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Supporting the well being of university student survivors of cancer

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Supporting the Well Being of University Student Survivors of Cancer

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Abstract

Young adult survivors of cancer present a unique set of needs and developmental factors to consider when working to support their well being (physical, mental, emotional, and social health). The experiences of these individuals can vary in many ways. This variety might include variables such as: age of diagnosis, type of cancer, type of treatment, resources available, family support, etc. The intent of this project is to examine and review the needs of young adult university student cancer survivors and address important considerations for professionals working to support their well being.

Interviews with cancer survivors and a supportive professional were conducted. The qualitative data collected were reviewed, summarized, and reported. It was found that a variety of resources and interventions could be useful in working to support the well being of young adult university student survivors of cancer. Participating survivors identified the following resources as important: the university counseling center, the university health center, the local hospital cancer treatment center, the university student cancer support group, the university recreation center, maintaining academics/daily routine, understanding and flexibility of professors, support of academic and career advisors, involvement in student organizations, as well as support from friends and family. Considering the individual experience of the young adult survivor, where they are within their personal development, the mental and emotional impact of their experience with cancer, and the resources they have had access to are all critical when working to support overall well being.

Introduction

According to the American Cancer Society (ACS) about one third of all women and one half of all men in the United States will develop cancer within their lifetime. In 2013 alone, ACS predicts that 1,660,290 new cases of cancer will be diagnosed (2013). Cancer impacts the lives of many and affects not only those who are diagnosed, but their families and loved ones as well. In the United States the National Cancer Institute (NCI) at the National Institutes of Health has reported that around 70,000 adolescents and young adults (AYAs), between the ages of 15 and 39 years of age, are diagnosed with cancer each year. It has been estimated that 11,630 new cancer cases are expected to occur among children 0 to 14 years of age in 2013 alone (American Cancer Society, 2013). Based on these statistics 5% of new cancer cases in 2013 will impact those under 39 years of age. While the childhood and young adult populations represent a small percentage of overall cancer patients, current mortality rates and the potential length of life as cancer survivor of those that are diagnosed at such a young age, make supporting the overall well being of these individuals critical.

There are unique aspects of young adulthood that may impact the types of services best suited to support the well being of this population of cancer survivors. It may be helpful to first clarify the definition of several key terms utilized throughout this paper: cancer, cancer survivor, and well being. The NCI at the National Institutes of Health define cancer as “a term for diseases in which abnormal cells divide without control and can invade nearby tissues” (n.d.). The phrase cancer survivor refers to those individuals who have been diagnosed with cancer from the time of their diagnosis forward until the end of their life. Therefore, young adult cancer survivors include those

who have experienced cancer in childhood, adolescence, and/or young adulthood.

Finally, the term well being refers to the physical, mental, emotional, and social health of the individual.

This project examines: cancer survivorship in the young adult population, developmental factors of emerging adulthood, the potential mental and emotional health impact of cancer on survivors, and recommended methods for supporting young adult cancer survivors. Interviews with four young adult university student cancer survivors and an oncology counselor were conducted. Their responses to interview questions have been summarized and shared within the results section to provide a first hand perspective of the young adult university student survivor experience. Findings from the literature review as well as first hand accounts of those interviewed have been summarized and included within the results, discussion, and recommendations sections.

Cancer Survivorship in the Young Adult Population

The American Cancer Society identifies childhood cancer as cancer that begins between the ages of birth and 14 years of age. In 2013 ACS predicted that about 1% of all new cancer diagnosis will affect this age group. When examining data from the most recently reported 5 years, 2005-2009, a slight 0.6% increase in the number of new childhood cases of cancer has occurred. Despite this recent increase in the number of new cases of childhood cancer, there has been a significant 68% decrease in the mortality rates of childhood cancer patients over the past 40 years. ACS predicted that 1,310 childhood cancer deaths will occur in 2013 (2013). Although childhood cancer mortality has been decreasing, mortality rates can vary significantly based on the type of cancer, the age of the patient, and other mitigating or challenging factors.

The type of cancer essentially describes the location of where the cancer originated or developed within the body. There are over 100 differing types of cancer that all begin with mutations, which then influence normal cell growth and cell division. Several types of cancer are known to be more common among children. Leukemia is the most common childhood cancer. It is a cancer that starts within the body's blood-forming tissue, such as bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood. Leukemia accounts for 31% of childhood cancers. Central nervous system cancer, which begins in the tissue of the brain or spinal chord, accounts for about 25% of childhood cancer. A nervous system cancer known as Neuroblastoma is common among children younger than 5 years old and accounts for 6% of childhood cancer. The remaining common types of childhood cancer each account for 5% or less of overall childhood cancers. Wilms tumor cancer, which affects the kidney,

represents 5%. Non-Hodgkin lymphoma, a cancer of the lymphocytes or white blood cells, impacts 4%. Hodgkin lymphoma is a type of cancer that affects the immune system, accounts for another 4%. Rhabdomyosarcoma, a soft tissue cancer that develops in striated muscle and can develop anywhere in the body, represents 3%. Osteosarcoma, a bone cancer that usually impacts the larger leg or arm bones, affects 3%. Retinoblastoma, an eye cancer that forms in the retina tissue, impacts 2%. And finally, Ewing sarcoma, another type of cancer that occurs within the bone or soft tissue, accounts for 1% of childhood cancer (American Cancer Society, 2013).

The American Cancer Society refers to adolescents and young adults (AYAs) as those between the ages of 14 and 39 years of age. AYAs have approximately 6 times the chance of being diagnosed with cancer than individuals younger than 14 years of age, and will account for approximately 4.2% of new cancer cases diagnosed in 2013 (American Cancer Society, 2013). While the survival rates for children 0-14 years of age with cancer have improved dramatically over the previous 3 decades, the survival rates for adolescents and young adults with cancer have remained stagnant, around 70% (Reynolds, 2011). Researchers attribute this alarming absence of significant decrease in the mortality rate of AYAs diagnosed with cancer to a variety of factors. There appears to be a limited amount of emphasis on prevention and early detection for cancer in adolescents and young adults. Many AYAs perceive themselves as not at risk for serious disease and may not seek medical attention for symptoms, which can cause a delayed cancer diagnosis and a delay in necessary treatment being provided (Martin et al., 2007). Delayed diagnosis can also occur when medical providers do not suspect exhibited symptoms to indicate cancer in younger patients. Some cancer symptoms may be

misattributed to experiencing stress, fatigue, or other common physical causes. Another possible reason for the stagnant mortality rate is that there are fewer available clinical trials for adolescents and young adults with cancer. More than 90% of children under 15 years of age with cancer receive treatment at institutions that participate in National Cancer Institute (NCI) sponsored clinical trials. Only 20% of the 15-19 year olds with cancer go to facilities with NCI clinical trials, and only 10% participate in trials. Of 20-25 year olds only around 2% enter into trials of pediatric or adult groups (Bleyer, 2002). This means that new treatment research is not as available to this age group as it is to children or adults with cancer, and simultaneously without new research the lack of understanding surrounding AYA cancers continues. Next, many cancer treatment facilities utilized by the AYA population are primarily focused on treating children or adults and often may not cater specifically to the needs of this age group. Finally, lack of health insurance coverage has also been shown to delay diagnosis in AYAs (Martin, Ulrich, Munsell, Taylor, Lange, & Bleyer, 2007).

The Surveillance, Epidemiology and End Results (SEER) Program gathers information on incidence, prevalence, and survival of those diagnosed with cancer in the United States. These data have allowed researchers Bleyer, Viny, & Barr (2006) to analyze the SEER data from the years 1975 through 2000 to examine trends for the 15-29 year old age range. Through this process the most prevalent types of cancer have been documented. Lymphoma has accounted for about 20% of all adolescent and young adult cancers, of which Hodgkin lymphoma represented 12%. The following types of cancer account for the remaining 80% of AYA cancers: skin cancer 15%, male genital systems cancer 11%, endocrine system cancer 11%, female genital track (primarily uterine,

cervix, and ovary) malignancies 9%, brain and spinal cord tumors 6%, leukemia 6%, breast cancer 5%, digestive track malignancies (primarily liver and colon) 4%, soft tissue sarcoma 3%, bone sarcoma (osteosarcoma and Ewing sarcoma) 3%, oral cavity/pharynx 2%, urinary tract 2%, respiratory system 2%, and other (including extragonadal germ cell tumors) 1% (p.6).

Surgery, medication, radiation, and chemotherapy are the primary modes of cancer treatment, and may be utilized separately or in combination. The type of cancer and its stage of development determine the type of treatment. Cancer stages are determined by how far the cancer cells have spread from the initial developmental site to other areas of the body. For some who experience physical side effects, surviving medical cancer treatment can be a significant accomplishment. Information about possible future consequences of cancer treatment should be discussed with the patient and family (Henderson, 1997). In their research, Richardson, Nelson, & Meeske (1999) found that there are some medical concerns for young adult survivors of childhood cancers that result from surgery, radiation, and chemotherapy. These concerns included: reproductive issues, osteoporosis, cardiotoxicity resulting in damage to the heart, hepatitis C from blood transfusions prior to 1992, second malignancies, and a higher risk of skin cancer from radiation exposure. Both radiation and chemotherapy can adversely affect male and female reproductive systems, causing decreased fertility or infertility (Davis, 2006). Early menopause in females can decrease estrogen production and heighten the risk of osteoporosis. Also, cranial radiation and corticosteroids may affect bone density after impacting growth hormone production causing increased risk for osteoporosis. Cardiac toxicity can result from radiation therapy to the chest and

anthracycline chemotherapy, which can result in long-term damage to the heart. For those who received blood transfusions prior to 1992, the Center for Disease Control (CDC) has recommended blood screenings for Hepatitis C to prevent liver damage that can result from this illness. Second malignancies can result from radiation treatment, and continued follow-up care is important so that any additional tumors or abnormal cell growth can be observed, examined, and treated. Radiation treatment has also been found to increase skin cancer risk within the area where the radiation field was targeted. Attention to any skin pigment changes should be observed and examined (Richardson, Nelson, & Meeske, 1999). Other side effects from high doses of chemotherapy and radiation can include: diarrhea, changes to sense of taste, nausea and vomiting, dehydration, loss of appetite, dry mouth, mouth sores, skin rash, hair loss, fatigue, and/or insomnia (The Cleveland Clinic Foundation, 2011).

In the United States, about 65% of high school graduates go on to seek a college degree (Berger, 2008). The university student population is comprised of students stemming from a wide variety of backgrounds and experiences. The cancer survivors within the university population are no different and represent an equally diverse cross section of the population. Some university student cancer survivors were diagnosed and treated as very young children. These students may barely remember their treatment or have their survivorship minimally influence their current daily life. Other students may have experienced their cancer diagnosis at an older age and may have more vivid or lasting daily impact based on the treatment experienced. These students may have just been diagnosed and could currently be experiencing more intensive medical treatment. Some students may be in the midst of balancing their academic responsibilities

simultaneously with treatment. With such a wide variety of experiences represented, it is difficult to generalize about the exact experience of each individual university student cancer survivor. Their experiences could follow one of the descriptions above, or they could currently be experiencing some combination of those descriptions, or their experience could look completely unique.

When assessing what students need and providing support, it is important to take into consideration where they are within their experience with cancer and how it is affecting them or has affected them in the past. It is critical to evaluate what support resources students have already accessed, what resources they may need, what resources they are ready to accept, and what resources they still desire. Universities offer a variety of resources and support systems to students. The university size, the general philosophy, the way funding is utilized, the location, the available student organizations, and many more factors all can play into what resources may be available to students within their university community. A similar range of factors can play into what support resources are available within the local community.

Developmental Factors

The average age range of university students lies between 18 and 25 years. The human developmental stage associated with this young adult age range has become known as “emerging adulthood” (Berger, 2008). On average, emerging adults have physically reached their maximum height; they are experiencing a stage of peak physical strength and reproductive health. Emerging adults typically encounter several common mental, emotional, and social developmental themes, including: continuation of identity development, life direction choices (education, career, family), increased sense of autonomy from family, and a growing importance of friendships, dating, and romantic relationships (Berger, 2008). There can be a wide variety of individual experiences and a range of how each of these developmental themes affect and hold true in the lives of each emerging adult. Culture, family, resources, income, health, and many more factors can impact the individual experience of emerging adults and can affect their development during this stage of life. Cancer survivorship can add another variable layer into the emerging adulthood experience of development. Survivorship variables that may impact development can be influenced by the individual’s experience with cancer type, stage, treatment, and support. How those experiences have been integrated into the individual’s understanding of himself or herself can also play a role in physical, mental, and emotional development.

Many emerging adults are in the process of searching for and developing their sense of identity. This stage of life can be filled with working to understand themselves and how they would like to be perceived by others. Developmental theorist Erik Erikson has described eight developmental stages that are each identified by a developmental

crisis or choice. The stage of “identity vs. role confusion” typically begins during adolescence (Berger, 2008). This stage can continue into young adulthood as individuals continue to individuate from family, move out on their own, attend college, and/or start a new job. During this time, individuals come into contact with new ideas and new opportunities to explore and examine who they are. Both the ways in which young adults perceive themselves, and the roles that they hold can be in a state of flux. During this time of evolving identity and responsibilities, university students may be exploring their own understanding of self: their cultural and ethnic identity, their sexual identity, their vocational identity, and interpersonal identity. Having cancer can impact how an individual sees himself or herself both literally and figuratively. Depending on where they are with their own development, this may be a new or older piece of who they are that is embraced, rejected, accepted, integrated, and/or pushed away.

Body image and physical appearance during adolescence and young adulthood can be a challenging subject. Many young adults are dissatisfied with some aspect of their appearance, and often there is a desire within this age group to appear similar to peers. Cancer treatment methods like chemotherapy, radiation, and surgery can impact appearance through hair loss, weight change, and surgery scars. These changes can pose a challenge to young adults who do not necessarily wish to appear different from peers. It can make the desire to continue with daily life without disclosing information about their illness a challenge when others may notice their physical changes (Grinyer, 2007).

Emerging adults often are becoming more autonomous from their parents and family. Experiences during this age range can include a greater degree of separation, as many 18-29 year olds move out of their family home. Depending on where cancer

survivors are in their diagnosis and treatment process, there can be increased dependence on parents for support. This can alter the amount of interaction and separation from their family support system. Parents may feel more needed by their emerging adult child and feel compelled to be more involved and supportive. Medical concerns and check-ups for those university student cancer survivors in remission can also increase the involvement of parents. Some emerging adults may feel able to manage their treatment independently; while others may rely more heavily on parents and family. It can be important to understand the individual family system dynamic so that the most effective way to support the well being of the survivor as well as their family can be identified.

During emerging adulthood, interactions with peers can take on greater importance. At university, the time spent with peers increases for many students. There are a range of activities in which students interact with one another: attending classes, eating on campus, living on or off campus with other peers, becoming involved in clubs and university organizations, and participating in activities and sports. In Erik Erikson's next stage of "intimacy vs. isolation," young adults may choose how connected they become to peers. During this stage, young adults often start to seek companionship through interactions with others or they become more isolated out of fear of being disappointed, rejected, or hurt (Berger, 2008). During this stage of development, dating also typically increases and romantic relationships gain more significance. For cancer survivors, the question of if, how, and/or when to share their survivor experience with peers or a romantic interest may affect interactions with others. Each survivor may have had differing experiences of how peers and friends responded at the time of their diagnosis or treatment. This experience of acceptance or feeling more isolated by their

illness may impact their perception of how others might react to their survivorship in the future. How survivors understand their illness and incorporate it into their own understanding of themselves can also impact the importance or lack of importance in sharing that part of their identity with others when starting a friendship or a romantic relationship. Katz (2007) found that there may not be a perfect time to share with potential romantic partners information about cancer diagnosis, treatment, or scars. Early disclosure in a relationship that ends may confuse the survivor and leave them with questions regarding why the relationship ended. Was information disclosed too soon? Was it related to cancer? Or was it just the natural progression of the relationship? Waiting too long may make a romantic partner feel the survivor was somehow dishonest, and perceive that he or she hid their cancer experience intentionally. As mentioned previously, treatment can impact fertility, but it also can impact soft tissue and hormonal changes that can result in sexual dysfunction or decreased libido affecting sexual intimacy (Tross & Holland, 1989). Changes in sexual function, sexual intimacy, and fertility options can impact the romantic relationship dynamic.

As emerging adults become more independent from their parents and family, financial independence can become a relevant concern. Young adults are typically expected to be healthy and often there is not the same level of importance placed on ensuring that young adults have health insurance coverage. This age group is known to have the highest rate of uninsured or underinsured individuals than any other age group in the United States (Collins, Schoen, Kriss, Doty, & Mahato, 2007). As mentioned previously, not having access to health insurance coverage can delay cancer diagnosis and influence the course of treatment. However, recent health care reform, though the

Affordable Care Act in 2010, has been credited for a recent decrease in the rate of uninsured young adults. The U.S. Department of Health and Human Services has outlined how this new legislation currently impacts young adults in their Young Adults and the Affordable Care Act Fact Sheet (n.d.). Young adults now can be insured as a dependent on their parent's health insurance plan until the age of 26. And, beginning in 2014, young adults 18-25 years of age may also be eligible for Medicaid health care coverage if their yearly income is below \$15,000 per year for a single person, or higher for couples and families. Although this new legislation may help more young adult cancer survivors have access to health insurance, it is true that even with insurance, cancer treatment and follow-up care can be costly, thus creating a financial strain on families as well as individuals who may be just beginning their financial independence. Assisting families and young adults in connecting to financial support can be an important way to meet basic needs and lessen financial stressors. Numerous non-profit organizations such as the Ulman Cancer Fund for Young Adults, the LIVESTRONG organization, and the Surviving and Moving Forward Fund for Young Adult Survivors of Cancer, work to assist families by connecting them to medical support, referring them to supportive resources, as well as provide academic scholarship assistance to survivors who are attending university (See Appendix A for a comprehensive list of resources). Taking advantage of such resources and funding can make a significant difference to families that are unable to make ends meet, or to individuals that are looking at shouldering the cost of their treatment or education independently.

As emerging adults are developing and solidifying their identity, they often are in the process of making decisions as to the direction of their life. These decisions include

choices and planning that will affect their future education, career, and family planning. University students make choices about what their educational focus will be and what future career options they wish to prepare for. Many students may experience some level of concern or worry about finding employment following graduation. These educational and career decisions can be impacted by many influences: student interests, culture, expectation of family, necessity, motivation, and opportunity are only a few. Cancer can complicate and threaten the possibility of future plans. Cancer survivorship may also impact student academic interests. A variety of fields may become more appealing as university student cancer survivors attune to the way in which they wish to use their career and life direction to make meaning.

Emerging adults also make decisions about family planning. Some young adults desire to have a family, to have children, to be single, to date, or to have a committed relationship. This is an age where long-term primary relationships tend to be established. Cancer treatment can impact fertility of both males and females, and may alter/limit childbearing years in female survivors. Those survivors who desire to have biological children and have a limited time window of when that would be possible may feel more pressure to find a partner more quickly than those without the same time frame constraints. It can be important for children, adolescent, and young adult cancer survivors to receive information on how their fertility may be impacted by treatment. Fertility counseling has become a common resource available to cancer survivors. Although depending on the age of the survivor during diagnosis and treatment, this may or may not have been a topic discussed directly with the survivor. Treatment considerations may have been made by parents at a time when the main goal was to

prevent the disease from causing death (Katz, 2007). Some university students are starting to make choices about whether or not they wish to have a family. Depending on cancer type and treatment received these students may also be finding out how their cancer experience has impacted the timing or possibility of having children. Other student survivors may have been informed at the time of their treatment and may have taken measures to store semen or eggs for future reproductive uses. Sexual function and interest can also impact desire for intimate relationship. These can both be impacted by cancer, cancer treatments, and the mental and emotional stressors experienced by cancer survivors.

Mental and Emotional Impact of Cancer

While the physical effects of cancer are diagnosed, measured and treated, mental and emotional well being are also impacted. We have already examined how experiences with cancer can impact young adult survivors during their developmental stage of emerging adulthood. We have also discussed some of the mental and emotional effects of cancer on young adults. But, experiencing cancer can bring up a whole host of thoughts, stressors, concerns, and questions at any age. Some physical stressors associated with cancer and cancer treatment (such as: pain, extreme fatigue, weight loss, and changes in sleep patterns) can impact and affect mental and emotional health as well. As mentioned previously, other stressors related to experiencing cancer can include, but are not limited to: disruption to daily routine, impact on relationships, financial concerns, confrontation with mortality, interaction with sense of identity as a cancer survivor, and uncertainty of how cancer may impact future plans and health. These stressors can result in confusion, anger, anxiousness, depression, regret, worry, disappointment, feelings of helplessness, and feelings of isolation (Burton & Watson, 1998). In her work *On Death and Dying*, Elisabeth Kubler-Ross (1969) discussed emotional stages when experiencing a traumatic event and facing the possibility of death. These stages do not necessarily always follow in direct sequence, but include: denial and isolation, anger, bargaining, depression, acceptance, and hope. Illness does not mentally affect individuals in the exact same way. As with many challenges experienced during life, individual personality type, interpersonal interaction style, coping style, support system, and environmental influences can all impact how cancer survivors react emotionally and mentally to their

illness. These factors should all be taken into consideration when working to assess mental health and support the survivor.

Confusion can be felt by young adult cancer survivors who ask such questions as: “Why me?” “How is this possible?” or “Isn’t cancer something that happens when people are older?” Following diagnosis, confusion with what to do, whom to tell, the implications for future, and where to go for different kinds of support can occur. Diagnosis can bring surprise, disbelief, fear, suspicion, loneliness, and a re-evaluation to commitments and relationships (Armstrong-Coster, 2004). This confrontation may result in feeling a sense of hopelessness, helplessness, and/or disillusionment. Confusion can also be felt by the family system of the individual diagnosed, by parents, siblings, and/or children. Confusion can be associated with Kubler-Ross’s stage of denial and isolation. This is a stage in which those diagnosed with a life-threatening illness may react with “There must be some mistake.” or “This cannot be right.” When inundated with traumatic news, individuals can deny what is happening and work to isolate themselves in order to have space to think about what happened. Both survivors and family members may experience this sense of disbelief, confusion, and desire for space to process the diagnosis and potential impact.

The next reaction can be a sense of anger. Survivors might feel that their experience with cancer is unfair, frustrating, and unexpectedly pushing them to face mortality in a way other peers do not need to do. Those diagnosed with a potentially terminal illness or experiencing a traumatic event may strike out verbally at family members. They may feel angry towards the illness, and towards the physical and emotional pain experienced. Individuals can experience anger and envy at others around

them that are “healthy” as they work to fight, manage, and integrate their experience of cancer.

Depression can be experienced following a major traumatic loss or change in life. Cancer can create both dramatic change and a sense of loss of what was previously “normal.” Daily routine disruption can occur because of diagnosis, treatment, and follow-up care. School, work, sports teams, clubs, and activities can all be impacted because of physical limitations during treatment, reaction of the survivor to their diagnosis, reactions of peers and mentors, and availability of support resources locally. Diagnosis can bring surprise, confusion, disbelief, fear, suspicion, the question of “Why me?”, loneliness, and a re-evaluation to commitments and relationships (Armstrong-Coster, 2004). Cancer survivors can experience a sense of hopelessness, disinterest in former activities, and limited ability to physically engage in what once was common routine b/c of cancer, treatment, and physical changes. Side effects like nausea, vomiting, fatigue, insomnia, and sexual dysfunction may also impact the survivor’s experience of feeling a lack of energy, disinterest, sadness, and loss.

Those who encounter a major traumatic event or potentially terminal illness can also experience a sense of acceptance as well as hope. Some cancer survivors experience acceptance when acknowledging their illness and the possible outcomes. For young adults integrating their identity as a cancer survivor into their self concept, facing treatment options, the possibility of death, and ways their lives are impacted can all be a part of experiencing acceptance. Acceptance does not necessarily mean the complete absence of other stages or emotions. It is still possible to feel acceptance for the illness, and also sad, angry, confused, and hopeful. Hope may look different to each cancer

survivor, and may also be experienced throughout the other stages of mental and emotional reaction. It can be a survivor's hope for recovery, hope for minimal side effects from treatment, hope for clinical trial success, hope to make the most of each moment, hope for life, hope for meaning, and/or hope to protect family members from their own suffering. Hope can occur in the face of fear and despite daunting obstacles.

Current Recommended Support

There are many ways to support the physical, mental, emotional, and social well being of young adult cancer survivors. As mentioned previously, it is important to consider the unique experiences and support system of the young adult university student cancer survivor when assessing what support may best fit the needs of the individual. Assessing for where the university student survivors are in their diagnosis, treatment, or remission timeline can help to better inform the type of services they may be most in need of. Considering ways to best connect with young adults and allow them to access support is essential when working to provide students with informational resources as well as interpersonal and emotional support. Medical treatment can impact physiological symptoms as well as psychological and social welfare. Psychosocial support can impact overall quality of life and assist with physiological health (Spiegel & Diamond, 2001).

When working as a practitioner to treat cancer survivors in recovery, Dr. Stewart Fleishman (2012) discussed tools that fellow practitioners can incorporate during treatment to encourage a healthy survivorship experience. His medical treatment support philosophy utilizes the acronym LEARN, which stands for: living, education, activity, rest, and nutrition. He encouraged practitioners working to support cancer survivors and survivors themselves to gain perspective on their illness by spending time concentrating and focusing on their life/living outside of the time spent in treatment. Next, he encouraged survivors to educate themselves on their individual type of cancer, treatment options, and ways to assist in recovery from treatment. Fleishman also stressed the importance of physical activity, and recommended light, moderate, or vigorous exercise

habits depending on physical strength and overall health. He also stressed the importance of rest and healthy nutrition to promote healing and overall health following treatment.

Physical health can be a concern of all cancer survivors despite where they are in their treatment. Students who are in early stages of diagnosis and treatment may find their day-to-day life (physical health, academic responsibilities, employment, and social interactions) altered or interrupted by the time and energy needed to manage their treatment and medical appointments. Practical physical and interpersonal support for these individuals can mean connecting them with local medical and mental health referrals. It can mean providing assistance with transportation to treatment and appointments, delivering meals, and lending a hand with chores. Medication options for physical comfort can be helpful for those experiencing pain and/or nausea. The pain experienced can be acute, chronic, disease related, and/or treatment related. Perception of pain can be influenced by the individual's amount of focus on the pain (Golden, Gersh, & Robbins, 1992). Physical health concerns can also occur for cancer survivors in remission. Maintaining health and continuing with recommended medical check-ups can be critical. For university student survivors, providing resources of where local treatment facilities are located may be important.

Linking young adults to resources tailored to their age group can provide material that students can relate to, and can increase their sense of belonging and interest in utilizing support services. Psycho-educational support can be critical. Research has shown that answering questions, working to provide connections to providers, offering second opinions and referrals can all help survivors gain the information they need to develop a clearer picture of their cancer, treatment, and supportive resource options

(Zebrack, Chesler, & Kaplan, 2009). Gaining information about the potential impact of their diagnosis and treatment on future physical and emotional health can be important to survivors (D'Agostino, Penney, & Zebrack, 2011). Fertility information and support service resources, like fertility counseling, can be critical to assist young adults in making informed decisions about their treatment options or current fertility options post treatment (Davis, 2006).

It is important to be mindful of the way material is presented to young adults so that they hear what is being said. It is recommended that when information is communicated to young adult survivors, it is done in a manner that is respectful, positive, and non-judgmental (Zebrack, Chesler, & Kaplan, 2009). Ferrari, et al. (2010) recommends that interaction style and approach should correspond with the individual survivor's level of maturity and independence. Zebrack, Chesler, and Kaplan (2009) spoke with focus groups of young adult cancer survivors and found that how people communicated information, feelings, and tasks to AYA survivors affected how they experienced their cancer and how they thought about themselves. Helpful types of communication and support included: answering informational questions and providing second opinion referrals, assisting with tasks and special accommodations, providing positive attention, promoting normal life, being emotionally available, offering professional counseling, and demonstrating love and hope.

Encouraging students to ask questions and share any concerns with medical providers can assist in empowering young adults to advocate for themselves and ask for the types of support mentioned above. Assisting students in communicating with their professors as they navigate academic supportive options can be necessary. Some

students in treatment may desire to continue with academic coursework; some may lessen their course load; and others may wish to learn about options for taking an incomplete or medical withdrawal from the university. Connecting students with the correct offices on campus, such as Dean of Students or Registrar, can be a way to simplify their academic stress or concern and better inform them of what options are available.

Maintaining a sense of normalcy can be important to cancer survivors. Engaging in regular developmental and social activities can provide a sense of stability and comfort to daily life. Social and interpersonal support from families, friends, significant others, community members, along with local and national cancer support services can assist in gaining or maintaining social, mental, emotional, and physical health. Making connections with other survivors can be important in normalizing a survivor's experience with cancer. There are many organizations, such as The Imerman Angels and Young Survival Coalition, that work to connect survivors and family members of survivors (See Appendix A for a complete resources list).

Support groups can offer the opportunity to connect young adult survivors with other cancer survivors. Support groups can be run by professionals and can implement educational, psychotherapeutic or cognitive behavioral interventions. They can also be self-help support groups created to provide support and advocacy by fellow survivors (Massie, Holland, & Straker, 1989). Cancer support groups offered by professionals at local hospitals may often be more populated by older cancer survivors. Finding or starting a group for university student survivors can allow students to connect with one another. Support groups provide a space for group members to connect with one another, to become more informed, to learn from the experiences of others, to have a space to

share their story, and relax with others who may have a mutual understanding of what they have experienced.

Although support groups can be useful for the reasons discussed above, individual counseling support can also provide benefits to young adult survivors. For those who are interested and willing to engage in the counseling process, having a space to process their personal experiences with a trained mental health professional can allow for reflection, exploration, and integration of their experiences. Counseling can be a place to discuss everything from the impact on interpersonal relationships to the disruption of a former version of normal. Golden, Gersh, and Robbins (1992) recommended individual counseling support, from a cognitive behavior therapy perspective, as a way to assist survivors in overcoming fears and discomfort related to physical changes resulting from cancer treatments. In their summary of psychotherapeutic interventions for cancer patients, Massie, Holland, & Straker (1989) shared that psychotherapy models utilized should respond to the level of illness of the individual being supported. They encouraged that frequency, duration, and type of approach may fluctuate depending on where a client is within their illness.

In his research, Zebrack (2008) surveyed 217 participants 18-40 years of age, who had been diagnosed with cancer between the ages of 15 and 35. More than $\frac{3}{4}$ of participants, 76.3%, wanted mental health counseling. Over half of the participants, 57.3%, were interested in counseling or guidance related to sexuality and intimacy. And, a very small percentage, 3.8%, were interested in alcohol or drug abuse counseling. In the population surveyed, mental health counseling needs were not met for 38.6% of participants. The need for counseling related to sexuality and intimacy went unmet for

82.2% of respondents. And finally, alcohol or drug abuse counseling needs went unmet for 75% of those who desired them. Many universities offer counseling services to students with minimal or no charge. University counseling and student support centers can also assist in connecting students to local mental health providers who offer affordable services and/or may work with students health insurance. Helping to overcome barriers that prevent student cancer survivors from accessing, seeking, or utilizing mental health support services is critical to meet the desire and need for mental health support for these survivors.

Individuals working to support the overall well being of university cancer survivors may need to become familiar with oncology related information including diagnosis, prognosis, treatment options, potential side-effects and outcomes (Massie, Holland, & Straker, 1989). Depending on the training and experience background of those working to support students, additional research and training around oncology may need to be done. It can also be important to gain additional awareness of personal response to working with individuals who are experiencing or who have experienced a life-threatening illness. Self care, support, and supervision can be useful when working to support others to prevent compassion fatigue.

Interview Process

Potential participants were identified by their invitation and/or participation in a cancer support group facilitated by the cancer survivorship chairs of two university student-run organizations. The researcher was present for each support group as a representative of the University Counseling and Student Development Center and aid to the group facilitators. All invited participants were students currently enrolled at a four-year institution. Participants were all contacted through email inviting them to participate in an interview about their cancer survivorship experience. Four young adults ages 21-25 years old volunteered to participate in an individual interview that consisted of 12 questions (See Appendix B for a complete list of interview questions). Participants included two female and two male students. Interviews were conducted and were audio recorded. The audiotapes were transcribed by the primary investigator. The qualitative data were reviewed and then organized so that the first hand survivorship experiences discussed within the responses of participants could be reviewed and included in the results, recommendations, and discussion sections. A telephone interview was also conducted with a hospital oncology counselor. The purpose of this interview was to include qualitative responses gained from a discussion around the oncology counselor's experience in working with young adult cancer survivors and their recommendations of what to consider and ways to best support the well being of young adult university student survivors of cancer. The project and procedures were approved and performed in accordance with policies set forth by the Institutional Review Board at James Madison University.

Results

Qualitative analysis examined over 50 individual responses to the various interview questions discussed. Comments reflected the unique and yet sometimes similar experiences of participating university student cancer survivors. Responses from a hospital oncology counselor about working with young adult cancer survivors were also examined, summarized, and included.

The age at which the participating university student cancer survivors were diagnosed with cancer varied greatly. Two participants were diagnosed at very young ages, ten months and three and a half years. The remaining two participants were each diagnosed after being enrolled in university at ages 19 and 21 years.

The types of cancer that university student cancer survivor participants experienced and their subsequent treatment varied as well. Two participants experienced Acute Lymphoblastic Leukemia, or ALL, and had each received fairly aggressive chemotherapy treatments following diagnosis. One participant had been diagnosed with papillary thyroid cancer, and was treated through organ removal and radiation. The final student had been diagnosed with Ewing sarcoma, a bone cancer located within the spine, and received an aggressive regimen of chemotherapy.

When asked what ways, if any, participants felt their experience with cancer had impacted their life as a university student, answers again varied. One student responded, “In a big way I don’t think it does... there was only one time where I couldn’t give blood because I had had cancer.” Another student said, “I think it gives me a different outlook on life...it made me realize that everyone has a story whether their problems are big or small.” Two of the four students mentioned that their experience with cancer has made

them more aware, involved, and passionate about becoming more involved in organizations that are working to fight cancer. Finally, one student described how their experience with cancer treatment had significantly life as a university student when they needed to take a year off from university to seek medical treatment. In addition, the student's follow-up care included support around significant physical complications resulting from the cancer treatment. A resulting heart condition has necessitated that the student's stress level be monitored, and academic course schedule limited to three classes. This has prolonged the time in which it has taken to complete a degree.

When asked how, if at all, participants felt their survivorship impacted their current interpersonal relationships with family, students each indicated that they suspect their survivorship has brought them closer to family members. Three participants shared that they felt their parents and family had been deeply impacted by their experience with cancer. One student specifically highlighted examples of how the relationship with the student's mother may have been strengthened: "She's an incredibly strong woman... She's my hero because of all that she had to do... She learned how to take care of my central line. She was basically like my nurse when she was at home." This student also disclosed how both an uncle and grandparent had been diagnosed with cancer recently, and they felt a connection to these family members. In this student's family, members continue to support one another through participation in survivorship events, like Relay for Life, as well as through encouraging one another. The two students who had been diagnosed during university shared how they felt they spent an increased amount of time with their parents during treatment in comparison to the time spent with their parents during university previous to their diagnosis. One participant described how he had

moved back home during treatment and lived with his parents. The other student shared that she felt her relationship with her parents shift when normal phone conversations had become predominantly focused on discussions about her health. This participant also added that she noticed a change in her siblings, stating that they, “Have been more responsive, and definitely check in more often than not.” One student reflected on not only how the experience with cancer may have impacted his family, but on how his father’s recent diagnosis had impacted him. This participant shared that he understood his survivorship differently by seeing his father go through treatment. And finally, three of the four survivors commented that they felt their family members were more involved in supporting and donating to organizations that work to fight cancer.

When asked how, if at all, participants felt their survivorship impacts their current interpersonal relationships with friends, participants had varied responses. Each participant mentioned that they had, at times, felt cancer was difficult to talk about with peers. To some degree each participant expressed how he or she felt closer to those peers and/or friends who seemed more comfortable speaking about the cancer. One participant stated, “I think that a lot of people don’t feel comfortable talking about it [cancer], and it’s not that, you know, I hold that against them but I am closer with those friends who have gone out of their way to kind of be there for me.” Another student commented, “Sometimes they’ll [friends] kind of avoid the topic of cancer, or it’s a little bit awkward.” One participant stated, “I guess a lot of my good friends were always there for me. So it did build strong relationships because of that. And also...it kind of scared some people off.” A final participant shared how her experience as a survivor at university has inspired her to be more involved in student-run organizations that

fundraise and increase dialogue on campus about the fight against cancer. This participant shared how getting involved and participating in the support has “helped build friendships with people... just finding other people surviving and affected by cancer.”

When asked how, if at all, participants felt their survivorship impacts their current interpersonal relationships with romantic partners, again participants responses varied. Two students shared that they felt their experience, as a cancer survivor, had not impacted their romantic relationships. A participant responded, “That’s [her cancer] never really been discussed. If anything, it would have no effect at all... it just kind of was pushed under the rug.” Another shared, “All my ex-boyfriends knew that I was a survivor, but it never really impacted anything.” The participant who had experienced diagnosis at 21 years of age shared how his diagnosis had significantly impacted his romantic relationship at the time. He stated that it was as if his girlfriend, “Got diagnosed as well.” This participant reflected on how his romantic partner, “Was definitely there for me and was a big help.” He shared that the experience of diagnosis and treatment brought him closer in his relationship to his girlfriend because of increased dependence and unity in facing his cancer together. Although, in the end, navigating his cancer survivorship was too stressful on their relationship for it to endure. This student expressed experiencing the most disruption to their romantic relationship following diagnosis. The remaining participant, when asked about how his survivorship impacts romantic relationships, discussed how his father’s cancer diagnosis had impacted his current romantic relationship, commenting that, “A big part of our initial connection was the fact that we both have parents who have had cancer. Her mother passed away from cancer, and because I was still in the process of struggling with my dad having cancer

that for some reason I was drawn to that. We bonded over that. And we helped support each other.” For this participant, again their more recent experience with their father’s diagnosis of cancer had impacted their interpersonal relationships in a way their own experience with cancer had not.

When asked what university services have felt most supportive of the participant’s overall well being (physical, mental, emotional, and social health) students each shared one or more ways that interactions with support systems at university have helped to increase their well being. The first student shared that they sought counseling support services at the university counseling center for general anxiety and test taking anxiety. This student replied that they learned to, “Be real with people about how I was feeling” and that their support from the university counseling center assisted them to, “progress to where I could handle that stress.” The second participant shared six main sources of well being support. The first was their interaction with medical and support staff at the local hospital. For this student the hospital was where they felt they were connected with the services and resources that they needed in the local area. They disclosed, “I can’t say it was easy that first year. It was definitely a lot of up and down and all around. Some days I would just be so happy, you know ignore it, and other days it was definitely more difficult... university was the only thing that kept me going, kept my head on straight.” They mentioned that continuing enrollment in classes even following surgery and treatment allowed them to maintain their daily routine and have a sense of normalcy in their day. The student expressed appreciating: the support of those professors who offered additional assistance, the availability of the University Recreation Center (UREC), emotional support from friends and family, and finally the connection

they felt this year through the support group as a form of support to their overall well being. The student shared that the support group has been “a nice outlet to meet other people that have been in your shoes, and meet other people to know that you are not alone.” The third participant discussed three ways that she has felt her overall well being supported while at university. She also shared that the support group was helpful, commenting that it, “Helped me come to terms with, you know, being a survivor, what to do with it and how to talk about it.” She discussed how her involvement with groups actively fundraising and working to raise awareness about cancer has felt supportive for her social well being. And lastly, she shared that the health center has been helpful in maintaining her physical wellness. The final participant shared three supports that have been meaningful to them. They also mentioned that the importance of the University health center’s support. This student has met regularly with a health center physician to discuss medication options and physical health while at school. This student also recognized that their academic advisor and their Career and Academic Planning advisor have offered support and guidance as they have worked to navigate their experience of diagnosis and cancer treatment occurring during their university experience.

Next, participants were asked, “What about life as a university student, if anything has not felt supportive of your overall well being (physical, mental, emotional and social health)?” To these questions, two students responded that there was nothing that felt unsupportive, one commented, “Honestly, I’ve felt supported in moments in need.” The remaining two participants cited aspects of academic work and stress as unsupportive. One student shared that tests, papers, and projects have felt overwhelming at times. She suggested that there be more dialogue between professors and more

consideration taken when planning the academic calendar so that not all professors use the same timeline during the semester, which seems to create weeks where everything is due simultaneously in many classes. The remaining student shared that at times they have felt not supported by several of their teachers. They mentioned that professors who are not as understanding of their physical and mental limitations have been a challenge to work with.

Participants were then asked what type of services would they like to see more of to support their overall well being, and what other type of services they would like to see exist. All four students replied that they were grateful for the university student cancer support group offered this year, and would be interested in seeing additional and continuing support group services offered to university student cancer survivors. One student commented they wish that there had been a support group available to them on campus “from day one.” Another shared that if it had been available their freshman year “it probably would have caught my eye.” A third student shared that she found the support group helpful especially because it was organized, facilitated, and advertised with the aid of survivorship chairs of campus student-run organizations. She felt that the invitation from other survivors to come discuss experiences with cancer felt less intimidating than individually seeking support services from the university counseling center. One of these students also added that while they needed to discuss academic limitations and request extensions from professors, following treatment they did not register with the Office of Disability Services. He expressed distaste for that descriptor and the implications he felt accompany it, and shared that he “didn’t really want to be officially considered one of the disabled.” The remaining fourth student discussed a

desire to see an expansion of the support group and also shared several services that she would have liked to see to support her well being while at university. She expressed a desire to interact with a staff member who could have offered her a mixture of academic support, tutoring, counseling support, and mentoring.

The final interview question invited each student participant to share any additional information about their experience that felt important to communicate to the investigator as they worked to gather current well being concerns, forms of support, and resources for university cancer survivors. The students commented on their individual experiences and expressed what resources they felt supported their well being and may be useful to others. The first student shared that being a survivor is something that he thinks about just about every day “trying to wrap his head around it.” This student has only come to know his cancer experience through the stories and descriptions of family members, because of experiencing his diagnosis and treatment at such a young age. He has been working to gain his own understanding of what being a survivor means to him in his life. This student shared, “I have felt much more impacted by my dad being diagnosed than being a survivor myself, because I’ve seen him starting treatment. I’ve seen him, you know, feeling sick... and I’ve seen just, you know, all the fear.” He expressed that cancer was always described to him as something he beat and overcame. It has been through witnessing the “scary side” of cancer that he has felt more grateful for his own remission and health. He recommended that supporting students with family members who have been diagnosed with cancer can be as necessary as supporting cancer survivors. Finally, he expressed gratitude for the organizations that are willing to talk about cancer. For him, finding that open invitation for dialogue around cancer has been a

relief. He explained that, “Part of it was that I didn’t understand being a survivor, but part of it was I didn’t even know how to bring it up or how to say I’m a survivor and I want to get involved.”

The second participant shared that she has been in remission for a little over two years. This student discussed how the amount she wanted to discuss her cancer has shifted since diagnosis and treatment. She discussed goal setting, and shared some of the benefits and challenges with searching for supportive resources online. She started by sharing that when it comes to her survivorship, “It’s affected me more the second year rather than the first, because you don’t really want to remember things at first, but then it’s like you start to accept it, and years later more things kind of come back to you.” For her, the first year she did not want to talk about her cancer or survivorship, and she did not want to meet with a counselor. She stated that this was “because I thought that I could just like do it myself. I thought I was strong enough. It was kind of like an inner battle.” She went on to describe that, “I thought this was something I was given, so this is something that I’m going to get over myself.” She shared that, “It’s important to know that every day is different... Some days you don’t want to talk, some days you just want to listen. And, some days you just want to spill your guts.” For this student setting small and large goals for herself has allowed her to reach those goals. An example of a past small goal she recounted while she was in treatment was working to take her medication accurately and on time. She described how, with 14 pills a day, this was an important task to manage. This participant commented that she found some very helpful online resources, discussion threads, and groups. She replied that while, “Google can be a scary thing because people tell you you’re going to die,” there are websites that can help you

understand the facts and “lower the medical [terminology] and kind of put it in college terms.” She also found recommendations and healthy recipes from others who went through a similar radiation treatment process online. She mentioned the importance, for her, of sitting down with her family and then sharing all of the information that she had found online because that helped dissipate any misunderstanding or unnecessary concern by family members after searching for information about cancer online.

The third participant reflected on the gratitude she felt after hearing the stories others have shared about their experiences fighting cancer. She expressed feeling fortunate for the support of her family and that she has not had any serious complications from the treatment she received at a young age. She shared how inspirational it has been to witness the resilience and strength of others who have faced more health complications and had less support from family members. She discussed how her mother focused on what needed to be done to support her, recounting how her mother would ask, “What do we have to do next? Is it treatable? Is it curable? Is she going to be ok?... Ok, great let’s just move forward with that.” It was from her mother’s example that her family members followed suit. The student shared that she didn’t use many online resources, also suggesting that, “The internet can be scary,” when you have cancer. However, she did recommend several sites that fellow cancer survivors found useful including: the American Cancer Society’s website, Look Good-Feel Better, Reach to Recovery, and relayforlife.org (See Appendix A for a more comprehensive list of resources). She also recommended that others working to support cancer survivors know about the American Cancer Society’s 24/7 hotline (1-800-ACS-2345) which is available for anyone impacted by cancer, including family members, friends, caregivers, etc., to have access to

professionals available to provide resources, as well as answer questions about cancer diagnosis and treatment.

The final interviewed participant discussed his recent experience publically sharing his story as a cancer survivor. He said the experience of discussing his narrative with an audience of over 100 people, “Really helped me out as a cancer survivor in getting some things off my back and just feeling a sense of relief.” He felt that other students and university community members didn’t really understand, “How difficult a cancer patient’s journey into survival really is.” He encouraged that more panel events could increase the dialogue and give others a better understanding of some of the challenges associated with experiencing cancer. He said, “Any opportunity there is to have cancer survivors share their stories can just open and kind of expose what they’ve been through. I think it helps, not just them the people going through it, but everyone.” He shared that for him participating in events like Relay for Life and student-run organizations working to fundraise and raise awareness around cancer have connected him with other student survivors and resources. He expressed his hope to build on his recent experience sharing his story and expressed a desire to become an advocate and resource for other cancer survivors.

Finally, a phone interview was conducted with an oncology counselor who is employed in a hospital cancer treatment center and has worked to support the well being of young adult clients. She shared that in her work with young adult cancer survivors she has seen some clients experience: varying levels of denial of the seriousness of their illness, anger at the illness occurring, disinterest in counseling at the time of treatment, increased dependence on parents and family members, and fear of reoccurrence after

remission. When working with those young adult clients who are not interested in counseling support or intervention, the counselor shared that she will often work to incorporate biofeedback therapy into her sessions. She has found this therapeutic technique helpful to teach relaxation and breathing which can assist with the management of anxiety. This clinician often works from a family systems perspective in her conceptualization of the client, placing her understanding of them within the context of their family system. This can be helpful when observing how the young adult's independence or dependence on parents and others can shift during treatment or when confronted with such a serious illness. She relayed that many clients are "at a stage of their life where they are breaking away from mom and dad, but it [their cancer] puts them dependent on mom and dad." She often will invite parents, family members, or significant others to join with them for a session, if the client expresses interest. In her work with young adults she mentioned that the survivor's romantic relationships can be important, and working with young adult clients to assess how their cancer treatment may be adding stress to the relationship can be an integral part of supporting their well being. Some clients wish to work on developing better communication and stress management skills to allow their relationship to have additional tools to survive the stressors of diagnosis, treatment, recovery, and remission. She explained that she has seen the importance of spiritual support in working with clients and recommended connecting university student survivors of cancer to spiritual and or religious support systems if they expressed interest in this avenue of supporting their well being. Finally, she shared her recommendation that exercise can be critical to help manage side effects and increase health, emphasizing that the hospital cancer treatment center in which she works

emphasizes the importance of exercise and healthy lifestyle. She recommended offering young adults the chance to participate in a six-week program that was developed out of Stanford University on chronic disease self management. This class essentially works with members to educate about exercise, communication, diet, sleep, mindfulness, relaxation, and essentially how to be healthy when experiencing a chronic disease. She conceptualizes cancer as a chronic illness because of the fear that it may return, and suggested that connecting cancer survivors who have been interested to such a class has proven helpful in her work as an oncology counselor.

Discussion and Recommendations

This project has provided an overview of items to consider when working to support the well being of young adult university student survivors of cancer. To meet the support needs of this unique population, it is important to examine the developmental factors of emerging adulthood, as well as the potential mental and emotional impact made by experiences with cancer. The young adult cancer survivor population includes survivors who may have been diagnosed during childhood, adolescence, or young adulthood. Working to identify where individuals are within their own process of diagnosis, treatment, and remission can assist in identifying what types of resources or support they need. It is important to consider what resources individuals currently have and what they still may require.

The experiences shared by the cancer survivors illustrate how the age of diagnosis, type of cancer, type of cancer treatment, and individual experience of this population of survivors can vary. The way in which participant cancer survivorship impacted respondents' university experience ranged from: very little or none, to significantly impacting daily life, class schedule, and overall time taken to complete coursework. Interviewed students who experienced cancer at younger ages shared how during university they began to understand their own survivorship in a new way, and how it has led them to be more active in connecting with others and advocating for those impacted by cancer. Student survivors, especially those diagnosed during university, shared how they felt their cancer survivorship experience has made them feel closer to family members, whom they relied on for support. Each student mentioned that knowing how and when to talk about their cancer experience with peers has been a challenge. But,

they also shared their appreciation for the stronger relationships that have developed with those friends who were supportive. Many shared how their involvement in organizations working to support and advocate for cancer survivors has offered the opportunity to connect with others impacted by cancer, and assisted in understanding and making meaning out of their experiences. When asked how, if at all, students experienced their survivorship impacting romantic relationships, two students expressed that it had little or no impact, and two shared how their experiences with cancer influenced the romantic partner they sought or the duration of the relationship they were in during treatment.

Participating students identified ways in which they felt their well being (physical, mental, emotional, and social health) was supported while at university. Students identified the following resources as important: the university counseling center, the university health center, the local hospital cancer treatment center, the university student cancer support group, the university recreation center, involvement in continuing with academics/daily routine, understanding and flexibility of professors, support of academic and career advisors, involvement in student organizations, as well as support from friends and family. Participants were also asked to share aspects of university that they felt did not support their overall physical, mental, emotional and social well being. Two students expressed that they felt supported when they needed support, and did not identify aspects of university life that felt not supportive. The remaining two students discussed how the demands of academics, increased stress related to tests, and lack of flexibility and understanding of professors had at times, felt unsupportive of their well being. When asked what services, if any, they would like to see more of, participants expressed a desire for the university student cancer support group services to continue and increase.

The discussion conducted with a hospital oncology counselor highlighted considerations to be mindful of when working to support the well being of each individual survivor. The counselor shared that some of the ways in which cancer has impacted the young adult survivors she has worked include: increased dependence on parents and family, a sense of denial related to seriousness of illness, anger at illness experience, disinterest in counseling at the time of treatment, and intense fear of reoccurrence after remission. The oncology counselor discussed the utility in offering interventions to educate survivors about the importance of exercise, as well as stress and anxiety management. She shared that she is also interested in how the client's experience with cancer impacts romantic relationships and the family system. She will support the cancer survivor, their romantic partner, and family members of the cancer survivor as needed.

This project has worked to provide an overview of information, supportive recommendations, and first-hand experiences of young adult university student survivors of cancer. The information provided may be useful in guiding those interested in supporting the well being of the university students who have been impacted personally by cancer. This study shares the specific perspectives of young adult university cancer survivors and may not represent the variety of young adult university student cancer survivors across the United States or internationally. The study was limited to invited participants who had identified themselves as cancer survivors through their involvement within university student-run organizations on campus associated with cancer on one university campus. All participants were currently active members of such organizations and had expressed interest or participated in the cancer support group offered throughout

the school year. Generalizability is limited based on the small, somewhat homogeneous sample size. It is recommended that future research might improve the variety of the population interviewed by increasing the sample's size and inviting a broader group of young adult university student cancer survivors. Increasing the number and the variety of support staff interviewed is also recommended and could provide an additional range of experience to reflect upon, increasing the types of interventions and available recommendations.

Appendix A:

Resources for Young Adult Cancer Survivors

American Cancer Society <http://www.cancer.org/>

The American Cancer Society is an excellent resource to gain information about health, cancer, treatment, research, and ways to become involved in supporting those impacted by cancer.

Twitter: <https://www.facebook.com/AmericanCancerSociety>

Facebook: <https://www.facebook.com/AmericanCancerSociety>

Youtube: <http://www.youtube.com/user/AmerCancerSociety/explore>

Business Address: 250 Williams Street N, Atlanta, Georgia, 30303

24/7 Phone #: 1-800-ACS-2345 or 1-800-227-2345

National Cancer Institute at the National Institutes of Health, Adolescents and young Adults with Cancer <http://www.cancer.gov/cancertopics/aya>

The NCI at the NIH have excellent summaries of information about cancer in the adolescent and young adult population. Their site is easy to navigate and the main page for AYAs discusses everything from diagnosis, treatment and clinical trials, coping and support, survivorship, resources, and literature.

Twitter: <http://www.cancer.gov/global/newmedia#twitter>

Facebook: <https://www.facebook.com/cancer.gov>

Youtube Channel: <http://www.youtube.com/ncigov>

Mail: 6116 Executive Boulevard, Suite 300, Bethesda, MD 20892-8322

Phone #: 1-800-4-CANCER (1-800-422-6237)

LIVESTRONG www.livestrong.org

The LiveSTRONG organization provides a wide range of support resources. They are based out of Austin, TX and provide free one on one support to anyone affected by cancer. Their website is easy to navigate and access information on available clinical trials, information on cancer, support topics, research, activism, fundraising, training opportunities, etc.

Twitter: <https://twitter.com/LIVESTRONG>

Facebook: <https://www.facebook.com/livestrong>

Youtube: <http://www.youtube.com/user/livestrongarmy>

Address: 2201 E. Sixth St., Austin, TX 78702

Phone #: 877-236-8820

Cancer Support Phone #: 855-220-7777

Fertile Hope <http://www.cancer.gov/cancertopics/aya>

Fertile Hope is a LIVESTRONG initiative that work to provide information on reproduction, support, and hope to cancer survivors at risk for infertility.

Critical Mass, The Young Adult Cancer Alliance <http://criticalmassevents.org/>

A non profit, currently supported by the LIVESTRONG foundation, dedicated to serve adolescents and young adults diagnosed with cancer. They have a variety of reports, media resources, and manuscripts specifically to AYAs and cancer.

Email: contact@criticalmass.org

I'm Too Young For This, Cancer Foundation Inc <http://stupidcancer.org/>

A non-profit dedicated to empowering young adults affected by cancer. Their website provides information tailored to connect with young adults. It shares ways to access support, connect with others, become involved, gain information and access their own “stupidcancer” talk radio webcast.

Twitter: <http://www.twitter.com/stupidcancer>

Facebook: <http://www.facebook.com/stupidcancer>

Address: 40 Worth St., Suite 808, New York, NY 10013

Phone: 877-735-4673

Email: contact@stupidcancer.org

The Ulman Cancer Fund For Young Adults <http://www.ulmanfund.org/>

Founded in 1997 by a three time cancer survivor, Doug Ulman, who first experienced cancer his sophomore year of college. The UCF now provides a wide range of cancer support, information, university outreach, scholarships, fundraising, research, and ways to become involved. Their mission is to “enhance lives by supporting, educating and connecting young adults, and their loved ones, affected by cancer.”

Twitter: <https://twitter.com/ulmancancerfund>

Facebook: <https://www.facebook.com/ulmancancerfund>

Address in Howard County: 6310 Stevens Forest Road, Ste. 210, Columbia, MD 21046

Address in Baltimore City: 921 E. Fort Ave, Ste. 325, Baltimore, MD 21230

Phone #: 410-964-0202 or 888-393-FUND (3863)

Fax #: 888-964-0402

Email: info@ulmanfund.org

Planet Cancer <http://www.planetcancer.org/>

Founded by young adults in their twenties who experienced cancer. It was created to provide an online community connection for young adults with cancer. They provide resources, peer support, and advocacy. Their member portal page: <http://myplanet.planetcancer.org/> provides blog info, pages to connect members, ability to post photos, join groups and forums, and chat with other members.

National Collegiate Cancer Foundation <http://www.collegiatecancer.org/>

Work to promote awareness and prevention within the young adult community while providing need based financial support to young adult cancer survivors pursuing higher education throughout treatment and after treatment.

Mail: National Collegiate Cancer Foundation, c/o Meghan Rodgers, 4858 Battery Lane
#216, Bethesda, MD 20814

Phone: (240) 515-6262

Surviving and Moving Forward:

The SAMFund for Young Adult Survivors of Cancer <http://www.thesamfund.org/>

Provide direct financial assistance and online support to young adult survivors. They have awarded \$900,000 in grants to young adults since 2005.

Twitter: <https://twitter.com/TheSAMFund>

Facebook: <https://twitter.com/TheSAMFund>

Mailing Address: The SAMFund, 89 South St., Suite LL02, Boston, MA 02111

Phone #: 617-938-3484

Email: info@thesamfund.org

National Coalition for Cancer Survivorship (NCCS) <http://www.canceradvocacy.org/>

The NCCS mission is to advocate for quality cancer care and work to empower people to advocate for themselves. Their website provides resources on employment rights, remaining hopeful, health insurance, questions to ask your doctor, etc.

Twitter: <https://twitter.com/canceradvocacy>

Facebook: <https://www.facebook.com/cancersurvivorship>

Youtube: <http://www.youtube.com/user/CancerSurvivorship>

Address: 1010 Wayne Ave, Suite 770, Silver Spring, MD 20910

Phone #: 1-877-NCCS-YES (1-877-622-7937)

Email: info@canceradvocacy.org

My Oncology Fertility <http://www.myoncofertility.org/>

MyOncologyfertility.org is part of the Oncofertility Consortium at Northwestern University. They provide resources and information for patients, parents, and partners on cancer and possible affects to fertility. Their site offers online videos, resources, and support.

Twitter: <https://twitter.com/oncofertility>

Facebook: <http://www.facebook.com/pages/Oncofertility-Consortium/274654090671>

Phone #: 866-708-FERT(3378)

Oncology Tube <http://www.oncologytube.com/index.php>

OncologyTube.com is a website dedicated to sharing and disseminating information about the latest medical oncology advances. They provide education, research, and news related to oncology topics.

Twitter: <https://twitter.com/oncologytube>

Facebook: <https://www.facebook.com/oncologytube>

Vital Options International <http://www.vitaloptions.org/yawc.htm>

Was founded in 1983 by Selma Schimmel after being diagnosed with breast cancer at the age of 28. It is a non-profit dedicated to facilitating a global cancer dialogue. They offer discussion forums, resources, and a video show called *The Group Room* (formerly a radio talk show and older shows are archived and available through the website:

<http://www.vitaloptions.org/grouproom.htm>).

Address: 4419 Coldwater Canyon Ave., Suite I, Studio City, CA 91604-1479

Phone #: 818-508-5657

Fax #: 818-788-5260

Email info@vitaloptions.org

Imerman Angels: One-On-One Cancer Support: <http://www.imermanangels.org/>

This non-profit works to connect cancer fighters, survivors & caregivers to one another for 1-on-1 support. They pair a cancer survivor with someone who has fought and survived the same type of cancer. Caregivers (family and friends) can also be paired with other caregivers and survivors.

Twitter: <https://twitter.com/imermanangels>

Facebook: <https://www.facebook.com/ImermanAngels?ref=ts>

Address: 400 W. Eire St., Suite #405, Chicago, IL 60654

Phone #: 312-274-5529

Young Survival Coalition: Young Women Facing Breast Cancer Together

<http://www.youngsurvival.org/>

Provide resources, connections, programs, and outreach to support in an effort to empower and offer hope to young breast cancer survivors.

Twitter: <https://twitter.com/YSCBUZZ>

Facebook: <https://www.facebook.com/youngsurvivalcoalition>

Youtube: <http://www.youtube.com/user/YSCYoungSurvival>

Email: info@youngsurvival.org

Look Good, Feel Better: Helping Women With Cancer <http://lookgoodfeelbetter.org/>

Their mission is to improve the self-esteem and quality of life for people undergoing cancer treatment. Assist through free group, individual, and self-help beauty sessions that are tailored to create support, promote confidence courage, and community.

Twitter: <https://twitter.com/lgfb>

Facebook: <https://www.facebook.com/lookgoodfeelbetter>

Youtube: <http://www.youtube.com/user/LookGoodFeelBetter>

Tumblr: <http://lookgoodfeelbetter.tumblr.com/>

Phone #: 1-800-395-LOOK (5665)

Leukemia Lymphoma Society: Young Adult Connect <http://www.lls.org/#!/aboutlls/>

LLS offers a weekly online chat that provides a forum for young adults facing cancer and cancer survivorship the opportunity to connect, they offer a discussion board, webcasts, programs, as well as more general resources for those impacted by LLS as well as other forms of cancer.

Twitter: <https://twitter.com/llsusa>

Facebook: https://www.facebook.com/LLSforacure/app_106171216118819

Youtube: <http://www.youtube.com/user/LeukemiaLymphomaSoc>

Phone #: 1-800-955-4572

Additional American Cancer Society Resources:**ACS Reach to Recovery**

<http://www.cancer.org/treatment/supportprogramsservices/reach-to-recovery>

The mission of reach to recovery is to help both females and males cope with their breast cancer experience. This program connects those who contact it with volunteers available

to discuss up to date supportive information and resources. Their website allows users to search for a Reach for Recovery program in their area by zip code.

Phone #: 1-800-227-2345 (same as the general ACS number shared previously)

ACS Relay for Life <http://www.relayforlife.org/>

Held in various locations internationally these organized overnight community fundraising walks raise awareness and money for the American Cancer Society. Participants and survivors also have the chance to celebrate what they have overcome, and remember those who are fighting or have fought cancer.

ACS Colleges Against Cancer <http://www.acscan.org/collegesagainstcancer>

Colleges Against Cancer is a nationwide organization of the American Cancer Society dedicated to eliminating cancer through four strategic directions: cancer education, advocacy, survivorship, and Relay For Life.

Stanford University School of Medicine: Chronic Disease Self-Management Program

<http://patienteducation.stanford.edu/programs/cdsmp.html>

A workshop given 2.5 hours once a week for six weeks to assist people with chronic health problems. Workshops are facilitated by two trained leaders. Information on the workshop overview, material covered, licensing, and facilitator training can be found on the website listed above.

To find locations offering this program click on the following link and search for your state: <http://patienteducation.stanford.edu/organ/cdsites.html>

Appendix B

Supporting the Well-Being of University Student Survivors of Cancer

Interview Questions

1. What is your age?
2. What gender do you identify as?
3. What has been most helpful for you, as you have developed your own understanding of what it means to be a cancer survivor?
4. At what age were you diagnosed with cancer?
5. What type of cancer are you a survivor of?
6. In what ways, if any, do you feel your experience with cancer impacts your life as a university student?
7. How, if at all, do you feel your survivorship impacts your current interpersonal relationships with:
 - a. family?
 - b. friends?
 - c. romantic partners?
8. While at University what services have felt most supportive for your overall well-being (your physical, mental, emotional, and social health)?
9. What about life as a University student, if anything, has not felt supportive of your overall well-being (your physical, mental, emotional, and social health)?
10. What type of services, if any, would you like more of to support your overall well-being?
11. What other type of services, if any, would you like to see?
12. Is there anything else that you would like to share about your experience that feels important for me to know as I gather current well-being concerns, forms of support, and resources for University cancer survivors?

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