to time of diagnosis to recurrence or death (Pieters & Heilemann, 2011). For the purpose of this study, the NCCS definition for survivorship was used as the time of diagnosis throughout the remainder of their lives.

Traditionally, survivors have been viewed as falling into four main categories. These categories include those who are undergoing active treatment of their disease, have completed treated for their cancer without further signs of disease, those experiencing recurrence, and those who are in advanced, terminal stages of cancer. With recent advances in technology and medications, there is a new category emerging in the population of Americans who are living with cancer (Miller, Merry & Miller, 2008). This includes those who are living with an incurable cancer characterized by periods of exacerbations and remissions. Miller et al., (2008) defined this chronic cancer group as those who require ongoing treatment, those in remission requiring therapy to maintain remission and those who are in remission with an expected favorable outcome but may require treatment in the future. This group becomes distinct from those without signs of cancer and the advanced disease or terminal group. This group is considered to be in a chronic, incurable state of cancer with chronic being defined as a disease that persists for greater than 3 months (CDC, 2013).

Chronic Lymphocytic Leukemia (CLL) is a chronic cancer that despite advances in treatment, is still considered an inherently incurable hematologic cancer (Abrisqueta, Crespo & Bosch, 2011; Beusterien, et al., 2010; Molica, 2005; Stephens, 2005). CLL is the most common form of leukemia with 15,680 new cases diagnosed in 2013 and is a type of cancer that starts in the lymphocytes or white blood cells within the bone marrow (ACS, 2013). As the disease progresses over time, it invades the
blood as well as other areas of the body such as the liver, spleen, and the lymph system. Invasion of these areas occurs as a result of abnormal accumulations of lymphocytes or white blood cells that lose their ability for programmed death or the process by which a cell naturally dies. As a result, the abnormal cells accumulate at variable rates. The symptoms experienced are related to the degree of tumor burden and/or the amount of disease present at any given time (Beusterien, et al., 2010; Elphee, 2008). This tumor burden and subsequent disease progression can be demonstrated clinically by symptoms such as an increasing white blood cell count, lymph node enlargement, anemia, low platelet counts, enlargement of the spleen, and/or bone marrow involvement (Elphee, 2008; Evans, 2011). Common symptoms of the disease include enlarged lymph nodes in the axilla, neck, stomach, or the groin (Lymphoma.org, 2013). Other symptoms can include bleeding, bruising, weight loss, night sweats, and shortness of breath (Lymphoma.org, 2013). Some of the common causes of death in CLL are related to the progression of the disease and include bleeding, sequelae of anemia, and infections.

CLL is predominant in western societies. It afflicts men twice as often as women and has an increased incidence in the elderly with 75% over the age of 65 years (Abrisqueta, et al., 2011; Beusterien, et al., 2010). The majority of patients with CLL (70-80%) are discovered during a routine blood count when they are noted to have a higher than normal white blood cell count and are asymptomatic at the time of diagnosis (Abrisqueta, et al., 2011; Beusterien, et al., 2010). The natural course for CLL initially begins in the indolent or slow phase in most cases, followed by disease progression (Evans, Ziebland & Pettitt, 2011). Chronic lymphocytic leukemia is
hallmarked by the presence of clonal, mature B lymphocytes in the peripheral blood, spleen, bone marrow, and lymphoid tissue. The presence of these abnormal lymphocytes interferes with cell mediated and humoral immunity and loss of immune memory. The CLL course may vary widely with about one third experiencing a relatively indolent course and no treatment, another third likely requiring treatment, and another third requiring intensive treatment with a more aggressive progression and perhaps death within a few years due to consequences of their disease (Elphee, 2008).

There are two primary staging systems for CLL to include RAI and the Binet system. Staging is done to provide a universal language between providers and can be beneficial in determining individual prognosis and treatment. Aside from standard staging systems, there are also key indicators including chromosomal abnormalities and markers which can further assist to determine an individual’s prognosis and the aggressiveness of disease.

Treatment of CLL is based on the severity of the diseases and aimed at the control of disease and symptoms versus cure. Frequently, those with CLL are not treated immediately and their treatment plan consists of a watchful waiting approach in which they are monitored regularly for symptoms and changes in blood counts. Among those who require treatment, patients who are frail or very elderly are more likely to be treated with a less toxic therapy (Lymphoma.org, 2013). Bone marrow transplant can be considered for a special subset of those with CLL. In general, transplant is reserved for those who are younger, have worsening disease or a more aggressive form of the disease.
The average median survival of CLL has increased over time and is attributable to the development of treatments such as purine analog drugs, monoclonal antibodies, kinase inhibitors, and hematopoietic transplant. These have subsequently resulted in an increase in 5 and 10 year relative survival rates (Brenner, et al., 2010). Currently, the median survival of a patient who is diagnosed with CLL is approximately 10 years, however, prognosis is extremely variable (Abrisqueta, et al., 2011). Recent advances in medications include intravenous monoclonal antibodies that originate identical immune cells that are clones of the parent cell and radioimmunotherapies that include antibodies labeled with a radionuclide and deliver radiation to the cells. These therapies have extended overall survival and resulted in a need for health professionals to better understand the needs of this population.

Problem statement

Advancements in chronic lymphocytic leukemia treatment have led to a growing population of survivors who are now living with this chronic, incurable form of cancer. These patients are diagnosed with a malignancy that has an increasing life expectancy characterized by periods of exacerbation and remissions. Although this chronic cancer group meets the NCCS definition for survivorship, this group has not been historically addressed for promotion of wellness and cancer screening since they are not disease free. A qualitative study was conducted by Evans et al. (2011) that invited 37 patients with CLL to tell their stories. Each story was followed by a semi-structured interview with questions aimed at topics of interest in the narrative. Themes that emerged from the study included the difficulties that patients experienced in coming to terms with the diagnosis, angst regarding the recommendations for watchful
waiting versus active treatment, a lack of information on the disease, feelings of being invisible to providers and dealing with the disease symptoms (Evans et al. 2011). The study suggested that further emphasis be placed on the needs of this group and emphasis should be placed on communication and emotional as well as professional support. Further research is needed to understand this unique group of cancer survivors, their concept of survivorship, their needs, and the quality of their lives (Stephens, Gramegna, Laskin, Botteman, & Pasho, 2005).

Purpose and Significance

The purpose of this study was to formulate a theory that captured survivorship based on the needs of the population with CLL. An understanding of the needs of the chronic lymphocytic leukemia survivor population provides us with a foundation for further understanding and the development of strategies based on these needs. This understanding gives nurses the tools needed to promote optimal wellness in patients living successfully with cancer as opposed to patients dying with cancer. Additionally, when a survivor with chronic lymphocytic leukemia experiences remission followed by recurrence of active disease, little is known about their needs and the issues they face as cancer survivors (Ferrell, Virani, Smith, & Juarez, 2003). Since this is the most common form of leukemia, professionals require understanding of this unique group in order to assist clients and their families with their needs and life issues. Additionally, more research is needed pertaining to age specific and cultural considerations of chronic cancer survivors and their families (Thewes, Butow, Girgis, & Pendlebury, 2003). Although the ethnicity and age of the participant was identified, they were not a primary focus of this study.
CHAPTER TWO

Literature Review

Stages and life needs of the survivor

One of the first publications to address the needs of the cancer survivor was Mullen’s Season’s of Survival: Reflections of a cancer physician (Mullen, 1985). As a cancer survivor, Mullen defined stages or seasons of the survivor including the first or acute survival phase, the extended survival phase, and the permanent survival phase. The first acute phase begins at diagnosis and extends through the aggressive treatment period. This period is dominated by the new diagnosis as well as the active treatment phase. During this phase, fear and anxiety are ongoing and the primary attention shifts from the family to the patient (Kaplan, 2008). The second extended phase includes the period from the completion of active treatment into the period of remission. This phase is marked by completion of treatment and the expectation to return to normal life and function although side effects of treatment remain. This phase begins observational phase where active treatment is complete and the fear of recurrence increases (Kaplan, 2008). Mullen’s third stage or permanent phase begins when enough time had passed that recurrence is unlikely. This stage is hopefully a successful transition to survivor and crossing the bridge to a new normal life. Additionally, this is the phase where many deal with the long term sequelae of previous cancer treatment (Kaplan, 2008). It is also at this time that the survivor has a heightened awareness of health and wellness.

Mullen’s narrative identified the stages of a survivor and the needs that are most commonly described during these stages. These issues originally identified emotions and fears such as fear of death and fear of recurrence (Mullen, 1985). Mullen does not
address those who are living with incurable cancers. The concept of chronic cancer was not identified and perhaps did not exist at the time of his original writings (Miller et al., 2008).

The life needs of the survivor have become more prevalent throughout the review of the literature following Mullen’s categorical writings. The literature includes various dimensions spanning Mullen’s acute, extended, and permanent phases of survivorship but generally excludes those who are living with incurable cancer. The psychosocial, physical, social, spiritual, family, economic, and emotional needs have been consistently identified throughout the survival continuum in those who have completed treatment and are considered to be free of disease (Mullen, 1985; Vivar & McQueen, 2005).

In one study addressing unmet needs in the cancer survivor by Hodgkinson, et al., (2006), the highest ranked needs included having the best accessible medical care and within that was good communication with patients and collaboration between the healthcare team and other services involved in their care. Additionally, patients identified the need for ongoing, up-to-date, and understandable information, for both themselves and others. They also ranked a reduction of life stressors as an important need for survivorship. Other life needs cited in the literature have also referenced relational, sexual, and vocational needs in those who have completed treatment for cancer. However, these studies have been limited to those who had a reasonable expectation to be free of disease at the completion of treatment. Traditionally, most of the survivor studies have excluded those who have residual disease, incurable cancer, or recurrence. Historically, the survivor’s life needs reflect a combination of personal
factors such as relationships and coping skills and situational factors such as social relationships and living circumstance (Thewes et al., 2003). These are also affected by the individual’s ability to learn and understand that their needs change over time and vary from person to person (Skalla, Bakitas, Furstenberg, Ahles, & Henderson, 2004; Van Der Molen, 2000). Age, culture, finances, education, fatigue, and presence of a consistent partner or relationship also influence the needs of the cancer survivor.

A conceptual framework and model for follow up, short term care, and long term care in cancer survivorship was developed by Gilbert, Miller, Hollenbeck, Montie, & Wei in 2008. This model is divided into two separate care plans linked through survivor transition after active treatment has ended. The first phase includes the acute or treatment phase that begins with diagnosis and treatment followed by a recurrence focused surveillance and management of the immediate sequelae of cancer treatment. These sequelae include issues such as fatigue, neuropathy, nausea, changes in bowel or bladder function, and skin changes. Once treatment is completed, the individual is then transitioned into long term care. The long term care model includes late effects of treatment and other consequences such as financial to include income and employment, psychological concerns to include fear of recurrence, social concerns and general health related effects such as early onset of cardiovascular disease, diabetes and osteoporosis (Ganz, 2001). Although this model provided guidance for patient direction to include follow up as well as professional direction in cancer survivorship, it has limited application to those with a chronic cancer such as CLL.

Theories used to address survivorship, as discussed throughout this paper, acknowledge survivor’s needs and a belief that these needs change along a life
continuum (Mullen, 1985; Thewes et al., 2003; Vivar & McQueen, 2005). Despite the literature on these reported needs and influencing factors, very few studies exist that identify the needs of survivors with chronic lymphocytic leukemia. Furthermore, there are few formal educational programs that focus on living successfully with cancer. There is a need to assist the healthcare team to better understand and subsequently improve the quality of care of this group (Miller et al., 2008).

**Living with cancer**

Health is traditionally defined as “a state of physical, mental, and social well-being and not just the absence of sickness or frailty” (CDC, 2013). Kagawa-Singer (1993) broadened the concept of health to include those with chronic illness. She described those with chronic illness as viewing themselves as healthy versus the traditional view of existing in a state of denial in which the individual lives their life denying their disease exists. She identified both health and illness as “anchoring opposites” (Kagawa-Singer, 1993, p. 295). Further, she suggested that the standard definition of health excludes those who are not able to be cured, leading them to a state of liminality or to live between illness and health, not belonging to either. Her study suggested that if this liminality can be overcome, then persons with chronic illness can view themselves as healthy. In a person with an incurable cancer, overcoming a liminal state can be achieved if they succeed in meeting the two dimensions of health: physical status and social construct. Physical status is measured by the degree of survivor impairment. With less impairment comes more social responsibility. Social responsibility is less clear and may include maintaining employment, preparation of meals, or child care. These tasks and duties are variable and change over time and are
defined by age, culture, and social groups. Personal social construct is subjective to the individual and is likely measured by their involvement in tasks or activities that fulfill their personal needs.

In theory, if a survivor is minimally impaired and their social construct is intact, they view themselves as healthy. Kagawa-Singer’s study suggested that cancer survivors with incurable illness could fulfill both physical expectations and social construct and therefore view themselves as healthy despite being diagnosed with an incurable, chronic cancer. Naus, Ishler, Parrott, & Kovacs (2009) further suggested that cancer be viewed as a chronic illness that requires adaptation over time. Again, returning to the notion of a new state of normal and incorporating cancer into self in order to more successfully integrate the illness into everyday life.

*Integration of palliative care and survivorship*

With patient survival increasing, the need for post treatment care has also increased. In an article written by Griffith et al.,(2010), an integrated framework was proposed that combines survivorship care with palliative care. They proposed that an integrative method would provide palliation with a goal of providing management of symptoms. Survivorship care “assumes that the patient has many years of productive living” (Griffith et al., 2010, p. 236) and therefore should focus on prevention of recurrence and disability. The framework was developed to begin in the post treatment phase for the management of long term needs that are not met. If cancer is perceived as a chronic disease, then, cancer requires ongoing management of symptoms throughout the person’s life. In an integrated framework, treatment related symptoms and psychosocial issues are addressed.
Recent advances have led to the evolving longevity of the cancer survivor. Advances include earlier detection and staging, the introduction of effective biologics and targeted agents (Miller et al., 2008). Survivors are treated with the overall goal of maintaining a stable disease state in those who have incurable cancer such as chronic lymphocytic leukemia and not on cure.

**Depression, anxiety and quality of life in chronic lymphocytic leukemia**

Little is known about the quality of life or psychosocial issues in patients with chronic lymphocytic leukemia. The lack of knowledge can be related to the indolent nature of the early disease, lack of clinical symptoms, or the perception that those diagnosed with CLL live a normal life. A watchful waiting approach towards their disease may induce more depression and anxiety (Levin, Yuelin, Rislind, & Rai, 2007; Molica, 2005; Shanafelt, Bowen, Venkat, Slager, Zent, Kay, Reinalada, Tun, Sloan, & Call, 2009). Shanafelt et al., (2009) conducted a study of what patients with CLL thought about their diagnosis. On a daily basis, over half of the CLL patients continued to think about their disease daily even after 2 years and there are no current studies that address when or if this resolves.

One of the most important issues affecting quality of life for survivors is the patient’s relationship with the physician and the choice of words used for explanations of their disease and treatment options (Shanafelt et al., 2008). Other sources of anxiety affecting quality of life included concern for family, uncertainty regarding disease, concern about side effects, and living with symptoms (Shanafelt et al., 2008).
Informational needs of the survivor and their families

Cancer patients require information about their disease and its treatments to provide them with an understanding of what to anticipate in the treatment of their disease. Information includes treatment side effects and possible complications to assist in preparing them for a “change in lifestyle and uncertainty that lies within their diagnosis” (McCaughan, & Thompson, 2000, p. 852). In a study conducted with patients in the acute treatment phase, Skalla et al., (2004), identified themes about the treatment process, educational needs, sources of reliable patient information, side effects, and expectations.

Treatment expectations were of particular importance since the “most distressing side effects reported were the ones the patient was least prepared to experience” (Skalla et al., 2004, p. 317). Treatment knowledge is vital to self-care activities and coping (Adams, 1991; McCaughan & Thompson, 2000). Patients reportedly learned primarily from infusion nurses, spouses, and other patients (Skalla et al., 2004). Of particular note was that the patients who received information from other cancer patients were more positive towards their treatment (McCaughan & Thompson, 2000).

Studies also reported that patients wanted all the information available but that obstacles existed in obtaining that information (McCaughan & Thompson, 2000; Skalla et al., 2004). Health care provider obstacles have been reported from survivors as a barrier to obtaining information about their cancer therapy. These obstacles included lack of access to providers, providers reported lack of knowledge or sensitivity to the life needs of cancer patients, and providers not wanting to answer questions (Skalla et
al., 2004). Other obstacles reported were patients feeling overwhelmed with information and having cognitive problems e.g. decreased memory and retention (McCaughan & Thompson, 2000; Skalla et al., 2004).

Family support was reported to have a positive effect. Therefore “patients seek information as a means to respond to the needs of their family” (McCaughan & Thompson, 2000, p. 855) and possibly receive additional support throughout their survivorship continuum (McCaughan & Thompson, 2000; Thewes et al., 2003). Other educational concerns included the impact of their diagnosis on family relationships. Despite 96.7% of patients reporting interest in the family impact, most reported the lack of information in this area (McCaughan & Thompson, 2000).

The need to include family members in survivor teaching plans was emphasized in several studies (McCaughan & Thompson, 2000; Mellon, Northouse, & Weiss, 2006). These studies reported that family information was of particular importance as patients reported a higher quality of life, higher levels of hardiness, and social support as compared to their family members. This may be due in part to survivors receiving more information or the continuous medical support and information provided to the survivor versus the family member who is not always present for these interactions. The needs of the family and the patient’s interest on the impact of cancer on the family strongly suggest a need to address caregivers in the survivorship plan of care.

The effects of information on extended and permanent survivorship and outcomes

Two studies have reported that developing a new cancer diagnosis on the completion of treatment was a catalyst to improved health behaviors including diet and exercise resulting in the teachable moment for the survivor (Andrykowski, Beacham,
Schmidt, & Harper, 2006; Wahnefried, Aziz, Rowland, & Pinto, 2005). In another study done by Trask et al., (2005), emphasized the importance of educating the survivor on a follow up plan as yet another teachable moment.

The benefits of diet and exercise have been proven in promoting wellness and reduction of recurrence in those who have completed cancer treatment and for prevention of other cancers (Pekmezi & Demark-Wahnefried, 2011). Two studies were found in the literature search and included self management programs specifically created for Breast Cancer patients, and a multidimensional rehabilitation program for survivors focusing on quality of life. Both studies showed improvement in quality of life and successful transition to survivorship (Cimprich, Janz, Northouse, Wren, Given, & Given, 2005; Van Weert et al. 2005). Despite the educational impact, the opportunity for wellness education is frequently missed by healthcare providers. Data demonstrated that only 20% of Oncologists currently provided this education when the patient was present for follow up (Wahnefried et al., 2005).

Living with cancer and healthier living

A literature review of incurable cancers revealed multiple studies that focused on palliative, end of life care, but none that identified the promotion of healthy behaviors such as routine health screening, diet, and exercise in the chronic cancer population. Additionally, no studies were found that have been conducted in survivorship programs that focused specifically on chronic incurable cancer survivors. Several studies on survivorship were found in the literature that focused on survivors who had completed treatment but did not include those with chronic cancers. Examples of these include a self management programs specifically created for breast cancer
patients and a multidimensional rehabilitation program for survivors focusing on quality of life. These studies showed improvement in quality of life and successful transition to survivorship (Cimprich, Janz, Northouse, Wren, Given, & Given, 2005). Despite the educational impact, healthcare providers frequently miss opportunities to offer guidance with self management and the promotion of health (Van Weert, et al. 2005; Wahnefried, Aziz, Rowland, & Pinto, 2005) particularly with those who are diagnosed with an incurable cancer.

*Do cancer survivors consider themselves survivors?*

A study by Pieters and Heilemann (2011), used a qualitative constructionist grounded theory method to study views on what it means to be a cancer survivor and their views on survivorship in women over the age of 70 with breast cancer. The women in this study believed that being a cancer survivor was not a natural outcome to a diagnosis and treatment for cancer and that it was an “external public definition that predated their cancer experience” and was “completely unfamiliar to them” (Pieters & Heilemann, 2011, p. 131). Their view of being a cancer survivor was a spectrum measured against the suffering of others to determine whether they earned the right to call themselves survivors and to what degree they may have earned it. If they felt they had earned the right to be a survivor, this was generally accomplished over time and after much reflection. The term survivor in some was considered a unification of like individuals that served as a symbol of communication, unity, optimism and strength. Regardless of survivor views, most were plagued by uncertainty and this was a constant partner to them and the hope of cancer freedom was overshadowed by the threat of recurrence. Pieters and Heilemann (2011) stressed the importance of their method of
study and listening to the voices of these women from their own context as an integral part of examining the survivorship experience.

*Literature review in grounded theory*

Literature review in grounded theory is described with varied approaches. Annells (1996) identified that research topics stem from a variety of places but that the actual question rises from “the researcher’s notions about the nature of reality, the relationship between the knower and what can be known and how best to discover reality” (p. 379). Glaser (1998) described the idea of entering into research with no preconceptions or ideas regarding outcomes, and he promoted the idea of teaching oneself not to know. Cutcliffe (2000) recommended that if a literature review needs to be considered, then the researcher should evaluate how much literature review is required and at what point in the process it should be done. Although Glaser (1978) recommended no preconception, he also recognized that some background information surrounding this research may be needed and that this can be done within other disciplines peripheral to the primary the topic studied. Miller & Fredericks, (1999), agreed and restated Maher’s hypothesis for knowledge of the literature in which the “probability of explaining a hypothesis given the evidence is greater if the evidence has not been observed at the time of the hypothesis” (p. 543).

According to McCallin, (2003, p. 206) “literature has a place, as everything is data”. In contrast to Miller & Fredericks (1999) Baker, Wuest, & Stern (1992,), stated that in grounded theory, a “researcher is a social being” who feels that “previous experiences are data” (p.1357). Therefore, no effort was made to enter into the study
without acknowledging what is already known. Baker et al., also expressed the opinion that this knowledge can be used for better understanding of the issue to be studied.

Wuest (2007), took a more pragmatic approach. Although she acknowledged that a literature review is probably best done once the core concepts are identified, she concedes that the literature review prior to the study is necessary and could have positive implications. First, in an academic setting, a review of the literature is necessary for the committee prior to the initiation of the research. Additionally, the researcher does have a need to know something about the domain and points out that when “empirical research is done it increases researcher sensitivity” in theory development (Wuest, 2007, p. 247).

Theoretical Framework

There are no existing theoretical frameworks for the target population as it relates to survivorship. The object of this study is to formulate a theory that captures survivorship based on the needs of the population with CLL. Cancer survivorship is defined as the period from cancer diagnosis to eventual demise yet the term is seldom used in the context of incurable cancers.

There are many reasons that incurable cancers were excluded from survivorship framework to include a more limited life expectancy and more limited treatment options in past decades. Prior treatment options were often toxic and offered little to no survival advantage. Hence, people diagnosed with incurable cancers were considered terminal and treated with palliative measures. The focus was not on promoting wellness in this population due to limited life expectancy and poor performance status. The post World War II era (1946-1964) brought about a baby boom. Advancing
technologies, earlier detection, the development of secondary malignancies or another
cancer as a result of the first cancer treatment, and an aging baby boomer generation
require that we understand this new and growing cancer population. The new era of
biologics has provided hope and increased quality and quantity of life and provides the
framework to rethink the current definition of a survivor to include those diagnosed
with a chronic cancer such as CLL.

There are two general theories that have been applied successfully as a
framework in traditionally defined cancer survivorship. Mishel’s (1981) theory of
uncertainty and the reconceptualized uncertainty in illness theory (1990), suggests that
chaos, such as a cancer diagnosis, forces the affected individual to evaluate the current
situation or cancer diagnosis and its implications. The person then evaluates the
situation, perceives it as a threat or opportunity and once successfully acknowledged
and appraised, coping can occur. Coping is accomplished through the use of social
resources such as family, friends, and professionals to decrease uncertainty and
therefore enable them to make a successful transition. The individual moves from their
current perspective, or a state of equilibrium, to a changed state which incorporates
their new experiences in order to again attain a state of equilibrium. Equilibrium is
accomplished through communication, cognitive reframing that encourages a positive
perspective, and the development of solutions (Mishel, 1999). Mishel’s theory is
suitable for qualitative method as quantitative methods are inadequate in measuring
uncertainty.

A theory of transitions in a book by William Bridges (2004), was applied by
Rancour (2008) as a theory applicable to the survivor as they move from active
treatment into observation. Bridges transition theory divides transition into three stages to include endings, the neutral zone, and finally beginnings (Bridges, 2004). In the ending stage, Rancour (2008), ascribed that completion of treatment can be a great source of confusion and stress for the individual. Interventions for the ending phase include the creation of rituals to release the patient and develop the freedom to move on (Bridges, 2004; Rancour, 2008). Rituals could include the use of metaphors and archetype to help the “individual not only survive an illness but to transcend it” (Rancour, 2008, p. 939). The neutral zone began the second phase. In this phase, there is a lack of direction and structure resulting in a feeling of crisis and chaos. Interventions during this period include solitude, resuming social ties and gathering support. The final phase, beginnings, was the summation of successfully accomplishing the first two phases. Progressing successfully through the end of treatment and the neutral zone initiated the beginning of opportunities to start again (Bridges, 2004). The theories described have been applied in patients with cancer at the completion of their treatment when deemed to be cancer free. The theories do represent an accurate depiction of the journey to and through survivorship. It is possible to have similar transitions within the chronic cancer group however, these theories do not adequately address those incurable chronic cancers such as CLL.
CHAPTER THREE

Methodology

Research design

This study utilized qualitative study utilizing interviews and participant observations to answer the objectives of the research. The objectives or aims of this study were to: 1) explore the concept of survivorship as seen by the participant with chronic lymphocytic leukemia 2) describe the needs of persons diagnosed with chronic lymphocytic leukemia 3) formulate a theory that captures survivorship needs of this population with CLL and can guide medical caregivers to address the needs of this population.

This study used grounded theory method to meet these research objectives. There are many varied ways to implement grounded theory method. The method has proven to be flexible and open to new ideas with a commitment to the greater social good. Jane Gilgun (2011) describes grounded theory method as an adaptable method of understanding the human condition using an open ended approach with the goal of better understanding behaviors. She reports this understanding can be accomplished through listening and understanding individuals and their stories.

George Herbert Mead and later, his student Herbert Blumer, founding fathers of symbolic interactionism, believed that the basis of substantive theory was communication between individuals in an attempt to explain a phenomenon around them (Blumer, 1969). This resulted in an interpretative summary of the individual’s actions and the meanings behind their actions. Blumer (1969) ascribed that symbolic interactions occur when a human interprets and define things through social interactions.
with society and each other. These interpretations or beliefs are often acquired and modified through current and prior experiences. Once these interpretations or beliefs are acquired, they theorize that humans act towards things in the way in which they have ascribed meaning through the use of symbols and other means of assigning significance. This study was intended to formulate theory by identifying symbolic interpretations, beliefs, and behaviors that the person with CLL has towards survivorship. More specifically, these will be accomplished using three tenets of grounded theory to include the use of symbolic interactionism, pragmatism, and Darwinism (Pieters & Heilemann, 2011). These tenets will provide the framework to understand how CLL and the term survivor has influenced their relationships to others, society and their own self concepts.

Darwinism assumed that an individual’s struggle for survival results in continually trying to adapt to their environment. In the person diagnosed with CLL, cancer becomes a part of their daily life. Their struggle to survive and cope with this diagnosis includes adaptation to the environment and the changes in their health. This study was aimed at exploring that adaptation and the changes that are made in order to deal more successfully with the diagnosis.

Pragmatism assumes that what is useful to an individual is their truth (Pieters & Heilemann, 2011). Grounded theory assists in the discovery of the needs and concerns of the individuals living with CLL and how they deal with these concerns. It is a theory that is utilizes data to search for patterns, symbols, and processes and then analyzes it in a systematic way (Cutliffe, 2000). Grounded theory is also advantageous because it does not define or assume associations that are within other survivor groups, and allows
for variables to develop that are unknown on initiation of the study. This method is most appropriate because the researcher used the data obtained from the interviews to identify concepts that have generated a theory on survivorship in people diagnosed with chronic lymphocytic leukemia. This information will assist medical professionals to better understand and develop appropriate interventions for this population. Grounded theory methods are also advantageous because they offer “explicit strategies, procedural rigor and seeming objectivity” (Charmaz, 2005, p. 510). Grounded theory’s primary strength lies in that it “generates inductively based theoretical explanations of social and psychosocial processes” (Baker et al., 1992, p. 1357).

Anselm Strauss (1967) first introduced what has become known as the traditional grounded theory method. This method provides consistent step wise procedures that serve to construct theory specific to a particular problem. The traditional method utilizes a constant comparative of data and research sites to identify emerging concepts and links these concepts back to theory. Outcome goals for grounded theory method include the importance of induction and deduction, generalizability, case comparison, and systematically relating of concepts grounded in theory. Although Strauss provided a system wise approach for grounded theory method, he strongly advocates for a researcher’s creativity. Strauss also recommended that the researcher possess a strong understanding of the goals of their research, and the methods to get there even if it deviates from the traditional approach.

Norman Denzin (Strauss, Denzin, & Gilgun, 2011), was one such creative researcher who initially began his research utilizing a traditional Grounded Theory method but found that this was too technical for his particular area of study. Instead, he
primarily relied on field notes as well as observation and interviews. His method became a form of grounded theory known as interpretive interactionism. Interpretive interactionism has a critical focus on collaboration and construction through the methods above, primarily resulting in knowledge as a local expert and therefore an advocate for social change.

Grounded theory method is the most appropriate method of study for the patient with a diagnosis of CLL as they are a population which is understudied in the context of survivorship. This method assists in further understanding this population through constant comparison of data and identification of emerging concepts in order to build generalizable theory and advocate for social change. Grounded theory moves beyond the phenomenology or interpretive phenomenology of the lived experience of a person with CLL in that it searches for concepts which in turn can generate theory to further understand this population. Ethnography could also be considered, however, this population is very diverse and includes various ethnicities and demographics. Limiting the population to a specific cultural group may adversely affect the depth and quality of the data for the CLL group.

Data collection method in grounded theory is based on concepts and themes that are extrapolated from the data. Data collection for this study utilized theoretical sampling. Theoretical sampling is a method of data collection and processing used in grounded theory in which the concepts identified in the previous interview serve to guide the next interview. This is accomplished by analysis of data which is done after each interview is accomplished (Corbin & Strauss, 2008). This allows the researcher the flexibility to follow where the analysis leads in order to collect the richest,
conceptually driven data. Hence, data collection is never collected too far in advance of the analysis. Sufficient sampling or saturation occurs when no new themes or concepts emerge although the richness of the data continues to speak to the researcher. With theoretical sampling, it is not unusual for the researcher to continually discover new insights even when writing results because of the depth of the data obtained (Corbin & Strauss, 2008).

The research literature on quality of life and needs in people with a diagnosis of chronic lymphocytic leukemia is limited (Molica, 2005; Shanafelt et al., 2009; Stephens et al., 2005). In a review of quality of life tools identified by Meneses & Benz (2010), none of the tools reviewed included patients that were living with chronic hematologic malignancies such as chronic lymphocytic leukemia. Use of a grounded theory method in this study is useful for interpretation of common behaviors in groups such as individuals who are diagnosed with CLL where little information exists.

The unique aspect of the grounded theory method in qualitative research is that it develops theory from data and more importantly, provides predictive and explanatory interpretation. Glaser & Strauss (1967), launched grounded theory method as “the discovery of theory from data systematically obtained from social research” (Glaser & Strauss, 1967, p.2). The outcome of the method is that the data yields a theory that “fits” the data and has “workability” once “operationalized” (Glaser & Strauss, 1967, p.3). Glaser (2002) believes that objectivity is obtained in the data through Grounded Theory method because of the multitude of cases that the researcher ultimately reviews during the course of the study allowing the emergence of themes.
Once thematic saturation has been reached, data is thoroughly evaluated. “A rush to theorize” may lead to a less than thorough evaluation and premature or incorrect assumptions and a forced fit. (Charmaz, 2005, p. 510) Once the data have been collected, there are also various levels of competence in data interpretation by the researcher based on knowledge and experience. This could result in a wide variance in the data’s evaluation and interpretation. Therefore, evaluation and validation by fellow researchers assists in rigor through the constant comparative.

Grounded theory is not focused on competing explanations between known and emerging research nor does it attempt to explain concept variation (Miller et al., 1999; Wuest, 2007). In order to diminish accommodation of theory, Olshansky (1996) supports the idea of including data to support theories but to also embrace negative findings. By reporting participant differences, the possibility opens for identifying new data for future prediction. Additionally, the researcher should be aware of theoretical saturation and look for new contextual meaning within the data throughout the study (Olshansky, 1996). The researcher must be cognizant of entering the study knowing that you have that knowledge and then entering without preconception and as Glaser stated, learning how not to know.

Although a systematic approach was employed in this study, this did not negate the need for discovery (Miller et al., 1999). In grounded theory research, the researcher remains open to incorporating the outliers with the understanding that we should allow for differences in “existing knowledge” (McCallin, 2003, p. 206).
There are varied methods used to critique the research and the predictive power therein, yet, all of these methods contain commonalities. Researchers have identified several methodological approaches to guide in grounded theory method (Glaser & Strauss, 1967; Glaser, 1998; Kools, McCarthy, Durham, & Robrecht, 1996, Lincoln & Guba, 1985; Wuest, 2007). Each has a different critique approach, but is accompanied by key concepts with an ultimate goal of trustworthiness and authenticity, fit, dimension, modifiability, generalizability, and pragmatism. The focus of this study was to focus on these key concepts with the use of expert nurses, ongoing content analysis, and protection of content and subjects.

*Population/Sample*

This study described the concept of survivorship and the needs of a survivor as voiced by individuals diagnosed with chronic lymphocytic leukemia in order to formulate a theory that captured survivorship based on the needs of the population with CLL. Purposeful sampling is the hallmark of grounded theory method. This is done so that focus is placed on those people who have personal knowledge of the subject matter (Cutcliffe, 2000; Wuest, 2007). It does not assume that “impartial observers participate” (Charmaz, 2005, p. 509) and it does not require a set sample size, although a target is identified, but is guided by saturation (Wuest, 2007). Sample selection, although purposeful, needs also be evaluated for method of selection, continuity of interview as well as diversity in the subjects to avoid issues of accommodation and context (Annells, 1996). Cutcliffe (2000), recommends that the researcher identify the sampling method in detail to avoid any confusion.
Purposeful sampling for this study began with the identification of those with a diagnosis of CLL. They were then further identified by the length of diagnosis and whether they had received prior therapy. Subjects with the longest diagnosis and received at least one prior treatment were interviewed first. This allowed for theoretical sampling utilizing a constant comparative and an increased depth of concept identification among those with more experience in living with the diagnosis for the longest period of time as well as receiving treatment for their disease.

Questions that were considered included the amount of oversight required for sample selection, degree of familiarity between the subjects and researcher, and the sample homogeneity or diversity within the subject group. The researcher practiced in one of 5 clinic sites. Coercion was controlled by engaging a third party research employee to be the primary contact for information on those potential candidates. The study candidates who receive care through the researcher’s individual office were contacted by a research employee, who has no personal link to the patient, and asked if they were interested in participating in the study. Those who were not interested were removed from the list. The researcher or Oncologist was not informed of any of the candidates who decline participation.

This study recruited eligible patients regardless of culture or religious preference. There was some degree of familiarity between the researcher and the subject. This familiarity was limited to the patient/provider relationship. Regardless of these issues, Cutcliffe (2000) states that if the sample can be sufficiently described, it will clarify the reader’s understanding and method of selection thereby strengthening rigor. With grounded theory, there is no set sample size and after the first interview,
purposeful sampling and theoretical sampling should be used (Wuest, 2007). A sample size of 15 was identified as a target based on committee feedback. A total of 13 interviews were obtained. One interview was erroneously referred and scheduled and during the interview was found to have been scheduled but had not received treatment. This interview was completed and will not be included in the results but discussed in the discussion section. There were several questions that reached saturation after 9 interviews. Two of those interviews were stopped shortly after they began, both at approximately 20 minutes secondary to physical symptoms the patient was experiencing. Secondary to the early cessation of the interviews and not yet reaching saturation of data, two additional interviews were conducted and saturation was reached. Glaser and Strauss define saturation in research when no further new concepts, ideas, or dimensions are identified (Glaser & Strauss, 1967).

Rigor was assured by utilizing constant comparative, dimensionality, and interplay between inductive and deductive reasoning and a systematic approach. Lack of structure and rules can lead to varied manipulation and interpretation of the data (Glaser & Strauss, 1967; Kools et al., 1996; McCallin, 2003; Miller & Fredericks, 1999). Therefore, structural guidance is needed as a set of rules for identification of “whether this is credible” (Miller & Fredericks, 1999, p. 540).

A qualitative grounded theory methodology, using participant interviews, was conducted at a local oncology practice consisting of 5 local offices. The study was conducted using one interview per participant with an original target sample size of 15. Saturation of data was reached after 12 interviews and thematic saturation was
achieved. Approximate duration of the study was 3 months. Eligible candidates were English speaking, willing to participate, at least age 18 and had a diagnosis of chronic lymphocytic leukemia for at least one year. Criteria for inclusion also included having received prior therapy, at least one treatment, for their diagnosis. The clinic population sampled was from various educational and socioeconomic backgrounds. Ethnic backgrounds included but not limited to persons of Caucasian, Russian, and Norwegian descent.

Those who were ineligible would include those who are non English speaking, under the age of 18, those who have never received chemotherapy or biotherapy for their diagnosis and those who are enrolled in Hospice services or end of life care.

Data collection after IRB approval

Rigidly structured interviews are an ineffective means for grounded method (Duffy, Ferguson, & Watson, 2002). Cutcliffe (2000) asks the researcher to consider whether there needs to be predetermination in the questions if the intent is pure discovery. Since discovery should be the intent of data collection these questions could be the most critical gateway for the research. Cutcliffe (2000) recommends that questions be considered carefully to guide the intent. Questions that are too structured, too liberal or aimed at a specific viewpoint could be deemed accommodating to the researcher and aimed at a forced fit to the theory the researcher has developed (Cutcliffe, 2000).

Subjects who were eligible, were invited to participate by word of mouth through the research coordinator, physicians, support Staff, nurses and nurse practitioners at five locations around Tacoma, Washington. A list of patient names and
diagnoses was obtained by the research employee who was employed by the practice and a phone call was placed to each individual who is eligible to participate. Those patients who agreed to the study were sent a consent form and study information by mail. The study was also discussed via telephone and if they agreed to participate, the contact information was forwarded to the researcher. Participants were screened based on their diagnosis and participant criteria. The participant was then contacted by phone by the research coordinator to schedule a time for an interview at the office that was convenient to them. They were subsequently scheduled for an interview, consented, and then proceeded with the interview. The names and other data were known only to the researcher and research coordinator and each participant was assigned a code by the researcher. The interview and demographics were referred to by that code. The identities and codes of the participants were only be known by the researcher. Each participant was assigned a random number as an identifier to protect confidentiality.

There was no coercion and the patient was assured that care would not be affected if they should refuse to participate. Persons with a diagnosis of chronic lymphocytic leukemia were the focus of this study and interviews consisted of participants with the diagnosis. There was a constant comparative analysis of the data and the information obtained in each interview was used to further identify categories and concepts that can were incorporated into subsequent interviews. This data was constantly compared to evaluate for emerging themes. Prior to beginning the interview, participants were asked to complete the demographic data. Prior to the interview, the researcher informed the participants that they were being recorded via digital recorder and that these tapes will remain confidential by the researcher. The
interviews were conducted during normal clinic hours, 0800-1600, at a pre-scheduled time in a private conference room in the clinic to which they are assigned. The participants were asked a series of questions in a semi structured interview. The recordings will be kept for a period of 12 months after the study is completed.

Aim 1 - Explore the concept of survivorship as seen by the participant with chronic lymphocytic leukemia.

Specific aim 1 questions

- Tell me a little about what it is like to live with CLL?
- Do you consider yourself a cancer survivor?
- How has your life changed since your diagnosis? (This can include both positive and negative changes)
- What are your current concerns?

Aim 2 - Describe the needs of persons diagnosed with chronic lymphocytic leukemia.

Specific aim 2 questions

- How have your physical, social, and/or emotional needs changed since being diagnosed with a chronic cancer?
- What does a person with CLL need from their healthcare providers?
- What kind of education would be helpful to a person with CLL at diagnosis and afterward?
- What is your experience with this?
- How have your physical, social and emotional needs changed since being diagnosed with a chronic cancer?
Aim 3- Formulate a theory that captures survivorship needs of this population with CLL and guide medical caregivers to address the needs of this population. The approximate length of the completed interviews varied by individual and spanned from 40 and 65 minutes.

Data management and analysis

Beck authored the three criteria for qualitative research evaluation and included evaluation criteria under the categories of “credibility, fittingness and auditability” (Beck, 1993, p. 265). She compares these qualitative criteria to the reliability and validity of a quantitative method (Beck, 1993). Each of the three criteria are defined and a set of questions are presented in each of these three areas to assist the reader and the researcher in assessing the qualitative reliability and validity within the study. Chiovetti (2003) expounded on Beck’s original work to identify additional methods to enhance rigor in conducting a grounded research study and included recommendations including personal journaling and careful monitoring of the literature,

In addition to criteria for implementation of the study, Wuest (2007) described her use of Glaser’s (1978) foundational 6 C’s for coding. These include “cause, consequence, condition, context, covariance and contingency” (Wuest, 2007, p. 255). She utilizes these as well as “process, degree, dimension, strategy and type to assess relationships among the categories. Regardless of the method chosen, there is considerable agreement that tools for precision are required to ensure rigor (Cutcliffe, 2000). Grounded theory utilizes constant comparative method in data analysis and is conducted as a constant comparative to the critique guidelines selected throughout the
study (Glaser, 1967). This constant comparative should be stringent but not too stringent as to restrict discovery (Glaser, 1992, Kools et al., 1996,).

Descriptive statistics were used to report participant characteristics. A reviewing panel of experts was selected by the researcher and advisor and consisted of the researcher, a survivor diagnosed with chronic lymphocytic leukemia, two doctorally prepared oncology nurse expert reviewers and one doctorally prepared oncology nurse who has expertise in the use of grounded theory method to ensure rigor in qualitative methods. There were no cultural issues during this study but if there were cultural concerns, a cultural expert specific to the culture in question was available to be consulted to ensure contextual meaning was accurately reflected.

Content analysis was performed separately and manually by the researcher and the oncology/grounded theory advisor. Transcripts were typed verbatim by a paid transcriptionist and reviewed for accuracy by the researcher. Using the transcripts by identifying number only, the completed transcripts were reviewed again by both the researcher and the expert. The recurring phrases and concepts from the transcripts were identified and labeled with codes (topic coding). Similar concepts were then grouped into categories (analytic coding). The data was then analyzed for emerging themes using the identified concepts and categories (Richards & Morse, 2007). Once the themes were identified, a sample set of interviews were reviewed by a CLL survivor to identify themes. The participant identified themes and these themes were compared for applicability and accuracy.

A representative sample of transcripts were sent and subsequently reviewed multiple times by volunteer expert members. The experts identified themes and they
were again compared to the identified themes to ensure saturation and thematic accuracy.

Although “pragmatism and symbolic interactionism are the source of foundational assumptions of grounded theory” (Wuest, 2007, p. 243), a systematic, rigorous approach is required to convert assumptions into data and subsequent theory. Grounded theory method is an attractive method to young researchers as it is improves a researcher’s capacity to generate theory relevant to their research (Glaser, 1967).

Protection of Human Subjects

This study utilized interviews. The risk of participation included increased psychological stress, sadness, or anxiety from reliving the cancer treatment experience. Coercion was limited by the use of a third party contact for subject referrals. There was minimal risk of injury by participating in this study. No apparent injury was reported. There were two participants who were experiencing symptoms of pain or difficulty with prolonged sitting and the interviews were ended early for the comfort of the participant.

All participants underwent an informed consent process and signed a institutional consent form as approved by the governing IRB. The researcher reviewed the informed consent, the confidentiality document as approved by Northwest Medical Specialties and the University of Hawaii Manoa IRB, and answered any questions the participants may have had prior to the interviews. A copy was provided to each participant. Several participants did not want a copy of the consent and were informed that a copy would be kept for one year and that they could request it if they changed
their minds. Any publications resulting from this study will be presented without any individual identification of those involved in the research.

Data protection

All identifying patient information remains accessible only to those directly involved in the study, is identified by code numbers and not personal identifiers, and is stored in locked research files and password-protected databases. The code numbers and names will remain known only to the researcher. The interviews, audiotapes and field notes will be kept in a locked file for one year. The risk of loss of privacy will be addressed by maintaining informed consents, confidentiality agreements and coding information in a locked file accessible only to the researcher. At the end of the study once data is obtained, this information will be personally destroyed by the researcher.

Women and minority inclusion in clinical research

This study was open to all adult patients, male or female, without regard to race, ethnicity, culture, or religion who met study eligibility criteria.

Assumptions

Utilizing a grounded theory method approach, this study provides the foundation for expanding knowledge of survivorship needs, and developing theory in an understudied and growing population of survivors living with chronic lymphocytic leukemia. It assumed that these survivors have personal stories of their survivorship, and that they may have different needs than those without active disease or recurrence. These needs were identified by the survivors themselves and further identified these needs over time. Future research should be built utilizing the results of this study in
efforts to promote wellness, address survivor educational needs, and develop stage based education programs for both healthcare providers and the survivors themselves.

Demographics

There were 12 participants in the study. The ages ranged from 55 to 88 years old. The mean age of the participants was 68.25 years. Gender was primarily male (n=10). The majority of the sample was married (n=8), two participants were single and two were divorced. One hundred percent of our sample was Caucasian. All completed high school (n=5) and seven had a college education or some university training. Eighty one percent of those polled were retired (n=9), one was employed and one was unemployed secondary to illness. Out of the sample, 67% were engaged in social activities outside the home and 8 described themselves as fully active. One of the participants described themselves as active but without strenuous activity and one had further restrictions but felt they could walk and participate in self care. One hundred percent of the 12 participants had received treatment in the past for a diagnosis of CLL. The majority (n=8) were not currently receiving treatment at the time of the study (Table 1).

Types of treatments received are featured in Table 2. Participants received between 1-4 treatments. The largest majority received one chemotherapy regimen in the past (n=6), three of the participants had received two different chemotherapy regimens, one received three prior chemotherapy regimens and one had received four chemotherapy regimens.
Table 2. *Types of chemotherapy treatments received*

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<th>Treatment</th>
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<tr>
<td>Fludarabine</td>
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<td>Rituximab</td>
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<td>Bendamustine</td>
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<tr>
<td>Cyclophosphamide, Vincristine + Prednisone and Rituximab</td>
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<tr>
<td>Fludarabine + Cyclophosphamide +Rituxan</td>
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<tr>
<td>Bendamustine +Rituxan</td>
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<tr>
<td>GA-101 + Bendamustine</td>
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<tr>
<td>Chlorambucil</td>
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Years since diagnosis ranged from 1 to 27 years with the majority ranging between 4 and 9 years (see Table 3).

Table 3. *Years since CLL diagnosis*

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CHAPTER 4

Results

Data analysis was completed and the data was grouped into six main themes (There’s a Cloud There, In the Beginning, Certainty of Illness, Lens of Life, Human Advocacy and Cures for the Incurable). These themes were developed from the answers provided to the study questions used during the individual interviews. Within each of the six main themes, multiple sub themes emerged. Related sub themes were then evaluated for relevance to the main themes and subsequently merged under the six applicable overarching categories.

“There’s a cloud there.”

Participants were asked what to describe what it is like to live with Chronic Lymphocytic Leukemia. After receiving the diagnosis of CLL, they reported feelings of overall life uncertainty (“cloud kinda hangs over you, it is a big question mark on your life”) and this uncertainty continues throughout their daily lives. Several of the patients used the word cloud to more fully describe this uncertainty (“like living under a cloud”), (“there’s a cloud there and it’s got your name on it and it’s gonna sweep in and you’re gonna go through the same thing you just went through a year before, the month before or whatever”). For those interviews that did not specifically use the word cloud to describe their lives since diagnosis, they describe very similar feelings of ongoing anticipation (“So it’s sort of you’re waiting for that sort of impending, you know, that thing that is going to happen and I don’t really know what it looks like but you know it is probably going to come up in the future and then you will have to deal with it”).
Since the disease is considered incurable, all of the participants described the acceptance of living with CLL and incorporating the disease as well as learning to live with it (“I had to let go of it back early on, realizing I can’t do anything about it. I just had to learn to live with it”). Although, they reported that they do not worry that they are in any imminent danger of death (“I’d like to see grandkids and I know I’m not gonna die tomorrow or anything”), there is a constant worry of illness (Do you worry about? Being sick? Yeah, oh yeah”). During the periods where there is an absence of symptoms, there remains worry about when the resurgence of the disease will occur (“It’s always in the back of my mind, what does this mean for me long term, is it going to be my demise? Is something else going to be my demise?”) and therefore, continue to make life changes such as infection precautions to prevent complications (“There’s a period of time when I am feeling good but you gotta keep in back of your mind that you still have a limited immune system and so there again you err on the side of caution”).

**Time.** The uncertainty of the disease course often results in the ongoing personal conundrum in assessing a reasonable life expectancy that is measured in time. (“My current concerns I guess are, you know is it 5 years, is it 10 years, is it 20 years?”, “What does it mean long term?”, How much longer to live you know?”). This prognostic timeframe and the focus on survival rates can sometimes result in more fear for the future. (“There is a, I don’t wanna use the term you live in fear, but you do because you kinda say if everything is cool do I have 5 more years, do I have 10 more years? What’s gonna happen?”). The participants sought to measure life expectancy through symptoms of disease progression such as their complete blood count and more specifically their white blood count (“waiting for results and you don’t know what you
have, one week, one month or 5 years”). Very often, blood counts are the individual’s only objective symptom for monitoring their disease (“I have not had any symptoms except the high uh white blood cell count”) and therefore are watched very carefully by the individuals as a measurement of wellness, disease recurrence and life expectancy. (“Then I went online and found out I was at zero stage, and you know that people at that point in time, which was in 2005, their longevity was about 12 years, so it seems you know seven years later, here I am getting a treatment and then you know another 5 years and I know the potential can change and more and more is found out as you go along, so I’m not looking at the twelfth year as you know, oh well here it comes”).

*Causes of disease and death.* There was a common interest among the CLL patients about the etiology of their disease. For the military veterans who served during the Vietnam era, agent orange was raised as a potential contributing factor versus cause of their disease (“one of the spin offs to exposure to herbicides is CLL”). Additional beliefs about etiology included heredity (“I mean, you got too many white blood cells that are bad is what actually is what starts it but what actually causes it? Is it hereditary?”) or environmental, (“Well what I heard too, that it can be caused from um, here in the last 10 or 20 years, uh your preservatives they use in food”).

There was also interest in the cause of death for someone with the diagnosis of CLL. Although several of the patients stated that they didn’t really want to know and had never asked, they had concluded that since their risk for infections was increased, it was likely the cause of death (“You know like by asking me a series of questions I could deduce from that, well, that must be what happens to you ultimately, okay your gonna die of infection or the blood won’t be able to carry all the oxygen to your body
or you know, blah blah blah. So that’s how I figured out, well, that must be how you actually die of this disease”). This was especially true for those who had been treated for infections in the past (“It’s kinda like you don’t die from CLL, you die from complications of CLL”).

Measuring disease (all symptoms assessed). Various daily activities or intermittent measurements were frequently described to self monitor the activity of their disease. These included routine evaluation of enlarged lymph nodes (“I did have little lumps under my armpits, that’s the only thing I had”), while shaving (The only time I really think about it is if I’m in the morning when I’m shaving or something I always check, see if I am swollen”), evaluation of complete blood counts during their visits (“Sometimes my white blood count will stay below the 11 range. Sometimes I do a blood test and I’m up at 13. So the last blood test I was up at 13 but I’d been there before and dropped back down. It seems to be, I don’t know what the deal is but for some reason it’s just fluctuating. I don’t know why but I am not worried about it because hell, before I was way up there!”) and other symptoms such as sweating (“is it menopause or CLL?”).

Phantom illness. Once their symptoms were assessed and there was an absence of symptoms (“There is such an irony there because I don’t feel any different”), they described resumption of normal function with the goal of establishing or maintaining normalcy in their lives and less worry (“I leave it there”, “I don’t think that worrying about it will help me at all”). The absence of symptoms in a personal diagnosis of CLL results in it being referred to as a silent disease (“I haven’t gotten sick yet, there is a kind of irony there because I know on paper that it definitely changed the numbers but
as far as how I feel, it is interesting because at every single appointment I say I feel
great, you know I feel fine, I don’t feel any of these symptoms that you go through the
list”). Others describe it as a phantom illness, (“It’s a phantom disease for me”, “It
doesn’t effect you daily life”), (“It is a non issue”, “just like having a cold”). (“If it’s
attacking me internally I don’t know it”). However, when symptoms are discovered
they are unsettling (“It dupes you into thinking you’re ok”).

*In the beginning: “I was scared.”*

Overall, the period after initial diagnosis was described as overwhelming (“My
head was swimming”, “panic city”). Initial diagnosis could be further divided into
those with and without symptoms at diagnosis. For those who presented with
symptoms, (“I was just kinda flu-like and didn’t know why and I was so drained of
energy all the time and kept getting sick and I couldn’t fight anything off until finally I
was running a fever for days and days and days”). They reported increased anxiety and
confusion over ambiguous symptoms (“I was really sick and didn’t know why”). Once
the diagnosis was made they reported a sense of relief (“It was a relief to find out”).
The period of initial diagnosis for those who presented with symptoms was marked by
feelings of fatalism (“Gonna die tomorrow”) but yet quite positive towards initiating
treatment to alleviate their symptoms (“All I remember is my first treatment”). These
patients became less anxious as time passed (“As it went on and on and then I thought
oh, maybe I can beat this”).

For those who were asymptomatic at the time of diagnosis, many report the
diagnosis being picked up during routine physical exam (“It was found by accident”).
They reported subsequent feelings of disbelief (“I thought there was something wrong
with him (Dr) since I was working full time”), and initially began to dwell on illness (“I had a tendency to let any symptoms upset me”, “I think I dwelled on that more in the first few years than I do now”). The initial referral to an Oncologist was also identified as a very stressful event and a catalyst to review their life (“Well boy I hope you got a cure here and all your rocks are in a pile because you don’t want them scattered around”). Both the symptomatic and the asymptomatic groups described the period after diagnosis as a “kind of a fog” and both groups reported relying on family or friends to listen and relay the information given to the patient early in the diagnosis. (“I remember a couple months afterwards my husband would say things like “all the doctors said this and this” and I’d go “he did”? And I was like I thinking I was there too, you know, so I started thinking, “well maybe I was just kind of overwhelmed and just didn’t hear a lot”).

Certainty of illness: “It’s gonna sweep you up and you’re gonna go through the same thing you did before.”

With a diagnosis of CLL, there is an expectation of certain illness. Participants describe this certainty of illness as (“you know it is coming again”) and along with the certainty is the readiness for treatment (“let’s get it over with”). Treatment is generally viewed as a means to return to normalcy (“Gonna be ok and you’re gonna bounce back”). Initiating treatment is viewed positively in most of those who are symptomatic as a means to return to normalcy (“the treatments as I got used to them, I felt better”), (“I was so sick for the first couple months that I basically just laid in bed. Then I gradually got stronger and stronger”). Once treatment is completed, they hopefully returned to their asymptomatic state again followed by the cloud (“You are in a holding
pattern and pretty soon you’re sick and then in limbo again”), assessing and waiting for symptoms to occur (“There’s a little bit of dread you know, waiting for it to come around again to where I have to get chemo again sometime but you just never know”).

**Lens of life: “You look at life differently”**

**Self.** After diagnosis, the participants reported a change in their outlook towards others and themselves (“You look at life differently”). In terms of describing themselves, several described an increased tolerance (“I’m more tolerant of people around me, especially family”), a new appreciation for life (“It has brought a new awareness and sensitivity that I might not have had”) and more empathy and patience in themselves and others (“It’s important to give people a little room as I would wish they would give me but I wouldn’t know about that until I needed it myself”). Additionally, they report having a fuller life as a result of the diagnosis and a belief that (“life is too short to be unhappy”). Although there is a general acceptance that life will change as a result of the diagnosis of CLL, (“It (my life) just changed and you have to accept the change”), there is a fear of changes in physical appearance as a result of CLL. Changes in appearance appeared to correlate with a transition from phantom illness to outward signs of a cancer diagnosis. This was particularly true in regards to hair loss (“First thing I said...is my hair or beard gonna fall out? Well that is the only thing that concerns me”), and other side effects of treatment (“I never really lost my hair. I never got the big steroid moon face or anything like that. In those respects I feel really, really fortunate-I just can’t imagine, from what I know about the chemo treatments or where you lose your hair. I didn’t lose my hair. You know, I mean I look fine”). Other outward signs of disease were observed by the participants and a gauge that was used to
determine whether they would proceed with future treatment (‘‘I see a lot of chalky people and a lot of them don’t have hair, a lot of them wear toupees and hats. I don’t wanna look like that. I don’t want to have that pasty look like you died yesterday’’). One of the issues reported by several of the males in the study was the onset of erectile dysfunction after diagnosis. The men reported that they were uncertain if this was related to the diagnosis. Emotions ranged from confusion over etiology, grieving as well as acceptance over the loss of function (‘‘I lost the ability to perform and we’ve loved each other for 40 something, pretty much longer than that and we’ve just accepted the fact that I’m probably never gonna get it back so let’s just go on’’).

*Others.* Most of the participants describe changes in their relationships or view of others after diagnosis. Several of them reported a better relationship with their spouses since diagnosis (‘‘I just always felt I was closer to my wife then I ever thought I would but as I look on it now, I’m closer now then I was when I thought I was close if that makes any sense’’) and (‘‘I get along better with my wife which was an ironic twist’’). Diagnosis was also the primary motivation for change and ultimatums in relationships, both in marriages (‘‘I said either you change or I’m outta here and my husband changed dramatically and our marriage got so much better and that was really because of cancer’’) and families (‘‘If I hadn’t known about this (CLL), I might not have pushed him (son) quite as much’’).

Within this population, there was a constant comparative with other acquaintances, friends or family members who have a diagnosis of CLL. The primary focus of their discussion centered on their blood counts, symptoms and treatment they are receiving or have received. (‘‘So I ask him, well how is Tony doing? You know, he
and I went back up to 100,000 and he got up to 120,000 at the beginning of the summer and I was at 102,000 in January and the doctor was going to start treatment. He went through the summer and he fished, came back and was 90,000. It dropped you know 30,000, so I am not sure exactly what they are doing”). In one example, the sudden demise of his comparison partner resulted in further angst and uncertainty (“My Bud over here, he had CLL. He’s there and we are talking and having a great time and he’s having outpatient treatment like me and then I came in and oh he died. What do you mean he died? He’s gone. You follow? He and I were the healthiest of the bunch out there so I mean you don’t know”).

Several of those interviewed reported both positive and negative changes in relationships and how they were treated by others after disclosure of their diagnosis. This was also affected by the amount of personal disclosure. Disclosure ranged from openly sharing information to limiting the circle of disclosure (“I almost don’t tell them because it doesn’t affect me) or avoiding disclosure altogether (“I don’t want them to feel sorry for me”). Positive outcomes of disclosure to others included two benefits held to raise funds for the patient and his family (“I mean people pulled together. It’s amazing how much people want to help in times like that”, “It restored my faith in humanity and the good side of people, they go above and beyond”). One of the negative outcomes of disclosure occurred when a participant decided to run for a local association office. During the meeting, the participant reported that he heard another member state (“Why put him in, he’s gonna die before long anyhow”).

One of the unintended outcomes of disclosure of their diagnosis were recommendations for alternative or integrative therapies by their friends and family
(“people come out of the woodwork holistic, we can go this way and you know if you eat so much Chai tea and this it will cure it, yeah, whatever you know”). This presented contention, primarily over beliefs (“We had a woman tell us the Lord will cure that child. Bring her to my church and we’ll lay hands on her and the Lord will cure that child and I told her that the Lord did. He sent the doctor to medical school you know, so thank you God”).

Survivorship: “Anytime I am on this side of the dirt I am a survivor.” Views on survivorship in this group were highly variable. At least two of those interviewed did not like the term survivor (“I would not use that word to describe myself”) or did not like the label used to describe them personally (“I wouldn’t put it in the top 10 of who I am”). Survivorship was also described as day to day survival, living with the diagnosis of CLL (“It’s always better on this side of the dirt than on the other side of the dirt”). There was a reluctance in the majority of patients to use the term survivor as it was viewed as something earned (“I’ve not suffered, it cheapens others experience”). Those who felt ill, had more issues with control of their disease or were hospitalized at the time of diagnosis as a result of their disease appeared more likely to consider themselves survivors (“absolutely and it’s a raging battle because I am not in remission”). Conversely, several described themselves only as a survivor when the disease is controlled (“I think that I am unless it should flare up again”).

Catalyst for action: “It (work) was just too difficult and I had to leave.” For many, a diagnosis of CLL resulted in a reevaluation of their lifestyle and in some instances, multiple life changes after diagnosis to include diet, exercise, discontinuation of driving, avoidance of infection, and limiting social activities. The diagnosis was also
a catalyst for more extreme life changes to include early retirement, contingencies for belongings, planning for others in their care, and the fulfillment of their bucket list.

**Diet.** The participants were split in their views on lifestyle changes after diagnosis. Those who have made changes in their diet and exercise do so with the belief that it helps them better control their disease (“I’m still keeping my blood count normal but I do that by eliminating other things, I used to eat a lot of fatty foods”). A second group has attempted to make dietary changes but experienced subsequent weight loss or weight gain directly related to their disease (“I had a slow weight reduction until I went through 6 months of chemo”, “Not eating good because I have a lot of pain in my spleen” or “I can’t eat a lot because my stomach fills up so fast”). At the other extreme were those who felt that they had been leading a healthy lifestyle prior to diagnosis and still developed cancer, hence, there was no need for changes (I’m not really physically not at all I mean that I really should be exercising more and paying more attention to my weight which has gradually gotten yeah you know more but then on the other hand I think well why? “You don’t really know what caused this anyway and so what do you change to make it better?”).

**Infection.** A common theme amongst the participants was a concern over their exposure to infections and the development of infections (“I wash my hands more, I pay more attention to that, on an airplane I’m like ugh you know some guy over there, I had never heard a more terrible cough in my entire life and I’m like ugh I need a mask”). Other changes in behavior after diagnosis included avoidance of social gatherings and crowds (you have to err on the side of caution because of a compromised immune
system, I can’t be around crowds”, “You become a germaphobe”, “I probably avoided a lot of social functions”). Another participant describes eating in a secluded area of the restaurant to avoid exposures (“I sit at a table away from everybody”).

One participant who had a history of sinus infections wore a mask during the summer months while doing yard work secondary to a fear of recurrent sinus infections (“I have to use nasal flushes now, especially during the summer when the pollen count is up, out and heavy, I have to be very careful as far as mowing the lawn. Simple things, weed eating, I have to wear a mask. I have to wear a shield over my face to keep stuff out of my eyes”).

Fatigue. Another common theme amongst participants was the impact of fatigue on their lives (“My energy never really has recovered, my memory was pretty off”, “I can’t do a lot of the things that I use to do you know. I mean, I get tired doing things that use to do easily and that’s kinda frustrating”).

Many report the idea of budgeting activities within the confines of fatigue in order to adjust to their limitations (“I had to budget my energy, pace myself a little better, eat and drink a little better, a lot less alcohol or anything like that”, “You learn that a lot of stuff isn’t worth wasting your energy on and it’s to the point I haven’t had the energy to waste”).

Retirement, responsibilities and the bucket list. Participants described various other life changes as a result of their diagnosis to include retirement, a tentative plan for caregiver responsibilities, belongings distribution and the development of a bucket list.

At least two participants retired early as a result of receiving the diagnosis of CLL (“I determined it wasn’t worth it so I retired early”). On reflection, one of the
participants stated that the diagnosis of CLL precipitated the decision and that this was likely premature but prompted by an uncertain future (“I now wish I worked a little bit longer”).

Participants also described the development of a plan to distribute their belongings (“Things to be done like my old cars that like my Dodge. God knows how much it’s worth, a lot I’m sure and but I have it co-titled with a friend. That way when I die, he has the legal right to drive that car and get it out of there”, “So you drive it, you enjoy it. I know it is going to somebody that cares about it and has a vested interest in it generally”). Along with plans for their belongings, those interviewed describe a contingency plan for caregiver responsibilities (“My mother is 91 and in a convalescent center. I do all the money part, I’m power of attorney so I think okay, what if something happens who does that?”). Those who have caregiver responsibilities often described these as a catalyst for self-care behaviors focused on health promotion (“I have to be careful that I don’t over-stress myself because if I over-stress myself, I feel it. I can’t fall down because I have to do these things so I think that may be why I do better than some other people psychologically”).

Lastly, participants describe the need to live their lives to the fullest and this need resulted in the development of a bucket list (“You better do all the things you wanna do because you just don’t know if you’ll be in the hospital 2 weeks from now or what”). Interestingly, the bucket list items discussed during the interviews were not necessarily immediate future plans and involved long term plans to include relocation (“I plan to purchase a motor home and move it down to New Mexico”).
Human advocacy: “Act like you’re gonna save them.”

Responses regarding the needs of the patient with CLL from their caregiver were grouped into four categories. The patients described the need for emotional, educational and medical expertise and insurance navigation.

Emotional experts. When describing what is needed from their medical professionals, the patients responded with the need for emotional support and the need for the professional to be emotionally present with them as they assimilate to the diagnosis (“Being with your patient emotionally I think is very important because you’re feeling very vulnerable, like what’s happening? My world is changing. I didn’t ask for this. I didn’t want these changes to happen”). The desire for hope was also a common theme (“Treat me like I’m gonna make it, act like your gonna save them”, “don’t act we’re dying”, “no false hope, but want hope”, “You know we can beat this thing, you know we can do this, just be positive I guess”).

This desire to be emotionally supported also extended into ancillary services. One of the participants underwent an ultrasound of a mass in the groin prior to diagnosis. The participant stated that he became very concerned when the technician’s demeanor changed (“This was a very personal investigation and then her countenance changed and you could see she saw something there that wasn’t an inguinal hernia and pretty soon there is whispering voices over her and voices coming in”). Additionally, one participant reported increased stress after transferring to a larger clinic. He stated that he had more anxiety when the caregivers were speaking a different language while providing his care. This changed provoked feelings of uncertainty and ongoing thoughts on whether there was something wrong with him or with his care. (“There’s
probably 4 or 5 different languages going on in the staff there. It’s just the way it is, and when they talk to each other, they are talking in another language. They’re doing what they need to do but that sensitivity level that you have from a smaller organization isn’t there).

Other characteristics described in this category included trust (“he’s like a wise father or something”), a calm approach, and a bedside manner that conveys hope.

**Medical experts.** There was a common expectation of expertise surrounding technically based procedures. These included intravenous skills (“There are people that their training and skills are a little better and they can get it right the first time and then there’s other people who seem to have a problem hitting the vein and going fishing. From a patient’s standpoint, this is unacceptable”) and bone marrow biopsies (“If I was to say anything about bone marrow tests though, we wanna make sure it’s done by someone who’s done it before”).

Participants also discussed the importance of honesty and approachability in their medical providers (Don’t skirt around an answer, be more upfront”, “When all you get is you’re doing fine and everything looks good, well, you know it makes you feel at ease but you still in the back of your mind think “What were they looking for, What did they come up with?”). Approachability was identified as feeling comfortable asking questions and receiving correct and honest information (“I can ask anything that I feel I need to ask, I know you guys will give us correct answers to the best of your knowledge”). Although there was a desire for honesty, they felt this information should again be delivered with the conveyance of hope (“Everybody in there (the infusion room), it seems like they are pulling for ya, you know what I mean?”).
other need expressed was the need for timely follow up from the provider and the office. Specifically, they wanted a quick turnaround time on reporting the results of blood work and imaging studies (“We didn’t get results, no phone calls back to let us know if they were ok or not”).

Educational experts. There was a wide variance in the desire for information. Some did a lot of research on their own after diagnosis while others had family members who did the research on the disease (“My family was on the internet”). In other examples, more information was desired than was provided (“more information on what you’re gonna feel and how you’re gonna feel in laymen’s terms”, “They would say whatever, he is looking good, well, but how good is it? What is good? What did you check for? Is there any other type of cancer?”). Several times participants were given some information but their understanding was limited secondary to the comprehension of medical terms (“So much jargon that it is just garbage”, “well the majority of books are all these studies that you know are eh...just the vocabulary”). The last category included several who wanted very limited or no information. This was related to feelings of being overwhelmed, more acute illness at the time of diagnosis, the disease being incurable (“I didn’t do much, I believe to me I didn’t care and really didn’t want to know everything”), and avoidance of prognostic information (“Why do I need to know the gruesome details about the disease?”).

Insurance issues. A major concern for several of the study participants was how to pay for treatments and navigate through a complex insurance process. This concern was exacerbated when they had disease progression that required treatment. As new drugs are developed, treatment options continue to change. New drug
recommendations are used with more frequency and are associated with higher costs to the patient (“How the hell am I gonna get this paid?”). This had led several providers to address insurance coverage and cost to the person upfront before treatment begins. This upfront discussion results in further anxiety for the person with CLL (“Well I say to medical providers, “don’t start off saying well we don’t know if that’s gonna be covered, nehnanehnana and start all that back pedaling because all that does is put even more fear into somebody who has enough fear right then to deal with”). Some had difficulty navigating through Medicare benefits or had copayments that they feared would limit their treatment options (“Dealing with Medicare when it comes to your coverage’s changing or something like that, it’s like butting your head against a wall”). Those who had private insurance and state assistance discussed the cost but felt fortunate that the costs were covered. Most of those interviewed also expressed concerns about the financial cost to the other family members.

Another group that discussed issues surrounding financial concerns was the veteran population. Several of the veterans expressed their opinions on their possible link between Agent Orange exposure and developing their CLL (“I am surprised by how many veterans in my age group and not just my age group, some older, some younger have cancer issues, Agent Orange issues”). They also expressed concerns over impending disability due to their condition and treatment. Several of the participants vented frustrations associated with their applications to the VA for assistance with treatment and their disability claims (“Frustration with claims, the VA said you didn’t have boots on the ground, you can’t prove boots on the ground. I did have boots on the
ground but I was TDY and I don’t have paperwork on it. What am I gonna do, take on Uncle Sam?”).

*Cures for the incurable: “Curing isn’t where their mind is.”*

One of the most interesting themes from this study revolved around the idea of cure in Chronic Lymphocytic Leukemia. There was a common thread of hope for cure (“I wish it was curable but it is treatable so you can live”). One participant describes the idea of cure as always present for them but not necessarily for those providing care (“The doctor you go to isn’t looking for a cure, curing isn’t where their mind is, cure is where your mind is”) and describes clinical trials at cancer centers as a path for cures in the future. Several participants described continuing with current treatment and maintaining stable disease in hopes of future improvement in therapies (“As time goes by more things come out”) or even in hopes of cure (“Now I know it seems like almost every month or every couple of months they come out with some new breakthrough in, I mean people live longer and live, who’s to say next summer they’re not gonna find something to cure it”, “I always think, how many more times can I do this? It’s not the treatment that takes much toll on my body but there’s gonna be a point in time where the body doesn’t respond to the same old treatment”).
Figure 1. Theory of Survivorship in CLL
CHAPTER 5

Discussion

To begin the discussion, Figure 1 is a diagram which represents the cloud theory in CLL survivorship. The beginning is frequently marked by anxiety and being in a fog following the diagnosis. Once they comprehend that there is no immediate risk of impending death and that the disease is incurable, the disease is incorporated as a cloud which is ever present and eventually incorporated into their lives.

Within this cloud, the person with CLL who has received prior treatment understands with certainty that disease symptoms will recur at some point and that treatment will again be needed. Disease is self monitored under this cloud by evaluation of outward symptoms such as lymphadenopathy and fatigue and by inward signs such as changes in blood counts. They also rely on medical professionals for an accurate evaluation of disease activity. They begin to measure disease in terms of time which is commonly evaluated against median survival and survival of familiar others such as friends or family.

Because of the cloud of the CLL diagnosis and the certainty of illness, the person with CLL makes changes in their lives. Some of these changes are as a result of diagnosis and some are in anticipation of certain illness in the future. These are often changes in their relationships and lifestyle, designation of belongings and assignment of current responsibilities. They do not absolve themselves of their responsibilities. Rather, they develop contingencies plans during the times that they become ill and may need additional treatment.
Within the diagnosis and the cloud that is present with CLL, there is an ongoing
desire for advocacy and the involvement of the medical professionals and insurance
providers to provide support to include financial, emotional and physical levels. These
needs continue throughout their life continuum.

The cloud represents the ever present illness but within that understanding is an
ongoing desire for cure. Patients are willing to undergo treatment to extend life and to
relieve symptoms but their desire is for a cure. Often patients will undergo treatment in
an attempt to extend their lives and hope that soon the next treatment is available.

In the beginning

In the beginning describes the participant’s experiences shortly before and/or
after diagnosis. For those who presented with symptoms, there was a sense of relief at
identifying the etiology of their illness. The symptomatic group also viewed treatment,
both initial and subsequent therapies, as positive and beneficial. Those that received
treatment shortly after diagnosis reported that they were quite accepting of subsequent
therapies stating that they knew the treatment worked to make them feel better. One of
the participants reported that he looked forward to treatment as an effective means to
control symptoms and return to normalcy and hence, may actually have decreased
anxiety on the part of the patient. This finding relates to previous study findings by
Else, et al., (2008), where quality of life scores were examined in both the treated and
untreated populations with symptomatic CLL and were found to improve after
treatment.

Those who were asymptomatic at diagnosis were in disbelief and often felt that
it was a missed diagnosis. Feelings of disbelief and fatalism were also reported in the
study findings by Evans et al. (2011). With the initiation of treatment there was an increase in anxiety and fear of the unknown particularly as it related to physical symptoms such as hair loss or other outward signs of treatment. Patient education and anxiety reduction, particularly regarding treatment, should be an essential part of the pre treatment plan for both groups. Nurses who provide care for the patients should understand that levels of anxiety and fears may differ depending on previous treatment experiences and should be assessed prior to treatment initiation.

In either presentation, the period after diagnosis was marked with fear and anxiety and a sense of being in a fog. This fog resulted in a limited comprehension of any information that was provided to them. Most reported that their families were the information gatherers, the listeners, and memory for the events that followed the diagnosis. This suggests the importance of including the family in education and information, particularly in the early stages after diagnosis.

There’s a cloud there

All of the participants reported initial feelings of fatalism and constant dwelling on illness and any symptoms that might be related to their disease. As they became more acclimated to the diagnosis, they reported feeling less anxious and that they could “beat” or at least control their disease.

Those studied also emphasized prognostic time in the interviews. In many cases this was referred to in terms of countdown of how many years they have left. Most did not want to be told how death occurs in CLL but many did want to know the prognosis measured in time. For those who sought information and were told not to worry, they found time information through friends or on the internet. Many expressed
dissatisfaction at receiving vague reassurance. Instead, they described the need for honest yet hopeful information to include prognosis. The importance of this information in CLL has been likely underestimated by the healthcare team. Molica (2005) suggests that at the time of diagnosis patients should be given information on prognosis, information on guidelines to initiate therapy and education on symptoms to monitor in order to recognize disease progression. In this study, the information that participants obtained regarding diagnosis of an incurable disease and prognostic timeframe was commonly used as a wakeup call and then the catalyst needed to make their plans.

In order to evaluate their disease in the silent stages, participants monitored their disease through every day activities such as shaving and showering to assess for lymph nodes. They also monitored their blood counts carefully, even when the disease was silent, to evaluate their disease. Some were unsure of what the actual numbers represented but all knew that an increase in their white blood cells was a likely indicator that the disease was becoming more active. Given their dependence on blood counts and any imaging study results to verify their status, timely follow up phone calls were critically important to them after every visit.

Many found what they perceived to be a like partner diagnosed with CLL. Although they were not aware of the individual prognostic factors or differences in CLL, the diagnosis served as a link with their partner for comparison of blood counts, treatment, and to evaluate how well they are doing comparatively. The link with a partner provided support but yet also provided a source of anxiety, particularly when the partner died. Simple discussions regarding a personal approach to their disease may
dispel any misconceptions regarding similarities and differences. Information and reassurance regarding misinformation is important as they learn to live with CLL. Timely result reporting was a high priority for those with CLL. Delay in receiving the results increased anxiety levels and disturbance in their coping. An emphasis on prompt reporting should be considered.

Etiology of CLL was also a common theme. For those veterans who served during the Vietnam era, Agent Orange was discussed. Several of the veterans belonged or joined groups that enabled them to obtain more information and speak with other veterans with the same diagnosis. For the others, an evaluation of lifestyle prior to the diagnosis was reviewed such as alcohol use. Others looked for a possible link to heredity secondary to other cancers in the family. Along with etiology was a need to understand how to control the disease. The participants understood that it was incurable, however, many were uncertain whether certain measures such as diet or exercise could help with control of the disease. Many received recommendations from friends to include prayer, complementary and alternative therapies, and diet changes for control. Some subsequently incorporated these practices in their daily lives. Ongoing discussion regarding evidence based measures could help to dispel some myths and avoid the unnecessary use of other therapies in CLL.

Certainty of illness

Whereas other studies of CLL report uncertainty, those interviewed in this study reported an understanding that their diagnosis of CLL would certainly involve exacerbations of illness. They used this certainty to incorporate this uncertain cloud into their everyday lives. There was a constant worry about illness and when...
resurgence of their disease would appear but reported that knowing that they would experience illness exacerbations helped to direct their life plans. When they became ill, treatment was viewed as a method to return to normalcy and hopefully, freedom from symptoms. It is at that point that the cloud begins again.

The plans for illness included retirement, contingency for care of others, designating their belongings, a bucket list, and lifestyle changes. Not all of those interviewed had dramatic changes in their lifestyle, yet, all of them did incorporate the avoidance of infections and management of fatigue into their daily lives. Fatigue is a common symptom of the disease (Levin, Li, Riskind, & Rai, 2007, Molica, 2005). Study subjects discussed intuitive methods for control of fatigue secondary to physical limitations versus formal instruction on control of fatigue as well as infection avoidance. Several interviewed stated that in the beginning they deduced that infection was a key problem for those with CLL by the questions posed by the provider during the visit but did not ask. Findings suggest that provision of proactive information regarding both infection and fatigue prevention would assist in maximizing the quality of life in those living with CLL.

*Lens of life*

The diagnosis of CLL was a catalyst for changes in self and others for many of those interviewed. Some reported that sharing the news about diagnosis resulted in positive support from others while a few did not share their diagnosis for fear of being treated differently or because of discrimination. The positive outcomes of support included raising money and the affirmation of friendships. One negative aspect was that some lost a relationship or a leadership role due to the lack of support when
learning about their diagnosis. Most however, described a better appreciation for life, leading a fuller life and more patience with others. Families became a higher priority for the majority and for many resulted in closer relationships with their spouses and children. Some of the other family changes included dissatisfaction with current relationships and an ultimatum for change. In one instance, the spouse did acknowledge the need for change that resulted in a restructuring of their relationship with very positive outcomes.

There was also a fear of physical changes. Changes in physical appearance were important as they were the bridge from phantom illness to overt signs of a cancer diagnosis. Receiving treatment without any outward signs of treatment effects, such as hair loss, was an important factor in whether some would continue with additional treatment. An unanticipated finding in this study was a common report of erectile dysfunction after diagnosis. Several of the men reported distress over difficulty with mechanical function after diagnosis. This issue may be related to age or other issues such as anemia and may warrant further investigation.

The diagnosis of CLL was also a call to action. Some made dietary changes believing they would have better disease control and some felt that since they already had the diagnosis, changes wouldn’t make any difference. Most had been approached by others with recommendations for cancer cures such as vitamins, tea and sweat lodges and needed to make decisions regarding these treatments. Not all of the participants had a choice in nutrition. Several were having difficulty with diet secondary to symptoms of pain, early satiety, and nausea. The need to address myths surrounding the use of integrative therapies should be emphasized in order for patients
to make informed choices incorporating nutritional services as needed to assist with
weight maintenance. Also, effective symptom management for better overall quality of
life cannot be overemphasized. Just as the completion of chemotherapy treatment
results in a heightened focus on health and the teachable moment, this study identified
increased interest in healthy behaviors at the time of diagnosis as well as completion of
treatment.

Fear of infection and managing fatigue were priorities for all of the participants.
They described measures employed to avoid infections including seclusion, avoidance
of crowds, wearing a mask and limiting social functions. Those interviewed reported
decreased social interactions as a result of their diagnosis and fear of infection. Fatigue
was common to most and resulted in the budgeting of activities. Fatigue levels were
also associated with decreased memory and tiring easily. Often activities were weighed
for importance to determine whether they were worth the energy expended.

Survivorship definitions varied significantly. The categories ranged from those
who did not feel they were survivors to those who were survivors after their disease
was controlled. Some felt they were survivors who were actively fighting their disease.
These were primarily the group currently receiving treatment or having symptoms such
as low blood counts directly related to the disease activity. A few identified
survivorship as incorporated into their daily life and others who are survivors only
when going through treatment. Several of those interviewed felt that survivorship was
related to suffering. In this group, increased suffering equated to a stronger survivor.
An interesting outcome of this study was that the responses regarding survivorship and
advice to other patients with a diagnosis of CLL were very positive. Responses were
hopeful and encouraging, suggestive of coping strategies that others should employ to remain healthy. This is in direct correlation with studies that report hope as a key component of coping (Bertero, & Eriksson, 1997). There was an overarching theme to stay positive, be involved in support groups, and to get a pet if necessary. One study suggests that patients who are most likely to adjust well to cancer are ones that accept their diagnosis, and use the word cancer to describe the condition, is determined to fight, obtains information, and has optimism (Greer, Moorey & Watson, 1989). This presents the question whether depression is higher in the untreated versus the treated groups secondary to the invisible nature of the disease at diagnosis or if depression relates to the length of diagnosis.

*Human advocacy*

The human advocacy theme was one of the highest in importance for the majority. Issues of need for emotional and educational support, medical expertise, and sensitivity were described. When describing needs from the medical team, the need for emotional presence from not only the physician but also ancillary services such as radiology was discussed. Use of simple terminology, speaking English during their testing, and body language were emphasized. Written or verbal information was often too complex to understand. Similar findings were discussed in the study done by Evans, Ziebland & Pettitt (2011) where participants reported “too much jargon” (pg 69). One of the interesting outcomes of this study was that the use of a different language during an exam or treatment often resulted in provoking feelings of uncertainty and the suggestion that there was something wrong with their care. This
finding suggests the need to more fully evaluate and understand cultural considerations when providing care to patients.

Participants also expressed the need for honesty, approachability, and the need to establish trust. This could be accomplished through medical expertise with technically based procedures, simple discussions and education, quick turnaround for results and a calm, kind bedside manner that conveys hope. In a study conducted by McDowell, Occhipinti, Ferguson, Dunn, & Chamber (2009), results suggest that decreased satisfaction with health care can result in an increase in unmet needs. Further, the quality of communication between patient and physician and the conveyance of empathy can significantly impact psychosocial and quality of life outcomes (Evans, Ziebland & Pettitt, 2011, McDowell et al., 2009).

Insurance was a genuine concern. The understanding and navigation through the complexities of the VA and Medicare systems can sometimes be difficult and even more so with advancing age and disability. Loss of income and looming disability is a very high source of stress and anxiety for most when faced with the higher costs of medical care, medications, and daily living expenses.

Another unintended outcome of the study was the emphasis on the desire for a focus on cure. All too often we are focused on treatment for the patient when they are focused on finding the cure. Study participants describe having their sights set on cure and until that time are hopeful that new drugs will continue to be developed and prolong their lives until cure is found.

An interview was conducted with a patient who had not yet received any therapy but was mistakenly included due to misinformation. The information that the
patient had never received treatment was only discovered during the interview. Since we had already begun, the information from the interview was included. This participant discussed the diagnosis of CLL as a non issue since it was silent at this point. The participant was employed as a medical professional and as a result had access to information and was self educated on the disease. She did report symptoms of mild fatigue which was easily managed at this point and ongoing concerns for infection.

The results of this study have laid the groundwork in beginning to understanding survivorship for those who have received treatment for CLL. Comprehension of what it means to have the initial diagnosis provides nurses and providers with a richer understanding of the emotional, physical, and social issues that surround a new diagnosis of CLL. Within the identification of two categories of newly diagnosed patients with and without symptoms, there is further understanding into quality of life differences and educational needs in both groups.

A critical understanding of the decisions which are likely to be considered after a diagnosis of CLL and certainty of illness is crucial in providing care to the patient. Many issues including the development of the bucket list, consideration of retirement, care of others, lifestyle changes and designation of belongings are born from the diagnosis. Health care should be aware of the changes being considered in order to serve as an informed navigator through the decision process.

The development of a survivorship care plan for patients with incurable, chronic cancers should be considered. The Commission on Cancer’s standards proposed for 2015 (ACoS, 2013) have recommended phase in of Survivorship plans by the year
The purpose of this survivorship plan is to develop and deliver a care summary to the patient as well as the other providers involved in their care. There are three standards for the survivorship plans to include preparation by providers who coordinate oncology treatment, a record of care received including disease characteristics, and a written follow up plan given to the patient on completion of treatment (ACoS, 2013).

Given the chronicity of CLL and the likelihood for multiple treatments, a survivorship summary to include a record of care as well as written follow up, acute and late effects recognition, and symptom management may be considered a continuity and educational tool for this disease and other similar types of chronic cancers.

The concept of fog after diagnosis as well as decreased memory with fatigue can guide us towards inclusion of the family in the education provided as well as the plan of care. Plan of care should include careful yet honest discussion of time surrounding the diagnosis with emphasis on hope throughout the phases of the disease. Prognosis and time appears to be an important catalyst for future planning. Vague reassurance was viewed negatively and most of the participants sought the information from other sources. This challenges the question on how much information is too much and provides the basis for further investigation.

During the periods of disease regression, patients continually monitor silent disease through symptoms and blood counts. They report limited discussion of questions regarding their disease with their health care team. Understanding common issues regarding issues such as symptoms and blood counts and developing proactive
education to discuss these concerns may lead to decreased anxiety, better self maintenance and increased quality of life.

Educational measures identified from this study included infection precautions, dietary measures, use of alternative and complementary therapies and side effects of medications including physical changes. Education should be simple, using plain language in a language that they understand. The suggestion of foreign languages used during a patient’s treatment being a source of anxiety is intriguing and could be considered for further study.

Survivorship planning for this group should focus on symptom management and promotion of wellness. Routine screening in this group may not be warranted or indicated depending on age at diagnosis and current federal guidelines.

Several unexpected issues were identified during the interviews. Insurance issues and financial concerns produced a high level of stress particularly when the information difficult to understand or the process complex. This calls for a higher level of advocacy on a national level to address these issues and further investigation of the barriers. The identification of erectile dysfunction in men after diagnosis was also an incidental finding of the study and warrants further investigation as a concerning symptom reported shortly after diagnosis.

**Nursing Implications**

Nursing implications should be focused on first understanding the defined needs of this group. Communication should be aimed at both the patient and the family members as part of a whole unit, both pre treatment and post treatment. This is particularly important early in the diagnosis where the patient may not hear or
understand what is being discussed. The development of a survivorship plan could be an effective means of communication between the patient and the team that cares for them.

Many of the patients who received vague reassurance from their medical team relied on the word of friends, acquaintances or the internet for information. This resulted in many misconceptions regarding their disease, etiology, prognosis and treatment. Patient education should be provided in simple and direct terms to both patient and caregivers. This education could be either written or verbal and should include an understanding of blood values, infection precautions and prevention, and fatigue management. Effective symptom management for better overall quality of life cannot be overemphasized. Since many present without symptoms, the patient’s understanding of the watchful waiting treatment approach is imperative to decrease anxiety and fears regarding their disease. Later, if the patient should require treatment, discussion of the treatment and side effects should be included in the plan.

Nurses should understand the significance of prognostic time, symptom discovery and timely delivery of test results to the person with CLL. Healthcare workers should be sensitive to the use of other languages in the presence of patients or the gestures used such as whispering. These actions for the patient, may result in increased anxiety and a fear that something is wrong.

Throughout the interviews, the patients continued to emphasize the need for honesty, approachability, and the need to establish trust. They wanted an honest method that was infused with hope. Some describe it as a kind, bedside manner. Others stated that they did not want to be treated like they were dying of cancer but
rather living with cancer. Today, the ongoing evolution of technology in Nursing can lend itself towards a technologic versus humanistic approach to the patient. Each patient in the study tried to describe their need for and the importance of emotional presence from the physician and nurses as well as ancillary services such as radiology. The incorporation of empathy and positive outlook from the healthcare team was a key factor in their overall well being. The incorporation of empathy training and demonstrating caring behaviors programs cannot be over emphasized.

Nurses should understand the concept of what living under a cloud means for the person with CLL and incorporate this into their plan of care. We should have an understanding of the comparative partner that is often chosen for comparison in order to clarify misconceptions and identify differences within the same disease spectrum. Additionally, nurses need to understand the changes that may occur in the patient’s view of themselves, others, and lifestyle changes as a result of their diagnosis. Nurses can be instrumental in assisting these patients with healthy lifestyle changes such as diet and exercise as well as symptom management.

Finally, the financial impact of the patient who is treated for CLL can be devastating for the patient and their family. The rising cost of drugs, the decreases in Medicare coverage and issues with Veteran benefits are an ongoing concern to the patient who is undergoing treatment for CLL. Advocacy for patient financial assistance programs and advisors to assist with financial aid are needed and necessary for this population.
Limitations

This study used a purposeful sample from local clinics. Therefore, the results may have limited generalized applicability. Several of the participants were known to the researcher and several were not which could have led to variance in responses based on familiarity. This study invited various ethnically diverse patients to participate but none were interviewed secondary to declining status or hospitalization. Since the population sample was Caucasian, the study results may not be generalized to other cultures, ethnicities, geographical regions, samples, races, or gender. The study was limited to survivors who have chronic lymphocytic leukemia which is hematologically based and understood to be systemic versus regional at diagnosis. This study is also limited to one hematologic malignancy and is not generalizable to other chronic non malignant diseases, other hematologic malignancies and other solid tumor types. Also, each of the participants may have received varied treatments for their disease that may have potentially altered their survivor experiences. Additionally, 4 of the study participants were diagnosed at a younger age than is typical for this disease and could possibly affect the study results. Finally, each participant had individual variances in prognostic information that could affect each participant’s view of their personal survivorship in living with CLL.
References


Centers for Disease Control (Publication Retrieved 5 Nov 2013): Website: http://www.cdc.gov/nchs


Leukemia and Lymphoma Society (2013). need name of article or reference or paragraph http://www.lymphoma.org/site/pp.asp?c=bkLTKaOQLmK8E&b=6300147 &gclid=CLSxyqfe37kCFcz7Aodh3sA1A


APPENDIX A

Demographic Questionnaire

Code
____________________________________________________________

Age
_____________________________________________________________

Sex
_____________________________________________________________

Marital Status
__________________________________________________________

Children and ages
_____________________________________________________

Ethnicity
___________________________________________________________

Highest Level of Education in years
_________________________________________________________

Are you employed?
___________________________________________________________

What was/is your occupation?
_________________________________________________________

If employed, how many hours per week?
___________________________________________________________

Social interests/hobbies
_________________________________________________________

Do you belong to any social clubs or groups?
__________________________________________________________

If so, do you attend any regular group functions? (list)
_________________________________________________________

How would you describe your activity? (circle one below)
Fully active, carry on all activities without limitations (0)

No physically strenuous activity but able to do light housework, office work (1)

Walking and capable of self care but unable to perform work activities, up for more than 50% of waking hours (2)

Capable of only limited self care, confined to bed or chair for more than 50% of the time (3)

Completely disabled, totally confined to the bed or chair. Cannot carry on any self-care (4)

Type of Cancer

____________________________________________________

Date of diagnosis

____________________________________________________

Age at diagnosis

____________________________________________________

Currently undergoing treatment? Yes or No

Have you ever received treatment? Yes or No

List all cancer treatments and when you received them

________________________________________________________________
APPENDIX B

University of Hawai‘i

Consent to participate in the research project:
A Theory of Cancer Survivorship Based on the Needs of Persons Diagnosed with Chronic Lymphocytic Leukemia

My name is Rose Bell and I am PhD student at the University of Hawai‘i at Manoa (UH) in the Department of Nursing. I am conducting a research study as part of my education. The purpose of my research project is to develop a theory of cancer survivorship based on the needs diagnosed with Chronic Lymphocytic Leukemia. I am asking you to participate in this project because you have been diagnosed with Chronic Lymphocytic Leukemia and have had at least one prior treatment for this condition. A total of approximately 15 participate will participate in this study.

Project Description-Activities and Time Commitment: If you take part in this study, an initial questionnaire will be administered that asked questions about you such as your age, education, diagnosis and treatment. After that, you will participate in an interview that will last approximately 90 minutes. I will record the interview using a digital recorder. I am recording the interview so I can later type a transcript - a written record of what we talked about during your interview in order to analyze the information from the interview. If you participate, you will be one of approximately 15 participants which I will interview individually. An example of the type of questions I will ask is how your concerns have changed since your diagnosis and what do you currently need from your healthcare providers? If you would like to preview a copy of all of the questions that I will ask you, please let me know now.

Benefits and risks: I believe there are no direct benefits to you if you participate in my research project. However, the benefits of participating in this study include the support from discussing your experiences and telling your story as well as helping me in addition to other professionals to better understand the needs of patients with a diagnosis of Chronic Lymphocytic Leukemia. If at any time you are uncomfortable or stressed by answering any of the end to review questions, we will skip that questioned, take a break, or stop the interview, or withdraw from the project altogether.

Confidentiality and privacy: Once you have agreed to this study, your interview will be assigned a random number by the researcher for identification. Your transcript will only be identified by that number for the duration of the study. I will keep all of the audio recordings and data from the interviews in a secure location for a total of one year. After that, all the data and recordings will be destroyed. The information which is identified by a number will be seen by the transcriptionist as well as five other researchers on a designated committee who have agreed to serve on this project. They will further review
the information obtained during the interviews. Only I will have access to your real information although legally authorized agencies, including the University of Hawai‘i Human Studies Program has the right to review research records. If you would like a summary of the findings from my final report, please contact me at the number listed near the end of this consent form.

Voluntary participation: Participation in this research is voluntary. You can choose freely to participate or not participate. In addition, at any point during this project, you can withdraw your permission without any penalty of loss of benefits.

Questions: You are free to ask questions that you may have about your treatment and your rights as a research participant at any time. If you have questions about this study, or a research-related injury you should contact the investigator Rose Bell at (253) 952-8349. If you have questions about your rights as a research subject, contact the UH Committee on Human Studies at (808) 956-5007, or (808) 539-3955 or e-mail at rbell@hawaii.edu.

Please keep the prior portion of this consent form for your records. If you agree to participate in this project, please sign the following signature portion of this consent form and return it to Rose Bell.


---

Signature(s) for consent:

I agree to participate in the research project entitled, *A Theory of Cancer Survivorship Based on the Needs of Persons Diagnosed with Chronic Lymphocytic Leukemia*. I understand that I can change my mind about participating in this project, at any time, by notifying the researcher.

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APPENDIX C

Definition of Terms

The following definitions will be used for this study.

Cancer Survivor- A person diagnosed with cancer spanning from the day of diagnosis through the remaining years of his/her life.

Chronic Cancer- A diagnosis of cancer that has no cure but has an expected long duration or frequent recurrence.

Constant comparative- A consistent, ongoing comparison of data.

Culture- The belief system, customs and arts of a particular group of people.

Deductive- A conclusion based on reasoning from known data.

Dimensionality- The spatial extension, size and direction of the data.

Health- The presence or absence of disease.

Incurable Cancer- A diagnosis of cancer where cure is impossible.

Inductive- The employment of logic, mathematical reasoning or both to determine a conclusion.

Life needs- A dynamic individualized group of things that a person must have in order to optimize their existence.
### Table 1. Participant Demographics

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