Young Cancer Survivor Connections: A mixed methods investigation of online communication, social support, and unmet needs

by

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I first became inspired to study social support during my freshman year of college. At the time I was training to become a backpacking trip leader for the Harvard First-Year Outdoor Program (FOP). Brent Bell, the director of FOP, explained to us trainees how he was writing his dissertation about how participation in FOP predicted students' levels of social support during the first two years of college. He described social support as these six types of connections: (1) your best friend; (2) your group you hang out with; (3) someone you go to for advice; (4) someone who would bail you out of jail (or, practical help when you need it most); (5) someone who makes you feel competent at what you do; and (6) someone whom YOU take care of.

Mid-way through my time at USUHS, in a fit of nerdy glee only experienced by doctoral students in psychology, I stumbled across Brent's source – Robert Weiss' 1974 book, *The Provisions of Social Relationships*, which describes the six types of social support that Brent explained years ago. For my dissertation, I used the Social Provisions Scale created by Cutrona and Russell based on Weiss' work. As a tribute to Brent (and a nod to my high school friend Devorah Edelman who teased me for my penchant to list and categorize everything!) I've organized these acknowledgments around those six types of social support.

Guidance: *Someone you go to for advice*

There is no one who provides more guidance on a dissertation than one's adviser, chair, and committee. First, I would like to thank my adviser, Dr. Michael Feuerstein. In 2002, he was diagnosed with a malignant brain tumor and was given a dire prognosis.

For over a decade since then, he has dedicated all of his energy to improving the lives of cancer survivors. His tenacity, determination, and level of dedication to cancer survivors has inspired me throughout my time at USUHS. Dr. Feuerstein has fueled my passion for serving this population. Dr. Feuerstein has also fundamentally shaped my development as a clinical health psychologist, sharpened my critical thinking as related to research, and tenaciously kept me on track to finish this project.

Dr. Neil Grunberg, my committee chair, has mentored me throughout my time at USUHS. In the early years at USUHS I'd find myself stopping into his office to ask a quick question, and three hours later I would walk out with my head spinning. Whenever I felt down on myself, Dr. Grunberg built me up with a pep talk, and whenever I felt confident, Dr. Grunberg fed me a whopping dose of humble pie. Dr. Grunberg has always pushed me to challenge myself. His passion for teaching and public service is an inspiration. He also fueled my interest in social psychology, which underlies this dissertation.

Dr. Andrew Waters, the third member of my committee, gave me a foundational understanding of statistics during my first year at USUHS. He has always been a resource for statistics since then. In his role as director of the MPS graduate program, he always responds to student concerns with his ceaseless respectful demeanor, levelheaded professionalism, thoughtfulness, and sometimes a stats joke or two. Like all students in the department, I deeply appreciate his dedicated efforts to make the program run smoothly.

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Dr. Sharrona Pearl, my undergraduate senior thesis adviser, bridged my college and graduate school experiences. In the acknowledgments for my senior thesis I wrote how Sharrona inspired me both as a scholar and as a personal role model and mentioned

how I looked forward to seeing her again… having no idea that eight years later, we would reunite in Philadelphia where she would become a new kind of mentor to me. Now a professor at UPenn, she continues to inspire me through her deft balancing of the roles of scholar, teacher, wife, mother, neighbor, and friend.

Throughout my graduate school externships I benefited from the mentorship of numerous excellent clinical supervisors, including Drs. Neil Bien, Joseph Snow, and Amanda Thompson, Ms. Susan Fleischmann, and Ms. Margaret Hume. Now on internship I am blessed with several inspiring mentors including Drs. Rose Biester, Susan Del Maestro, Phil Gehrman, Lea Girsh, Jason Goodson, Rebecca Helms, Sol Kalkstein, Johanna Klaus, Elyssa Kushner, Marla McLaughlin, and Erin Ulloa.

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Reliable Alliance: ***Practical help when you need it most***

This dissertation simply could not have taken shape without the instrumental help of many people and institutions. I owe a deep debt of gratitude to the U.S. Department of Defense and the American taxpayer for supporting my entire doctoral education, including the USUHS intramural grant that funded this dissertation. I am constantly humbled by my military classmates who undertake a substantial service commitment along with their education. Although I can never compare to the sacrifices they make, I hope that I too will be able to serve the public in my career.

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Social Integration: ***The group you hang out with***

When I look back at my graduate school years and remember all of the BBQ dinners, picnics at drum circle, board game and pizza nights, playground playdates, DC Minyan Tot Shabbats, MCM 10K runs, weekend getaways, and hundreds of shabbat meals, I am (1) amazed that I ever got any work done in grad school, and (2) utterly grateful for all these social groups and events that kept me grounded. Moving to Philadelphia has made me acutely aware of how much I left behind in DC.

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Attachment: *Your best friend (and more)*

Brent summarized attachment as "your best friend" but really this category encompasses emotional support that comes from loved ones. I am deeply blessed to come from a large, loving, extremely supportive family of blood-relatives and in-laws.

The road to a PhD is a long one and it helps to have many role models in the family who trod this path before: from my grandfather Jerome Rosenberg and grandfather-in-law Ira Kukin, to my father Eliot Cohen, Uncle Jonathan Rosenberg, Aunt Jeanne Sauber Rosenberg, to my cousin Dena Cohen and the most recently minted PhD, my brother Rafi Cohen. You are all my role models, and I'm excited to add a Dr. Moskowitz to this list. My grandfather Felix Cohen, who was a psychiatrist and a World War II veteran, also inspired me.

My parents Eliot and Judy Cohen built a loving warm home for my siblings and me, and encouraged all of us to pursue our intellectual and professional interests and use them for the public good. They provide a constant source of inspiration through their devotion to family, moral integrity, intellectual thirst, and tireless work ethic. My siblings are a constant source of companionship, encouragement, and humor. Thank you Rafi for all the babysitting and the dissertation commiserating. Thank you Nathan for the hospitality with sheets, and for making me laugh. Thank you Becky for being my confidante, cheerleader, sounding board, au pair, and best friend.

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Opportunity for Nurturance: *Someone whom YOU take care of*

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DEDICATION

In memory of the USUHS MPS family members whom we lost in the last 3 years: Dr. Brenda Elliott; Dr. Kimberly Speck; and Ms. Corinne Simmons.

In honor of the participants of FD1 Estes Park of June 2014, who showed me up close how all of this matters.

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Michal C. Moskowitz, MS

May 15, 2015

ABSTRACT

Young Cancer Survivor Connections: A mixed methods investigation of online communication, social support, and unmet needs:

Michal C. Moskowitz, MS, 2014

Thesis directed by: Michael Feuerstein, PhD, MPH, ABPP, Professor, Medical and Clinical Psychology and Preventive Medicine and Biometrics

Statement of Problem: Young adult cancer survivors (YACS) are an understudied population that experiences greater psychosocial distress and unmet needs compared to other age groups (19; 85) and unique needs for social support (226). This study examined how young adult cancer survivors (YACS) access social support online and in person, and how social support is related to long-term adjustment.

Methods: The study consisted of Phase 1: qualitative interviews with 15 YACS related to online and in-person social support; Phase 2: cognitive interviews with 10 YACS piloting survey questions, and Phase 3: survey of 158 YACS.

Results: YACS participated in a variety of online support formats including blogs, Facebook, anonymous forums, and Twitter. YACS also described developing multiple types of cancer social network roles and in-person support activities. Having a larger number of general social network roles (β = .190, B = .062, p = .026) and types of connections with other cancer survivors (β = .207, B = .055, p = .024) is associated with higher levels of social support. Social support is associated with better long-term adjustment to cancer, i.e. greater positive impact of cancer (β = .226, p = .005), lower negative impact of cancer (β = -.347, p < .001), and fewer unmet emotional needs (β = -.393, p < .001). Having a wider variety of general social network roles and cancer social network roles is indirectly associated with better long-term adjustment to cancer through its association with increased social support. Participating in more online support activities or a higher number of in-person support activities was not associated with social support.

Conclusions: Involvement in a broad general social network, as well as having a variety of in-person connections with other cancer survivors, is associated with greater social support and better long-term adjustment to cancer (i.e., greater positive impact and lower negative impact of cancer, and fewer unmet emotional needs). This study did not provide evidence that online activities are associated with social support or cancer survivor outcomes. Exploratory analyses found that in-person connections with other cancer survivors moderates relationship between online activities and positive impact of cancer.

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CHAPTER 1: Young Adult Cancer Survivors

OVERVIEW AND DEFINITIONS

"Cancer" is an umbrella term that describes a group of more than 100 diseases in which abnormal cells divide uncontrollably and may invade nearby tissues and spread to other parts of the body (154). The definition of a cancer "survivor" is controversial (20; 120; 201). The term “cancer survivor” originated with Fitzhugh Mullan, a physician and cancer survivor who wrote about three periods of cancer survival: acute survival (the period after diagnosis), extended survival (the period immediately after completion of cancer treatment), and permanent survival (the period after which an individual is highly unlikely to face recurrence). The National Cancer Institute has adopted a broad definition, declaring that “an individual is considered a cancer survivor from the time of cancer diagnosis, through the balance of his or her life” (153). However, in its 2005 report, “Cancer Survivorship: Lost in Transition,” the Institute of Medicine identified survivorship as a distinct time in the cancer trajectory, in which people who have completed primary treatment for cancer experience distinctive concerns and unmet needs (95). Any strict definition of who is or is not a cancer survivor may be problematic in its inclusivity or exclusivity (119). This dissertation operationally defines a cancer survivor as someone who previously received a cancer diagnosis and has completed primary treatment for cancer (surgery, chemotherapy, radiation, and/or bone marrow transplant) and is not receiving hospice or end-of-life care. The study uses this definition because of the distinct concerns and needs that emerge during the post-treatment phase recognized by the Institute of Medicine.

Although using the term “survivor” adds clarity in distinguishing patients undergoing active treatment from people who have completed cancer treatment, it is notable that not all people who have been diagnosed with cancer embrace the term. A qualitative study of Australian breast cancer survivors (N = 20) found that many women disliked the term "survivor" because they did not want their experience with breast cancer to define them (34). Others were bothered that the term “survivor” implied that cancer was finished and would not return, even as the women feared cancer recurrence. Similarly, a qualitative study of 39 American breast cancer survivors found that although some women embraced the survivor identity, others disliked the term because they felt it belied their fear of recurrence, they did not believe they had been close enough to death to merit the term survivor, or they did not feel comfortable embracing the social label of a cancer survivor (112). A cross-sectional survey of 490 prostate cancer survivors found that most (57%) preferred to be identified as "someone who has had prostate cancer" and only 26% preferred the term "cancer survivor" (21). These objections to the implications of the term “survivor” notwithstanding, this dissertation uses the term for the sake of clarity and conciseness of terminology.

The age range defining "young adulthood" in oncology is likewise controversial and complex. Many have suggested combining adolescents and young adults (AYAs) into age ranges of 12-30, 12-35, 15-24, 15-30, 15-40, or 16-39, whereas others have suggested differentiating between adolescence (approximately 12-18 years old), emerging adulthood (18-25), and young adulthood (25-35) (65). The Adolescent and Young Adult Oncology Progress Review Group, a public-private partnership between the National Cancer Institute (NCI) and Livestrong, adopted a broad range and defined

AYAs as age 15-39 (2). This partnership recognized the wide variation in maturity and psychosocial needs in this age span. However, it set a lower limit at age 15, the age at which provision of care at pediatric hospitals begins to drop, and it set an upper limit at age 39, because adults in their 30s are physiologically similar to adults in their 20s and are likely to feel more in common with younger adults than with middle-aged or older adults (2)**.**

No clear-cut age range defining young adulthood appears in the developmental psychology literature. Young adulthood is associated with several developmental tasks, not all of which may be achieved within a specific age range. Developmental psychology describes young adulthood as a period typically characterized by achievement of several tasks, such as completion of higher education, career entry, marriage, and parenthood (102)**.** Specification of an exact age range defining young adulthood is difficult, particularly as the median ages for first marriage and parenthood have risen in the United States over the last several decades, while many people are eschewing marriage or parenthood altogether (161). Developmental psychology textbooks may broadly define young adulthood from ages 18-40 (102), although individual theorists vary in their specific age cut-offs or definitions of sub-periods within young adulthood. For example, Arnett (6) described the late teens through early twenties, particularly ages 18-25, as "emerging adulthood," a distinct developmental period of role exploration and identity formation. Levinson (135)broadly defined early adulthood as ages 17-45, but described several stages within that range, including early adult transition (age 17-22, a bridge between adolescence and adulthood), entry life structure for early adulthood (age 22-28, a period of creating a structure for adult life), the age 30 transition (age 28-33, an opportunity to refine and revise the entry structure for adult living), and culminating life structure for early adulthood (age 33-40, a time to complete this structure and achieve youthful aspirations).

This dissertation references a substantial amount of the literature that has combined adolescents and young adults into a single category. The tendency to combine adolescent and young adult cancer survivors into one group originated with the National Cancer Institute's Progress Review Group, whose report on adolescent and young adults (AYA) with cancer (2) launched the AYA movement. Despite the developmental heterogeneity within the AYA range, this movement has highlighted the shared developmental and clinical characteristics common to these age groups, as well as the unmet clinical and research needs specific to these groups (2).

The decision to choose a broad age range combining AYAs versus a narrower range focusing only on adolescents or young adults entails tradeoffs between internal and external generalizability of the sample. This study recruited participants who are young adults, broadly defined to include emerging adults and young adults, ages 18-39. The background section of this dissertation will focus on young adult cancer survivors rather than adolescents or older adults where possible and will note the definitions of young adulthood used in each study. Population-based cancer data such as Surveillance Epidemiology and End Results (SEER) will be reported in the age ranges that are available to describe young adults, although those ranges do not perfectly overlap with the chosen age range for this study.

EPIDEMIOLOGY & DISEASE CHARACTERISTICS

Risk and Incidence

Americans have a 40% lifetime chance of developing cancer and a 21% risk of dying from cancer (105). Although the majority of cancer diagnoses (77%) occur among adults over age 55, risk among young adults remains significant. A 20 year old has a 1.5% risk of being diagnosed with cancer by age 40. In the U.S. there are over half a million (555,711) young adults age 20-39 who have been diagnosed with cancer, including patients undergoing active treatment as well as post-treatment survivors. Incidence of cancer in each subgroup of young adults between age 20-39 has increased from 2001-2011, the last decade for which data are available: Incidence rose slightly from 35.6 per 100,000 to 37.5 per 100,000 among 20-24 year olds, and from 131.4 per 100,000 to 139 per 100,000 in that time (105). During that decade, cancer in each age group of older adults (55-64, 65-74, 75+) has declined (105). Incidence of cancer rises with increasing age within the young adult age span. Between 2002-2011, overall incidence was 37.9 per 100,000 among 20-24 year olds and 138.0 per 100,000 among 35-39 year olds (105).

Survival Rates

Cancer survivorship is distinct from cancer survival. Cancer survivorship research and practice focuses on symptom burden, behaviors, health, well-being, and function in cancer survivors (76), whereas survival rates describe the percentage of patients who are alive at a specified time point after their cancer diagnosis (105). Although this dissertation focuses on cancer survivorship, some brief context on cancer survival in this population is warranted.

Cancer is the leading cause of disease-related death among adolescents and young adults (age 15-24, 25-34, and 35-44) in the United States (218). Although overall, cancer 5-year survival rates have improved from 48.9% in 1975 to 67.6% in 2005, survival rates among AYAs age 15-39 have remained essentially unchanged in that time period (30; 105). Survival rates among AYAs vary depending on the cancer. For example, during 2000-2007, 5-year survival rates of thyroid cancer, testicular cancer, and Hodgkin lymphoma were above 90%, 5-year survival percentages of CNS tumors, colorectal cancer, and non-Hodgkin lymphoma were between 60-75%, and 5-year survival rates of acute myeloid leukemia, acute lymphoid leukemia, and lung cancer were all below 50% (30).

Cancer sites

The types of cancers that peak in young adulthood are distinct from cancers that predominate in childhood and older adulthood (199). Cancers that peak in young adulthood include osteosarcoma, Ewing sarcoma, gonadal tumors such as testicular cancer and ovarian cancer, and Hodgkin lymphoma (29). The incidence of different cancer sites also varies according to age within the range that encompasses young adulthood. Between 2000-2009 in the U.S., the most common cancers among 20-24 year old males were testicular cancer, followed by Hodgkin lymphoma, melanoma, non-Hodgkin lymphoma, and brain and nervous system cancers (105). Among 35-39 year old males, the most common cancers sites were melanoma, followed by testicular cancer, non-Hodgkin lymphoma, Kaposi sarcoma, and colorectal cancer (105). Among 20-24 year old females, the most common cancers were thyroid, followed by melanoma, Hodgkin lymphoma, cervical cancer, and brain and nervous system cancers (105).

Among 35-39 year old females, the most common cancers were breast, followed by thyroid, melanoma, cervical, and corpus and uterine cancer (105).

Etiology

The etiology of cancer in young adults is largely unknown (29). Some cancers are associated with viruses, such as cervical cancer (human papilloma virus), non-Hodgkin lymphoma (Human Immunodeficiency Virus and Epstein-Barr virus), Hodgkin lymphoma (Epstein Barr virus), and possibly glioblastoma or gliomas (human cytomegalovirus, JC virus, and simian virus 40 and osteosarcoma (simian virus 40) (29). Hormonal factors may be implicated in some cancers such as testicular cancer (29). Genetic predisposition (germ-line mutations in cancer-associated genes) appear to be involved in the etiology of several cancers in young adults, including central nervous system tumors, osteosarcoma, and breast cancer (29).

Treatment

Treatment for cancer may involve a combination of interventions including surgery, chemotherapy, radiation, corticosteroids, anti-angiogenic agents, endocrine therapy, and bone marrow or stem cell transplant. Surgery, the oldest modality of cancer treatment, is used for nearly all patients with solid tumors (163). Surgery may be used for cancer prophylaxis, diagnostic clarification, tumor removal or debulking, and/or palliative care (163). Chemotherapy refers to more than 100 chemical agents which are administered to kill cancer cells or stop or slow the spread of cancer (3). Chemotherapy is usually administered systemically rather than to a targeted site of the body with some exceptions.

Radiation therapy destroys or damages cells that are dividing, including cancer cells, by directing high-energy waves (x-rays and gamma rays) or charged particles (electrons) at the cancerous area (149). Treatment is delivered daily or several times per week in divided or fractionated doses, which enable normal cells to repair in between administration (149). Radiation therapy can be administered via external beam radiation or it can be delivered via brachytherapy, which implants vehicles that deliver radioactive material inside the body. Corticosteroids such as prednisone and dexamethasone are analogs of the hormone cortisol (145). They are used to treat cancers of lymphoid origin by inducing apoptosis in lymphoid cells and to a lesser extent are used to treat other hormone-responsive cancers (145). In the last decade, another type of cancer treatment called anti-angiogenic therapy has emerged as an adjunct to chemotherapy for some types of cancers. Anti-angiogenic agents are used to block cancer cells from developing vasculature that provides blood supply to the tumor (118).

Post-treatment effects

Exposures such as chemotherapy and radiation are associated with long-term medical risks or complications for AYA cancer survivors (184; 219). Chemotherapeutic agents have toxic effects on many organs, including cardiac toxicity (such as acute myocardial ischemia, arrhythmias, and/or congestive heart failure, particularly as a result of anthracycline chemotherapies), renal toxicity due to damage to the renal and distal tubules, acute and chronic liver disease, lung injury, damage to reproductive organs which may cause infertility, and neurotoxicity including peripheral neuropathy, altered mental status, and in some cases seizure or coma (84). Radiation may cause chronic permanent effects by damaging tissue and blood vessels, leading to fibrosis, fistulae, and/or tissue necrosis. Extremity bone cancers (sarcomas) often necessitate limb amputation, although limb-sparing approaches have been more common (184). Adverse effects of hormonal therapy include osteoporosis, atherosclerosis, and loss of fertility (111). A subset of cancer survivors (estimates vary between 17-75%) experiences cognitive impairment due to cytotoxic effects of nearly every type of chemotherapy, which may penetrate the blood-brain barrier (151; 178).

Cancer survivors are also at increased risk of developing second cancers (219), often due to radiation (149) or prolonged administration of certain chemotherapies, such as alkylating agents, which appear to cause leukemia (48). Hodgkin's disease survivors have an increased relative risk of 6.1 (95% CI, 5.0-7.4) for developing a solid tumor, which translates into a 25-year cumulative 23.3% risk of developing a solid tumor (209). In particular, mediastinal radiation (radiation delivered to the middle of the chest cavity) is associated with an increased risk of breast cancer in Hodgkin's disease survivors, with increased relative risk of 5.2 (95% CI, 3.4-7.6). Survivors of central nervous system tumors have increased risk of developing subsequent CNS tumors, and survivors of testicular cancer are at risk of developing gastric and pancreatic cancers as well as tumors of connective tissue (219).

YOUNG ADULT DEVELOPMENT AND CANCER

Developmental Tasks of Young Adulthood

To understand the psychosocial impact of a cancer diagnosis during young adulthood, it is important to provide a developmental context for the age group. Developmental tasks of young adulthood may include identity formation, psychological separation from parents, accepting responsibility for one's own body, establishing intimate relationships with a partner, starting and raising a family, choosing a career, obtaining professional education and training (for some), and assuming a social role (73; 102). The sequence in which young adults complete these tasks has become increasingly variable over the past several decades, suggesting that the path to adulthood has become increasingly individuated (180). Young adults create plans and expectations for how they will achieve their life goals during this stage, and an inability to carry out life goals during young adulthood may interfere with the individual's sense of agency (180).

How Cancer Impacts Young Adult Development and Needs

Cancer may disrupt or reverse any number of the developmental tasks of young adulthood, as well as survivors' sense of agency and control (60; 224). The AYA HOPE study (N=523), a cancer-registry based study of adolescent and young adults (age 15-39 at diagnosis, median 11 months post-diagnosis, range 4-22 months), found that approximately one-third of respondents in all three age groups (15-20, 21-29, and 30-39) reported that cancer had a negative impact on their plans for the future and goal setting (34.6%, 31.2%, and 31.1%, respectively), although nearly half of respondents reported that cancer had a positive impact on their plans for the future (47.4%, 47.5%, and 47.1%) (22). Nearly half reported that cancer had a negative impact on their sense of control over their life (46.3%, 47.8%, and 48.9%) (22).

Given the potential for cancer to disrupt several important developmental tasks of young adulthood, a wide range of unmet needs are common among young adult cancer survivors. A study of adult cancer survivors of mixed sites (N=116) comparing survivors diagnosed between age 18-40 (M=35 years old, SD=4.8) with a gender- and cancer-type-matched sample age 64 or older (M=73 years old, SD=4.3) found that at 6-7 months post-diagnosis, young adult survivors had lower levels of social functioning, higher levels of financial difficulties, higher sexuality needs, and higher health systems and information needs than the older matched sample (85). Similarly, a US population-based multi-state sample of 752 adult cancer survivors of mixed sites who were 8-16 months post-diagnosis (M=1.03 years, SD=0.19) found that survivors who were younger (age 18-54) at diagnosis reported significantly more concerns overall ($\beta=3.481$, $p<.001$) compared to adult survivors who were age 55 or older (8). Specifically, younger survivors were more likely to report concern about being physically unable to have children (OR=4.2, 95% CI: 1.66-10.5), difficulty pursuing the career of their choice (OR=2.5, 95% CI: 1.76-3.63), inability to change jobs for fear of losing health insurance (OR=2.5, 95% CI: 1.71-3.51), feeling angry (OR=1.9, 95% CI: 1.54-2.35), being less able to provide for their family's financial needs (OR=1.9, 95% CI: 1.48-2.41), job discrimination (OR=1.7, 95% CI:1.10-2.60), problems with family or children (OR=1.7, 95% CI:1.27-2.38), and not being able to get the information they need about cancer (OR=1.7, 95% CI: 1.22-2.33), among other problem areas (8).

Unmet needs may persist for years following completion of treatment. A qualitative study of 14 Australian young adults age 18-24 with a cancer history (brain, leukemia, Hodgkin's lymphoma, non-Hodgkin's lymphoma, and lung cancer) most of whom had completed treatment (mean 3.8 years post treatment), identified six domains of unmet needs (157). These included information, healthcare provision, daily living, interpersonal support, re-establishment of autonomy/resumption of developmental tasks, and emotional distress. One study of 1,040 adult cancer survivors (age 20 or older at diagnosis, mean current age 61.9, SD = 13.8) 2-5 years post-treatment found that younger age (measured as a continuous variable) was associated with greater information needs in all six domains assessed: tests and treatment, health promotion, side effects & symptoms, interpersonal & emotional, insurance, and sexual function & fertility (19). A study of 204 testicular cancer patients and survivors (mean age 35.6, SD = 10.5, mean 2.2 years post-surgery) found that 62.5% had at least one unmet need, and younger age and being unemployed were associated with greater likelihood of having an unmet need (25).

Demographic variables associated with greater likelihood of reporting unmet needs in one study of young adults (N=879, age 18-39 at diagnosis, mean current age = 29.7 years, SD=8.08, mean time since diagnosis = 4.7 years, SD=4.01 years) included: relationship status (not married or in significant long-term relationship), not being employed, low education level, non-white face, being female, younger current age (15-29 vs. 30-40), and younger age at diagnosis (15-19 vs. other age ranges) (no odds ratios reported) (221).

Interpersonal Relationships in Young Adult Cancer Survivors

Formation of healthy, supportive peer relationships and intimacy in a partner relationship are central developmental tasks for young adults (70; 73). Yet at a period in life when close relationships are especially important, diagnosis and treatment for cancer often disrupts social life (60; 224). AYA survivors have described in qualitative studies how cancer led to social isolation or disruption of close relationships (68; 117). Social support is one of the most common coping strategies reportedly used by young people with cancer (128). Survivors of various ages, including adolescents, adults, and parents of pediatric cancer have reported that they receive a great deal of support during cancer treatment, but that support declines during the transition from patient to survivor, leading to increased isolation (98; 110; 132; 170)). Yet at this time of transition from patient to survivor when support is declining, adolescents and young adults report experiencing a heightened need for support (110; 166).

Friends and family provide an important and valued source of support for young adults with cancer (60; 226). In the AYA HOPE study, the majority of participants across all three age groups (15-20, 21-29, 30-39) reported that cancer had a positive impact on their relationships with spouse/significant other (61%, 58.5%, 69.2%), mother (77.5%, 65.7%, 62.5%), father (67.1%, 59%, 60.6%), and siblings (79.7%, 61.3%, 64.9%). The majority of survivors age 21-29 and 30-39 also reported that cancer had a positive impact on their relationships with friends (60.4% and 62.4%) and children (63.5% and 60.9%) (22). However, qualitative studies indicate that support from family and friends may be insufficient; family and friends may not understand young adult survivors' feelings and experiences, or may feel so uncomfortable--for example, they do not want to be reminded of mortality, or they find it too upsetting to talk about cancer--that they withdraw from the person with cancer (117; 166). A quarter of young adult cancer survivors report needing information about how to talk about their cancer experience with family and friends (115).

Qualitative studies show that young adult survivors have a desire to connect with other survivors with a similar demographic and medical background (117; 166; 183). Many young survivors consider meeting peers with cancer to be an even more important support need than support from friends and family (222). In one study using a modified Delphi panel to generate and rank a list of unmet needs (N=37), 100% of young adult survivors rated "opportunities to meet other young people with cancer" as a top five support need, whereas only 50% of young adult survivors rated "support from friends and family" as a top five need (222). A larger survey study (N=1088) of young adult cancer patients and survivors age 18-39 at time of study entry (M=31), diagnosed between ages 15-35 (M=26.5), found that support from family and friends were the first and second most important support needs, respectively, of survivors who had completed treatment, with opportunities to meet peers with cancer as the third most important support need (226). Respondents who were farther from diagnosis in time ranked the need to meet other young survivors more highly compared with those who were diagnosed more recently (226). Similarly, the AYA HOPE study found that, a median of 11 months post-diagnosis, 88.3% reported a need to meet other AYA cancer patients/survivors, and that need was unmet in 43% of survivors (115).

There are several reasons young adult survivors seek some type of connection with peers who are also cancer survivors. Connecting with “similar others” helps survivors normalize their experience (166). They may seek friendships with others who are similarly excluded or stigmatized (68). In addition, connecting with peers also may enable young survivors to share common areas of concern, such as coping with uncertainty, body image, intimacy, sexuality and fertility, or career problems (223). Young adult survivors report that connection with other young survivors also helps address feelings of depression, anxiety, self-blame, and stress (166). Further, associating with others who are in a more difficult situation enables young adult survivors to perform "downward comparison," which improves self-concept (74; 222). Finally, connecting with similar others enables young adult survivors to form a greater sense of group identity or community, which is a developmentally important task at this stage (222; 227).

SUMMARY OF SECTION 1

This section provided an overview of young adult cancer, including incidence, survival rates, cancer sites most commonly diagnosed in young adulthood, diagnostic variables, treatment, and long term and late effects. This section also described developmental tasks of young adulthood that may be interrupted due to a cancer diagnosis at this stage of life, including establishing intimate relationships with a partner, starting and raising a family, and embarking on a career. Cancer frequently produces a negative impact on young adults' lives and leads to a wide array of unmet needs in several domains including health care access and information, fertility, sexual function, body image, diet and exercise, academics and employment, emotional distress, and interpersonal relationships. Social support appears to be a particularly important need for young adult cancer survivors. Specifically, young adult cancer survivors have expressed widespread interest in meeting other young adult survivors. The linkage between social support and health and well-being, especially in cancer survivors, is discussed in the next section.

CHAPTER 2: Social Relationships and Health

INTRODUCTION AND DEFINITIONS

This section discusses the linkage between social relationships and health outcomes. First, this section defines and explains functional and structural measures of social relationships (social support and social networks). Following is a discussion of the different types of social support as well as additional dimensions of assessing support, such as differences between types of relationships that provide support and the distinction between perceived vs. received support. The section provides a historical overview of the research linking social relationships with physical and mental health outcomes in the general population, followed by a review of the literature on social relationships and health and well-being in cancer patients and survivors. Finally, the section concludes with a discussion of the mechanisms suggested to account for the impact of social relationships on health in general and among young adult cancer survivors in particular.

Social relationships can be described in functional or structural terms. Functional measures of social relationships describe what relationships do for an individual. Some conceptualize these functions as types of transactions or exchanges between people (26). "Social support" refers to the functions that social relationships provide for the individual, such as demonstrating love and caring, providing guidance or advice, or sharing resources (43; 104; 198). There are several conceptualizations of the sub-types of social support, which will be discussed below.

Structural measures of social relationships describe the existence or organization of relationships (47; 104; 198). Examples of structural measures include the number of people with whom one has regular contact, frequency of contact, and types of social roles held by a person (e.g., spouse, relative, friend, employee, neighbor) [58, 67]. "Social networks" are webs of social relations around an individual, and they can be assessed in several structural terms such as size, intensity of contact, density, reciprocity of ties, or other properties (182; 203).

When referring to joint effects of functional and structural aspects of social relationships on outcomes, this section will use the generic umbrella term "social relationships" (104).

MEASURES OF SOCIAL RELATIONSHIPS

Social Support

The term social support was introduced in 1976 by psychiatrist Sidney Cobb, MD, in his presidential address to the American Psychosomatic Society (43). Cobb argued that “social support facilitates coping with crisis and adaptation to change,” (page 302) and reviewed evidence of the benefits of social support throughout the life span. He defined social support as information leading to three types of beliefs, which he categorized as emotional support, esteem support, and sense of belonging.

Two years before Cobb's address, Weiss (214) delineated six major functions or provisions of social relationships in the individual's life. These categories encompass the categories of social support proposed by Cobb and others (28; 104; 197) and will be described in detail here.

1) *Emotional support/Attachment*: Weiss [64] described how attachment is provided by intimate relationships, such as relations between spouses, partners, close friends, or siblings, in which the individual feels sense of security and comfort. Cobb

(43) defined emotional support as “information leading the subject to believe that he is cared for and loved” (page 300).

2) *Social integration*: Weiss described social integration as a sense of belonging to a group, which provides companionship, social engagement, and social activity (214). Cobb (43) defined social integration as "information leading the subject to believe that he belongs to a network of communication and mutual obligation,” (page 300) or belonging to a network of people who share information and resources. Others refer to social integration as social anchorage (62) and describe it as a feeling of membership or being anchored within social groups. Cohen and Wills (47) refer to this type of support as social companionship, diffuse support, or belongingness.

3) *Esteem support/reassurance of worth:* Weiss described how relationships affirm an individual's competence by valuing the person's skills or ability to fulfill a social role [64]. Cobb defined esteem support as “information leading the subject to believe that he is esteemed and valued,” (page 300) which affirms a person’s sense of self-worth (43). Other theorists (197) conceptualize esteem support as a subset of emotional support.

4) *Instrumental support/reliable alliance* is defined as assistance with practical, tangible needs or problems, such as groceries, transportation, cooking, or financial aid (28; 198; 214).

5) *Information support/guidance* is defined as provision of facts, advice, or information to help a person meet particular needs (28; 198). Weiss theorized that guidance is especially important during stressful situations because it assists the individual in formulating a plan for coping with the stressor (214). Other theorists call

this form of support appraisal support and define it as information that helps a person interpret a situation and make appropriate decisions (198).

6) *Opportunity for nurturance* is described by Weiss as a sense of being needed because the individual is responsible for the well-being of another person, typically a child (214). Other theorists have not included opportunity for nurturance in their conceptualizations of social support (c.f. (26; 28; 47; 62; 104; 198). In contrast to the other five subtypes of social support, which describe provisions that the individual receives from others, opportunity for nurturance is a provision that the individual gives to others. However, Weiss (214) noted that opportunity for nurturance provides meaning in a person's life, which sustains a person's commitment to goals and activities. This conceptualization is consistent with the helper-therapy principle (168), which posits that individuals reap their own benefits, such as increasing self-efficacy, through helping others.

Although Weiss conceptualized opportunity for nurturance as a parent-child or teacher-student relationship, it may also apply to peer support among people with cancer. Reviews of cancer support groups have cited the helper-therapy principle as a theoretical basis explaining how cancer peer support groups or programs benefit their participants (37; 83). A study of an online intervention for low-income breast cancer patients (N=231) found that among participants who wrote or read at least one message on the discussion board (n=177), women who were high in both expression *and* reception of empathy showed the greatest reduction in breast cancer concerns (89). The authors interpreted this finding by suggesting that bidirectional help is a critical factor in peer support groups (89).

Table 1 depicts the different sub-types of social support included in multidimensional measures of social support. As seen in the table, the different measures use slightly different terminology to describe the same basic phenomena. Also, as seen by the table, Weiss's conceptualization, operationalized in a social support measure by Cutrona and Russell (57), includes the most domains of social support.

Table 1. Multidimensional measures of social support

	Social Provisions Scale (SPS) **(57)**	**Interpersonal Support Evaluation List (ISEL)** **(46)**	**Inventory of Socially Supportive Behaviors (ISSB)** **(15)**	**MOS Social Support Survey** **(181)**	**Social Support Behaviors (SS-B) Scale** **(211)**	**ENRICHD Social Support Inventory (ESSI)** **(148)**
Emotional support	Attachment		Emotional support	Emotional/ informational support (combined), affectionate support	Emotional support	Emotional
Instrumental support	Reliable alliance	Tangible	Tangible assistance	Tangible support	Practical assistance, financial assistance	Practical
Informational support	Guidance	Appraisal	Directive guidance	Emotional/ informational support (combined)	Advice/guidance	Informational
Belonging	Social integration	Belonging	Social interaction	Positive social interaction	Socializing	
Esteem	Reassurance of worth	Self-esteem				
Nurturance	Opportunity for nurturance					

Social Networks

Social networks are conceptually distinct from social support (182), and measures of social networks and social support show only modest correlations (47). Social networks appear to act on individuals through mechanisms that extend beyond social support, such as social norms and social constraints (182). Social network theory assumes that social structure of a network determines the flow of resources, information, and communication, which shapes individual behaviors and attitudes [61]. Social network analysis is "a method whereby the ties people have to one another and the characteristics of those ties are examined and subsequently used as a means of explaining the behavior of people involved in them" (26), page 14.

Sources of Social Support

Several social support researchers have distinguished between broad categories of social relationships that provide support. Informal ties or "primary group" members include family members and close friends with whom one shares an emotional bond (62; 136; 198). Formal ties or "secondary group" members includes acquaintances or contacts made through organized settings such as the workplace, health services, religious institutions, or volunteer settings (62; 136; 198). Different types of social ties may provide different types of support for a person who is experiencing a stressful life event. A study in two populations, elderly adults and new mothers, found that number and frequency of contact with family members was associated with greater attachment (emotional support), opportunity for nurturance, and reliable alliance (instrumental support), whereas number and frequency of contact with non-family members was associated with greater social integration and reassurance of worth (esteem support) (56).

Support from others who have experienced a similar trauma or crisis, such as cancer, can be called "experiential support" (183). Snyder and Pearse coined the term "experiential support" to describe support received by hearing the experience and insights of others who had been diagnosed with breast cancer, which was a theme that emerged in their qualitative study of 70 young breast cancer patients and survivors (mean age = 35.2 years, 86% diagnosed within the past three years) (183). Over half of the participants in their sample described accessing experiential support. Similarly, Thoits theorized that members of a person's "secondary group" (e.g. acquaintances or contacts made through professional, health service, religious, or volunteer settings) who have endured a similar stressful life experience may be more effective than primary group members at providing information or appraisal support (198).

Participants in cancer support groups have described the unique benefits of experiential support. In a qualitative study of 93 cancer support group participants ages 38-85 (median age 62, time since diagnosis or treatment not reported), participants described how support groups provided support that they could not receive in other relationships (202). Groups and fellow group members created a sense of community that mitigated against the isolation that participants experienced outside the group; provided empathy and validation of strong emotions, whereas family and friends without cancer sometimes dismissed the participants' feelings or refused to talk about cancer; shared information and advice gleaned from personal experience; provided an opportunity to engage in reciprocal caring by helping other members; and increased participants' empowerment, optimism, acceptance, and their sense of personal control and agency (202). Similarly, in a small pilot study of a cancer support intervention for young adults (N=14, mean age = 29.7, range 24-34, 8 participants post-treatment, 11 participants within 2 years of diagnosis), participants described how the intervention helped them by showing the universality of their shared experiences, introducing them to other young adults with cancer, creating a non-judgmental and supportive environment to share thoughts and feelings, and providing useful information (169).

This differentiation between primary group support vs. experiential support is consistent with social comparison theory, which posits that individuals seek comparison with similar others in order to more accurately appraise themselves (74). In particular, individuals who are in an anxiety-provoking situation seek affiliation with other individuals who are in a similar anxiety-provoking situation--in other words, "Misery doesn't love just any kind of company, it loves only miserable company" (176) (page 24). Therefore, it is expected that young adult cancer survivors would seek connections with other young adult cancer survivors in order to appraise their own experiences and attitudes related to cancer, as well as to seek emotional and informational support and reduce isolation (117; 166; 183). Taken together, the literature indicates that young adult cancer survivors can benefit from having a variety of social relationships with family, friends, and other young cancer survivors, since each of these relationships can perform different functions for the individual.

SOCIAL RELATIONSHIPS & HEALTH: OVERVIEW OF EVIDENCE

General Health Outcomes

Evidence linking social relationships with physical and mental health outcomes has accrued over the past several decades. In Sidney Cobb's 1976 speech introducing the term social support, he described how the benefits of social support begin at birth, citing the higher complication rate among mothers with low social support and low birthweight of babies who were unwanted (43). He then described how social support promoted positive outcomes in adulthood, including medical treatment adherence, recovery from illness, and adaptation to life stressors such as unemployment, bereavement, aging, and retirement (43). The same year, epidemiologist Dr. John Cassel addressed the American

Public Health Association and described how psychosocial factors such as social support might protect organisms from the physiologic or psychological adverse consequences of exposure to stress (38).

Since the 1970s, a large body of evidence has accrued demonstrating the link between social relationships and health outcomes. A series of community-based longitudinal epidemiological studies in the 1980s illustrated how reductions in the number and frequency of social ties over time predicted increased risk of all-cause mortality or risk of death from ischemic hart disease, cancer, cerebrovascular and circulatory disease over nine or ten-year follow up ((26) (104)).

A recent meta-analysis of 148 studies (N=308,849) found a 50% increase in odds of survival (OR = 1.50, 95% CI: 1.42-1.59) attributable to social relationships, including functional and structural aspects of relationships (100). Studies that obtained complex measures of social integration (e.g. measures that combined multiple aspects of social relationships such as marital status, network size, and social network participation) found, on average, a 91% increase in all-cause survival odds (OR = 1.91, 95% CI: 1.63-2.23). These results remained stable regardless of age, sex, initial health status, follow-up period, and cause of death (100).

Social Relationships & Cancer Survivorship

Several studies have demonstrated a positive relationship between social ties and survival among people diagnosed with cancer. A meta-analysis of 87 studies conducted by Pinquart and colleagues (162) found the protective effects of greater perceived social support (RR=.75, 95% CI: .65-.87), larger social network size (RR=.80, 95% CI: .72-.89), and marital status (RR=.88, 95% CI: .82-.94) on improved cancer survival. The study found that the protective effect of social network size was stronger among patients of younger age and among patients with breast cancer.

Social support predicts emotional well-being and health-related quality of life among cancer survivors in several longitudinal studies. A 1996 review of social support in cancer found that emotional support was associated with improved adjustment to cancer, self-esteem, mood, and coping in adult cancer survivors (93). These findings have been supported in several more recent prospective studies across different cultures: A prospective study of 286 newly diagnosed Korean women with stages I-III breast cancer found that in the year following diagnosis, decreased emotional support predicted deteriorated depressed mood (132). Similarly, in a study of 131 women diagnosed with breast cancer at age 40 or earlier, lower social support predicted higher depression over a 10 year follow-up period (82). A prospective study of 206 mixed site cancer survivors in the Netherlands found that receipt of emotional support at 3 months post-diagnosis predicted greater experience of the positive consequences of cancer, such as greater self-confidence, improved relationships, or greater appreciation of life, at 8 year follow-up (177). In a prospective study of prostate cancer survivors (N=175, mean age 64.8, SD 7.5) higher levels of social support at baseline (mean time since diagnosis = 15 months) predicted improved health-related quality of life at two-year follow-up (228).

Similarly, several cross-sectional studies of young adult cancer survivors have linked social support with better adjustment and quality of life. A cross-sectional study of young adult cancer survivors (N=64) found that social support positively accounted for 11.6% of the variance in post-traumatic growth (137). Among adolescent and young adult survivors of childhood retinoblastoma, lower social support was associated with greater internalizing behavior problems (e.g. withdrawn, depressed/anxious, and somatic complaints) (208). In a sample of 101 young breast cancer survivors age 31-49 (mean = 3.36 years post-diagnosis, range 1-15 years), social support was significantly correlated with quality of life and accounted for 17% of the variance in quality of life (174).

Interestingly, although there is strong epidemiological evidence linking social relationships with physical and emotional health and well-being, along with mixed evidence of the efficacy of peer support-focused interventions at improving immediate psychosocial outcomes such as social support and distress (99; 141), there has been a disappointing lack of evidence that social support interventions produce long-term benefits (44; 99; 141). A few isolated studies have found that group-based psychosocial interventions reduced mortality and recurrence at long-term follow-up (4; 186), although other studies have failed to find a survival benefit (64; 81; 124; 125). Some found improvement in psychosocial functioning at 1-2 year follow-up (81; 124), whereas others found that psychosocial improvements were not sustained over time (64). Cohen (44) suggested that the discrepancy may lie in the fact that the epidemiological studies observe reduced mortality associated with naturally occurring social relationships, which may provide support for months or years, whereas the support interventions only convene temporary support for the limited duration of the intervention. Therefore, he hypothesized that emphasizing naturally occurring social networks may provide a more reliable and effective target for bolstering long-term support and thereby improving health outcomes (44). A greater understanding of the ways in which cancer survivors maintain and bolster naturally-existing support networks may assist in promoting well-being over the long term.

MECHANISMS LINKING SOCIAL RELATIONSHIPS TO HEALTH

Several mechanisms may account for the impact of social relationships on health, including the buffering effect of social support, social engagement, access to resources, social influence, and self-efficacy and self-esteem. The proposed mechanisms most relevant to this dissertation will be discussed in detail below, along with an illustration of its particular relevance to cancer survivors.

Buffering Effect of Social Support

Cohen and Wills (47) described how social relationships are linked to health through two main pathways: the main effect of social relationships (which encompasses the other mechanisms to be discussed below) and the buffering effect. According to the buffering hypothesis, social support serves as a buffer against a harmful stress response. There is some evidence that the perception of a supportive person leads to increased activity in the ventromedial prefrontal cortex (VMPFC), a reward-related region of the brain which inhibits the fear response (67).

Social isolation--which may be a common concern among young adult cancer survivors (166; 194)--is itself a chronic stressor, which activates the physiological stress response through the HPA axis and impacts immune and neuroendocrine function (26; 67). Social ties are fundamental for survival in many species, and social disconnection serves as a threat that activates a neural alarm system which includes the amygdala, dorsal anterior cingulate cortex (dACC), anterior insula, and periaqueductal gray (PAG) (67). This "neural alarm system" in turn activates autonomic (sympathetic nervous system) and endocrine responses (67). Repeated activation of the HPA axis due to chronic social disconnection leads to glucocorticoid desensitization, which in turn causes increased basal levels of inflammatory gene expression in circulating immune cells (67). It is hypothesized that social isolation accelerates the organism's rate of aging, which thereby increases mortality (28).

Loneliness--another concern described by cancer survivors (170)-- is associated with depression, anxiety, lower health-promoting behaviors and greater risky health behaviors, and impaired physical health (198). A study of ovarian cancer patients (n=68) found that even when adjusting for diagnostic variables, patients with lower social support had higher levels of tumor norepinephrine, which is associated with enhancement of cancer progression (139).

Social support may also change a person's appraisal of a potentially stressful situation so that it is not seen as threatening or unmanageable (47). Thoits (196) linked the stress-buffering hypothesis with Lazarus and Folkman's conceptualization of coping, which they defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" ((130) page 141). Thoits conceptualized social support as a way of assisting the individual, through behavioral or cognitive means, to cope with the problem itself and to cope with the emotions caused by the problem (196). Therefore supportive persons can provide coping assistance that is behavioral problem-focused, cognitive problem-focused, behavioral emotion-focused, or cognitive emotion-focused (196). Behavior problem-focused support may entail providing resources of services to reduce the burden of the stressor, such as providing information about college scholarships or fertility services for young cancer survivors. Cognitive problem-focused support enables the individual to re-evaluate the stressor so it appears less threatening, for example, helping the survivor to reconsider the positive or negative impact that cancer had on the survivor's life. Behavioral emotion-focused support may encourage a person to engage in healthy habits of exercise, diet, and sleep to help reduce stress and stabilize mood. Cognitive emotion-focused support helps normalize the individual's emotional response, for example, reassuring the young cancer survivor that feelings of continued fear and uncertainty after cancer are normal.

Social engagement

Another possible mechanism linking social relationships with health and well-being emerges from the sociological theoretical notion of symbolic interactionism. Symbolic interactionism posits that social interaction enables individuals to create a social sense of self, or an awareness of his/her position in society (188; 189; 195). The individual adopts social positions or roles, which provide purpose and meaning in one's life (195). These social roles also provide a set of scripts or expectations that organize the individual's behavior and provide guidance on how to act (195).

Thoits’ identity accumulation hypothesis posits that the accumulation of social identities (e.g., spouse, parent, employee, student, church member, friend) enhances psychological well-being and organizes the individual's behavior (195). Contemporary sociologists and public health researchers argue that social roles and identities may constrain and regulate behavior in ways that impact health (28; 198). For example, the belief that one matters to others, that others are relying on him, creates a sense of obligation, belonging, and attachment that influences the individual's health behaviors (28). This accumulation of social roles and accompanying sense of obligation may be particularly relevant to young adults who are beginning to assume greater responsibility for others in their lives, such as partners and young children.

Access to resources

Social relationships serve as conduits that increase access to tangible goods, whether through advice, direct service, networking contacts, or referrals to other providers (26; 28). By improving access to resources such as jobs, health care, economic assistance, health information, and housing, social relationships can lead to improved health outcomes. For example, Pinquart (162) suggested the possibility that cancer patients with better social networks might receive more vigorous cancer treatments because their network members might provide them with crucial information about hospitals, care providers, or types of treatment. In addition, cancer support groups provide access to information about cancer diagnosis, treatment, and management of side effects (37).

Self perception: Self-efficacy and self-esteem

Successful fulfillment of life tasks and social roles creates greater feelings of internal locus of control--the sense that a person has control over his own life--as well as greater self-worth and self-esteem (198). According to social cognitive theory, social support also promotes self-efficacy, the individual's belief that he can accomplish tasks and behaviors to produce desired results and avert detrimental ones (9-11). Self-efficacy in turn enhances the individual's engagement in health-promoting behaviors by influencing goals, expectations of the outcomes of behaviors, and the perception of facilitators and impediments to the behavior (12). Several studies have shown that social support and self-efficacy are negatively related to post-partum depression (58; 131) and positively related to exercise (63; 171) and nutrition (5).

Social support can promote self-efficacy by providing guidance, reassurance, or positive feedback to the individual (10). Social relationships can also increase self-efficacy by exposing the individual to vicarious experiences of success. In other words, if an individual struggling with a stressor (for example, a young adult cancer survivor) witnesses someone in a similar position (i.e., another young adult cancer survivor) overcome barriers to achieve a difficult task, the individual may become more motivated and confident in achieving that task as well (10).

SUMMARY OF SECTION 2

Social relationships, assessed in functional terms (social support) and structural terms (e.g., social network involvement), are strongly related to physical and psychological health and well-being. Among cancer survivors, social support is linked to better adjustment, lower incidence of depression, and better quality of life. Naturally-existing informal social support, which is likely more enduring than formal, structured, time-limited interventions, has been suggested as a target for bolstering long-term health and well-being. Several mechanisms linking social support with health and well-being have been suggested. These mechanisms include buffering against the negative effects of stress, spreading behavioral norms that promote health, providing individuals with a social role that enhances psychological well-being and organizes behavior, reducing the inherent stress of isolation, bolstering self-efficacy and self-esteem, and providing access to resources. All of these mechanisms may explain how social support might reduce

YACS’ unmet needs and directly or indirectly change how they perceive the positive or negative impact of cancer on their lives.

CHAPTER 3: Online Social Connections and Cancer Survivors

INTRODUCTION AND DEFINITIONS

This section provides an overview of online support and communication, particularly among cancer patients and survivors. The section opens with definitions and explanations of basic terms related to online communication. Next is an overview of the literature about online communication and social relationships in the general population, including a discussion of whether online communication displaces, extends, or fills in deficits in offline relationships. Following is an overview of online support for people with cancer, including a review of the types of support offered online, the unique attributes of online support groups, and evidence of the benefits of online support. Finally, the section will conclude with a discussion of the limited literature regarding support through social media use among people with cancer.

"Online communication" refers to Internet-mediated interaction using technologies such as email, instant chat, web-based discussion boards, and social network sites (to be defined below). "Offline communication" refers to non-computer mediated interaction such as face-to-face contact or telephone conversations.

“Social media” are defined as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0 [a term that describes emerging web technologies], and that allow the creation and exchange of User Generated Content" (114) (page 61), (156). Examples of social media include wikis such as Wikipedia, blogs, photo and video-sharing sites such as Flickr and YouTube, and social network sites such as Facebook (114).

“Social network sites” are web-based services in which users: 1) create profiles with their personal information, which may include text, photos, video, or other content; 2) designate other users with whom they are connected; and 3) view their connections and the connections of others in the system (31; 114). Most social network sites enable users to communicate via private messages and/or public comments (31). Social network sites are extremely popular, especially among youth. Of American young adults (age 18-29) who are online, 72% use social network sites (134). Social network sites are generally used to communicate with members of users' offline social networks rather than meet and establish connections with strangers (31; 190). Social network sites are used not only to maintain relationships with close friends, but also to establish, maintain, and strengthen contacts with other acquaintances.

“Online support groups” describe Internet-based programs that enable users with a common concern, such as a medical diagnosis or psychological stressor, to interact and communicate as a community online (72). Although online support groups may take several forms, the dominant structure is a forum or discussion board which enables users to write messages, called posts, which are visible to the entire community of users and are accessible through archives to enable asynchronous communication (13).

ONLINE COMMUNICATION AND SOCIAL RELATIONSHIPS

Unique Aspects of Online Communication

From its inception, the distinctive characteristics of computer-mediated communication made online interaction qualitatively different from face-to-face interaction. According to Walther's conceptualization of computer-mediated communication, online interaction eliminates visual and contextual social cues which would otherwise inhibit communication, thereby enabling communicators to become less self-conscious about their self-presentation (212). Online communication therefore facilitates "hyperpersonal" dialogue, which features an unusually high degree of intimacy and self-disclosure (212). Walther's notion of hyperpersonal communication is consistent with decades of social psychology research on deindividuation, which indicates that as people become less identifiable, their inner restraints are reduced (75).

Although Walther's conceptualization of hyperpersonal communication was published 18 years ago, it remains consistent with current perceptions of online interaction. For example, a mixed methods study on social media use conducted in 2007-2008 revealed participants' perceptions that "Sometimes not being face-to-face makes it easier to share information;" "you are more open minded online;" "some people are more willing to share personal thoughts online rather than face-to-face;" and "you can connect and share problems and feelings with them without the risk of facing their reaction or judgment" (200) (page 174).

Walther's conceptualization is consistent with decades of empirical studies of computer mediated interaction, which found more uninhibited communication in computer mediated interaction (121), greater self-disclosure between computer-mediated conversation partners than in-person partners (109; 122), greater self-disclosure in computer mediated communication under conditions of visual anonymity and higher private self-awareness (109), and a significant increase in relational intimacy over three separate days between computer-mediated partners but not between face-to-face conversation partners (97). The Internet-enhanced self-disclosure hypothesis posits that the Internet facilitates self-disclosure to friends, which in turn increases social connectedness and well-being (204). Increased online self-disclosure mediates the positive relationship between online communication and quality of friendships (204).

Who benefits from Internet use: “Rich-get-richer” vs. “Social Compensation”

Two hypotheses theorize who benefits the most from online connection-- those with stronger or weaker offline social networks. The "rich-get-richer" hypothesis (127) (page 58) suggests that people who are highly sociable and have existing social support will socially benefit more from the Internet by using it to reinforce existing social networks. In contrast, the social compensation model or poor-get-richer hypothesis posits that the Internet is more beneficial for introverted or socially isolated people, who compensate for the lack of in-person connection by seeking social connection online (127; 146).

The "rich get richer" hypothesis first appeared in a longitudinal study, which found that Internet use in extraverts was associated with increases in community involvement and decreases in loneliness at one year follow-up, whereas the opposite pattern appeared among introverts (127). This finding has been supported in subsequent studies (133). The social compensation model also has been supported. There is some evidence that online communication may facilitate communication for shy people by reducing inhibitions and rejection sensitivity (175), and that among Dutch adolescents (N=307), participants with low perceived friend quality, more online communication predicted reduced depression at one-year follow-up (179). In a sample of college students (N=286), among participants with lower self-esteem, greater use of Facebook was associated with greater connectedness to the university community one year later (69; 187). The authors speculated that Facebook helps students with low satisfaction and low self-esteem overcome barriers to turn latent connections into real social connections, thus establishing bridging social capital (69; 187). Qualitative interviews from the follow-up study confirmed that Facebook "breaks the ice" and reduces the awkwardness of contact between casual acquaintances, thereby facilitating social connections (187).

The social compensation model is also analogous to the finding in a systematic review that adult cancer patients and survivors with poorer interpersonal relationships (i.e., low social support) at baseline generally benefit more from various psychosocial interventions (e.g., less intrusive thoughts following an expressive writing intervention, improved quality of life in physical function after a psychoeducation group, improved physical health after a peer support group and an education group, reduced depressive symptoms after a nutrition-focused psychoeducation program, increased social support after a coping program) compared to patients or survivors with stronger interpersonal relationships (193). This review, along with the social compensation model of online connection, both suggest that people without strong naturally existing face-to-face connections are most likely to benefit from alternatives, which may consist of formal support interventions or online activity.

ONLINE SUPPORT FOR CANCER

Internet usage among cancer survivors

Data from the National Cancer Institute's Health Informational National Survey (HINTS) indicate that between 2003-2008, slightly more than half of adult cancer survivors (median age 50-64) used the Internet, and Internet use is more common among those who are younger, non-Hispanic white, more highly educated, reside in metropolitan areas, and report better general health (41). Cancer survivors who are younger, more highly educated, and 2-5 years post-diagnosis are more likely to use the Internet as the first source of cancer information (41). Among cancer survivors age 18-49, 75.9% reported using the Internet. Although Internet usage is increasing in penetration among all age groups, the higher degree of Internet use among younger cancer survivors remains consistent with recent findings of the Pew Internet & American Life Project. As of May 2013, nearly all 18-29 year olds (98%) and 30-49 year olds (92%) use the Internet, compared to 85% of all American adults (229). Similarly, a review of online cancer support groups found that younger age is associated with greater likelihood of using the Internet for cancer-related information and online cancer support groups (107). Other factors associated with higher use of online cancer support and information include higher education, higher income, and female gender (107).

Expression of online cancer support

Online support groups are available for a variety of medical conditions, such as cancer, HIV/AIDS, multiple sclerosis, diabetes, depression, or dozens of other conditions (72; 215). Types of support offered in a wide range of online health communities parallel the types of support provided in-person: users of online communities express emotional support (empathy, understanding, encouragement), information (advice, referrals, situation appraisals, conveying factual information), esteem support (compliments, validation, relief of blame), network support (presence and companionship), and, least commonly, tangible assistance (7; 49; 50; 71; 142).

A review of online communities for adult cancer patients and survivors found that users of online cancer support communities participate in order to gain emotional support, seek information, and manage uncertainty about the future (107). Specific examples of information support by cancer survivors in online support groups include sharing strategies for dealing with side effects, learning what to expect with regard to treatment procedures, recommending particular treatments and medications, and exchanging experiences with alternative treatments (61; 80). Examples of emotional support include sharing philosophies for coping with cancer, expressing distressing emotions, and encouraging, nurturing, and valuing each other (80). Users of online discussion boards have described how these online communities reduce isolation and provided a unique place for users to feel understood and supported (50; 61; 80).

Online vs. in-person support

Although online cancer support groups offer the same types of support that people offer offline (e.g. emotional, tangible, information, esteem, network support), online cancer support differs from in-person support in several ways. Online support groups have several distinctive attributes (213): First, they are interactive, enabling the user to search for relevant content, participate actively in discussion, and self-navigate amid a wide array of available material (213). Second, they provide a perception of the presence of others, regardless of distance in geography or time (e.g. reading archived threads or messages still creates an immediate emotional sensation of another's presence) (213). This sense of presence may even enable the user to introject others' voices into his mind, such that the user reads the message as a dialogue with a character in his imagination, shaped by his own expectations, wishes, and needs (191). Third, they facilitate connections between the user and hundreds of others who have shared the same life experience whom the user otherwise might not have had the opportunity to meet in person (61; 213). Fourth, by facilitating communication with strangers, online support communities provide social distance, which enables users to overcome stigma, embarrassment, or ineffective support provided in-person by friends and family (79; 213). Fifth, online support communities provide anonymity and privacy, enabling the user to hide his or her identity as well as sociodemographic factors, symbols of status, aspects of physical appearance, or other factors that inhibit communication between people (191; 213). Sixth, online support communities provide "interaction management" -- the freedom to engage and disengage at will as well as the ability to edit messages (191; 213).

Online support groups have other practical advantages: They tend to be accessible regardless of physical limitations or illness, which might preclude attendance at in-person support programs; their number of participants is unlimited; and they are cost effective (215). Online support groups also enable participants to write expressively about their cancer experience, which may itself be therapeutic. Expressive writing interventions (not conducted online) lasting between 15-30 minutes per session on 1-5 days have been shown to improve quality of life, satisfaction with social support, physical symptoms, and benefit-finding in cancer survivors and other populations at 3-6 month follow-up (51; 54; 78; 138; 158; 215), although two studies found no effect on mood (78; 138), and one study found that the intervention only produced effects (reduced intrusive thoughts) in participants with low baseline emotional support (138).

Online support groups also have potential drawbacks including the absence of non-verbal cues in communication, the lack of quality control over medical information in unmoderated groups, the possibility of anonymity enabling disruptive or harassing exchanges, or displacement of real-life social contacts (215). A textual analysis of online support groups for breast cancer, fibromyalgia, and arthritis (N=27,384 postings) found that these potential drawbacks rarely occur (210). However, a textual analysis of an online support groups for Parkinson's disease (N=1013 postings) identified some problems including frustration over lack of replies, disappointment over the anonymity and lack of personal information about other users, distress over the sudden unexplained disappearance of other users, and frustration about the inadequacy of support that remains only online (7). Although this study could not report the age range and mean age of participants because data were taken from an anonymous online support group, it is likely that the users were older adults, because Parkinson's disease almost exclusively affects older adults (206). Therefore it is unknown whether these findings are age-specific.

In a systematic review of various formats of peer support interventions (including one-on-one face-to-face, one-on-one telephone, group face-to-face, group telephone, group Internet), group Internet peer-support interventions and one-on-one face-to-face peer support interventions produced the most consistent improvements in psychosocial functioning (findings by age group not reported) (99). The authors speculated that participants in Internet peer support groups benefited from the flexibility and convenience of online support as well as the extended duration of engagement with online support programs (99).

Who uses Online Support?

There is some evidence supporting the social compensation model of online interaction, namely that online support service use is higher among people with weaker offline support. Some of this evidence comes from the Comprehensive Health Enhancement Support System (CHESS), an online intervention for low-income breast cancer patients undergoing treatment within six months of diagnosis. Among breast cancer patients within 6 months of diagnosis invited to participate in CHESS (N=231), non-users and "lurkers" (people who posted fewer than two times) reported having greater social support and lower need for information at baseline than women who actively posted to the program (88). Among users of CHESS, women with lower functional and emotional well-being at baseline were more likely to give and receive emotional and informational support in the discussion group (90), and women with low perceived support were more likely to read emotional support messages (123). A small study of young adult survivors of childhood cancer age 18-29 (N=14) found similar results with an online social networking intervention. Participants with little social support from family and friends and low family interaction were more likely to participate actively in the site (147). These findings suggest that among people with a history of cancer, those without strong naturally occurring social support or social networks might participate more in formal online support interventions (88; 147).

Benefits of online cancer support

A cross-sectional study of 372 current cancer patients (mean age 42.5, age range not reported) using structural equation modeling found that online communication was associated with increased social interaction, which predicted social support in the model, which in turn predicted lower stress, better coping, and reduced depression (18).

The evidence on the impact of online cancer support groups is mixed: Some reviews found that online cancer support communities for survivors and/or current patients of a variety of cancers (including breast, prostate, colorectal, and ovarian cancer; no age range specified) increase empowerment, reduce unmet information needs, and reduce depression (99; 107). A review of online support groups for cancer survivors (definition of cancer survivorship and age range of participants not specified; cancer sites included breast, prostate, colorectal, and mixed cancer site support groups) found that online support interventions did not produce significant benefits (e.g. adjustment to cancer, health status, health-related quality of life, social support, or self-efficacy) but noted that the methodological weaknesses in reviewed studies made it impossible to draw firm conclusions (101). A review of different types of health-related online support groups (including diabetes, depression, kidney disease, and breast cancer) found mixed evidence of whether interventions improved depression or social support (72).

Barak and colleagues argued that many studies of online support groups with negative findings have focused on inappropriate outcomes (13). They argued engaging in online support groups primarily increases well-being in general ways (e.g. increasing empowerment, optimism, self-confidence) rather than by reducing specific areas of distress or causing particular therapeutic change in emotions, cognitions, or behavior. They explain that empowerment refers to sense of control, perceived capability to cope with challenges and overcome obstacles, and the ability to make personal decisions through accessing relevant resources (13). These authors argue that online support should focus on promoting adaptive coping rather than reducing distress or psychopathology. In the conceptualization of these authors, online support groups increase empowerment by enabling participants to reduce inhibition in communication, express their emotions through writing, share information and knowledge, develop a sense of belonging and social cohesion, and examine their decision-making processes (13).

The benefits associated with online support may vary according to the ways users engage in online support. A study of the Comprehensive Health Enhancement Support System (CHESS), an online intervention for low-income breast cancer patients undergoing treatment (N=231), found that use of information services on the online system (e.g. questions and answers, articles, resource directory) was associated with greater participation in health care and health information competence at 4-month follow-up, whereas more frequent use of communication services on the system (i.e., discussion board), was significantly associated with reduction in negative emotions at follow-up (86). This intervention study also found that expression of empathy on discussion boards was associated with a reduction of breast-cancer related concerns (e.g., breast cancer-related worry, side effects and symptoms, body image concerns) over 4 month follow-up (89).

Social Media & Cancer: New means of online support

Previous studies of online cancer support among patients and survivors have mostly examined online discussion boards but have not kept pace with developing Web 2.0 technologies such as Facebook or Twitter (101). It is unknown how research findings regarding the use of online support groups, which facilitate communication with strangers, would apply to the use of social network sites, which facilitate communication primarily with existing offline contacts (31). Cancer survivors have created hundreds of Facebook groups for information, support, and awareness, and patients have created collaborative knowledge repositories such as WikiCancer (35). However, there is little empirical research on how and why cancer survivors seek and receive online support using social media, the unique benefits and concerns associated with cancer-related social media use, how cancer-related social media use differs from online cancer support groups or in-person support, and the target audience of online communication using social media (e.g., how much cancer survivors are communicating over social media with other cancer survivors versus members of their own general social network).

Only a few previous studies have examined naturalistic use of social media for cancer support. One study conducted narrative analyses of YouTube videos identified by searching for "cancer survivor" or "cancer stories" (40). The videos illustrated themes of loss of control, the unexpectedness of a cancer diagnosis, and emotional responses to diagnosis (40). One study conducted qualitative analysis of 16 blogs of young women diagnosed with cancer (age range 23-39, mixed cancer sites including breast, colorectal, ovarian, Hodgkin lymphoma, sarcoma, and melanoma, blogs maintained for a median of 25 months, range 8-51 months) (116). Analysis of the blogs identified four groups of problems faced by the writers including pain and fatigue, insurance and financial problems, infertility, and posttraumatic symptoms and anxiety (116). Another study conducted a content analysis of breast cancer groups on Facebook (23). The investigators identified 620 breast cancer groups on Facebook, of which 44.7% were created for fundraising, 38.1% were created for awareness, 9% were created for product or service promotion related to fundraising or awareness, and only 7% (46 groups) were created for support (23).

One qualitative study explored social media use among teenagers age 12-18 (N=20) with unspecified chronic illness who were long-term patients (duration not specified) at a Canadian hospital (207). This study found that adolescents reported using a social network site (Facebook) to stay updated with school events and keep in touch with friends outside the hospital (207). Participants said that they do not post items about their illness on Facebook, preferring to project an image of normalcy on Facebook while sharing details about their illness face-to-face only with family and close friends (207). It is unknown how these findings would apply to young adult cancer survivors.

Since 2010, a small number of social media intervention studies for cancer survivors have been published (126). One such study was a small pilot of a social networking intervention for young adult cancer survivors age 18-29 (N=14) who were at least two years post-treatment (147). This private online community, accessible only to users, enabled participants to create a personal profile, share pictures and videos, create a blog, create and participate in group discussions, and exchange private messages with other participants (147). In a paper describing pre-intervention characteristics associated with program use, the authors found that users who had lower social support, lower interaction with family members, lower survivorship self-efficacy, and higher depression participated more actively in the program than users with high social support, interaction with family, or self-efficacy (147). The authors analyzed the content of videos posted by participants for portrayal of cancer identity and stereotypes (185). They found that self-perceived negative stereotypes about cancer survivors (e.g., inattentive, isolated, sad) were positively related to depression, whereas self-perceived positive stereotypes about cancer survivors (e.g., mentally strong, brave, able to cope, new insights) were positively related to cancer survivorship self-efficacy (185).

SUMMARY OF SECTION 3

Cancer patients and survivors have been using online support groups to access the same types of social support accessed in person, such as emotional support, informational support, esteem support, sense of belonging, and opportunity for nurturance by expressing empathy and providing toward others. Online support is characteristically different from in-person communication, in that it provides a perception of the presence of others, regardless of distance in space or time; it facilitates connections with hundreds of others who may share the same experience; it provides social distance that can help the user overcome stigma or embarrassment; and it enables the user to manage social interactions by engaging or disengaging at will. The social compensation model of online interaction posits that individuals with lower levels of in-person social support compensate for those social deficits through online communication. There is some evidence supporting the social compensation model among users of online cancer support, in that individuals with lower baseline social support appear to engage more in online cancer support interventions. Reviews of online support have found mixed conclusions about whether online support groups produce measurable positive outcomes on domains such as empowerment, unmet information needs, depression, adjustment to cancer, health status, health-related quality of life, social support, or self-efficacy.

It is unknown how findings from online cancer support groups would apply to Web 2.0 technologies (social media). There is limited literature on how cancer survivors use social media to access social support. Social media are distinct from online support groups in that some forms of social media, such as social network sites, facilitate online interaction with the individual's general network (e.g., friends, family, classmates, colleagues) rather than facilitating anonymous discussion between a community of strangers with a common specific concern. Because young adults are the heaviest users of the Internet and social media, both in the general population and among cancer survivors in particular, it is important to understand how young adult cancer survivors use social media to access cancer-related social support.

CHAPTER 4: Summary of Rationale

Young adults have been an understudied population in cancer survivorship research (2). They experience greater levels of distress and greater unmet information needs than older adult cancer survivors in several domains including tests and treatment, health promotion, side effects and symptoms, interpersonal and emotional well-being, insurance, and sexual function and fertility (19; 85). A median of 11 months post-diagnosis, over half of cancer survivors age 21-39 report that cancer has had a negative impact on their plans for having children, financial situation, body image, and sexual function and intimate relations, and nearly half (46-48%) report that cancer had a negative impact on their sense of control over their life (22). In addition, over 30% of cancer survivors age 21-39 report that cancer had a negative impact on plans for the future and goal setting, plans for work, plans for education, and dating (22).

In young adults, cancer is associated with social isolation and disruption of relationships (68; 110; 117; 194) at a stage in life when social relationships are central to healthy development (73). Social support is one of the most common coping strategies used by young people with cancer (128). Greater social support predicts reduced mortality in adult cancer survivors (162) as well as better adjustment, coping, and mood (82; 93; 132; 177; 208).

Taken together, these findings--higher levels of distress, unmet need, and negative impact among young adult cancer survivors; isolation that young adult cancer survivors experience during this phase in social development; and the well-known association between social support and psychological outcomes demonstrate the challenging puzzle of how best to bolster social support in this population in order to optimize survivorship outcomes. Three questions bear on this challenge. First, which categories of people (e.g., friends, family, other cancer survivors) provide support for young adult survivors, and what kind of support do they provide? Second, how do young adult survivors access support through different media, such as face-to-face contact and emerging communication technologies? Third, what are the benefits associated with each source and medium of support?

The first question--who provides support (i.e. which types of relationships, such as friends/family vs. other cancer survivors)—has received limited attention in the literature. Although the extensive need for social support in this population is well documented, very little research has distinguished between the benefits associated with different sources of support. Young adult survivors describe the importance of support from family and friends, but they also note that such support is often inadequate to meet survivors' needs for connection because of their inability to relate (117; 166). Young adult cancer survivors express a desire to meet other young adult survivors (166; 183; 226) but may have difficulty meeting other young adult survivors due to the lower base rates of cancer in the young adult age range compared to older adults. It has been suggested that experiential support, which is obtained from other people who have endured a similar trauma or crisis, such as a cancer diagnosis and treatment, is a unique and important type of support (183; 198). Participants in cancer support groups, including young adults, have described the benefits that such groups provide, including creation of a sense of community that mitigates against isolation caused by cancer; freedom to express thoughts and feelings that cannot be shared with friends and family; advice gleaned from others' shared experiences; and the opportunity to help others (202).

However, young adults do not rank professional support groups highly as a support need (226). Young adult cancer survivors frequently feel that they cannot relate to other cancer survivors who attend cancer support groups, who are often several decades older and have very different concerns related to their stage of life (117; 166; 183; 194). There is little prior research on how young adult cancer survivors obtain experiential support when young adult-specific support groups are unavailable, or when they choose not to attend formal support groups.

The second question--through what media young adults access support--has also received limited attention. Young adults with cancer express preference for Internet-based resources and services (167). Unlike in-person support groups, online support for cancer survivors is more convenient and accessible, because it is available at any time and any place with an Internet connection (24). Internet-based support may be especially appropriate for young adult cancer survivors because younger age is associated with higher prevalence of Internet access, both among cancer survivors (41) and in the general population (134). Previous studies of internet support groups found that younger cancer patients were more likely than older patients to participate in internet support groups when offered the opportunity (90; 106) and were more likely to offer emotional support within Internet support groups (123). Despite the high uptake of social media particularly among young adults in recent years, literature on online support among cancer survivors has focused on older web-based technologies (e.g., online support groups using discussion boards) rather than newer social media such as blogs and social networking sites (101), with a few exceptions (40; 116; 185; 205). No previous studies have explored how and why young adults access support online through different avenues (e.g., through personal blogs, general social networking sites such as Facebook, or cancer-specific websites such as Stupid Cancer and hospital-based support websites) or the differences between support accessed via social media compared with face-to-face support.

The third question--what are the benefits associated with social support--has been widely explored among older adult cancer survivors, but less so among young adult survivors. Further, there has been limited research that differentiates between benefits associated with various sources (experiential vs. primary group) and media (face-to-face vs. online) through which cancer survivors access support. The social compensation model suggests that people who have weaker offline social connections may benefit most from online social contact by using it to compensate for deficits in face-to-face relationships (127; 146). There is some evidence supporting the notion that breast cancer patients and young adult survivors of childhood cancer who have lower social support at baseline show greater use of online support interventions (88; 147). It is unknown how these findings would apply to young adult survivors, and whether they would carry over to dynamic online activity such as blogs or communication about cancer on social network sites.

Drawing from theory (stress-buffering hypothesis, Thoits' conceptualization of social support as coping assistance, social compensation model) as well as previous empirical evidence, a conceptual model was created for this study (Figure 1).

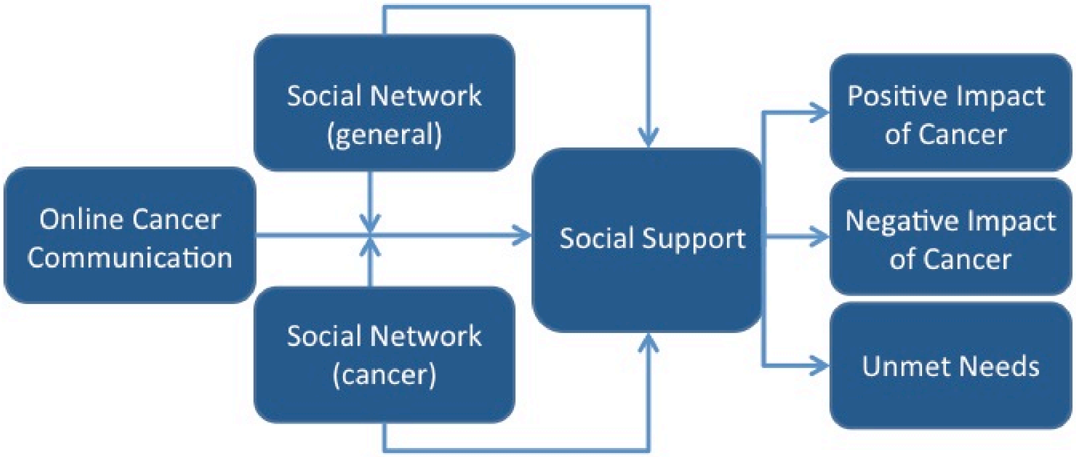


Figure 1. Conceptual Model

According to the model, online cancer communication is positively related to social support. Consistent with the social compensation model, offline social network involvement moderates the relationship between online communication and social support, such that online cancer communication is more strongly related to social support among individuals with weaker offline social network involvement (i.e., online communication enables individuals to compensate for deficits in offline contacts). Cancer-specific social network is calculated separately from the individual's general social network because it is theorized that others who have experienced the same stressor (i.e., other young adult cancer survivors) provide social support differently than one's primary group (i.e., friends and family). In the model, higher social support is associated with better survivorship adjustment outcomes, i.e. perceptions about how cancer made a long-term positive and negative impact on the individual’s life, as well as unmet needs.

In assessing the benefits associated with online and offline social activity and social support, this study focuses on two survivorship adjustment measures, unmet needs and perceived impact of cancer (i.e., positive and negative impact of cancer on several aspects of the young adult’s life). These two outcome measures reflect highly prevalent concerns among young adult survivors (19; 22; 25; 85; 115; 157; 166; 221). Further, theoretical mechanisms link social support with these survivorship outcomes. According to Cohen and Wills' buffering hypothesis (47) and Thoits' linkage of the buffering hypothesis with Lazarus & Folkman's conceptualization of coping (130; 196), social support can reduce the impact of a stressor such as cancer by helping the individual reappraise the stressor (thereby potentially affecting the perceived impact of cancer) and providing resources to manage the stressor (thereby reducing unmet needs). Although Thoits’ conceptualization is nearly 30 years old, it is still widely accepted and used, cited by over 350 peer-reviewed journal articles since 2010.

This conceptual model is analogous to the model tested in a study of blogging among new mothers (144). Using structural equation modeling, the investigators found that blogging (but not social network site use) was positively associated with feelings of connection to family and friends, which was positively linked with social support, which in turn was positively associated with marital satisfaction and negatively associated with several adverse psychosocial outcomes including marital conflict, parenting stress, and depression (linked with social support indirectly via parenting stress).

Therefore, the objectives of the present study are to: (1) identify the different sources of support for young adult cancer survivors (specifically, the differences between support from friends and family versus other young cancer survivors); (2) identify the different media through which young adult cancer survivors access support, including face-to-face interaction and new communication technologies; and (3) determine the relationship among sources of support, medium of support, and survivorship adjustment outcomes (positive impact of cancer, negative impact of cancer, and unmet emotional needs).

CHAPTER 5: Specific Aims

The overall intent of the project is to describe the different sources of social support accessed by young adult cancer survivors, the different media through which young adult survivors access support (i.e., online versus face-to-face), and the benefits associated with different sources and media of social support.

Aim #1: To describe, through a qualitative study, the ways in which young adult survivors communicate about cancer to access support online, including format of online communication, content of communication, and target audience.

Aim #2: To determine, through a cross-sectional survey, the association between online cancer communication, social network involvement, and social support.

Hypothesis 2a: Online cancer communication, general social network involvement will be positively associated with social support, and cancer specific social network involvement will be positively associated with social support.

Hypothesis 2b *(exploratory)*: Social network involvement will moderate the relationship between online cancer communication and social support. Online cancer communication will be more strongly associated with social support among those who have low social network involvement than among those who have higher social network involvement.

Aim #3: To determine whether social support is associated with impact of cancer and unmet needs.

Hypothesis 3a: Social support will be positively associated with positive impact of cancer.

Hypothesis 3b: Social support will be inversely associated with negative impact of cancer.

Hypothesis 3c: Social support will be inversely associated with unmet needs.

Aim #4: To determine whether social support mediates the relationship between social activity measures (online cancer communication, social network involvement) and survivorship outcome measures (impact of cancer and unmet needs).

Hypothesis 4: Social support mediates the relationship between online cancer communication, general social network involvement, cancer social network involvement, and outcome measures (impact of cancer and unmet needs).

CHAPTER 6: Methods

OVERVIEW

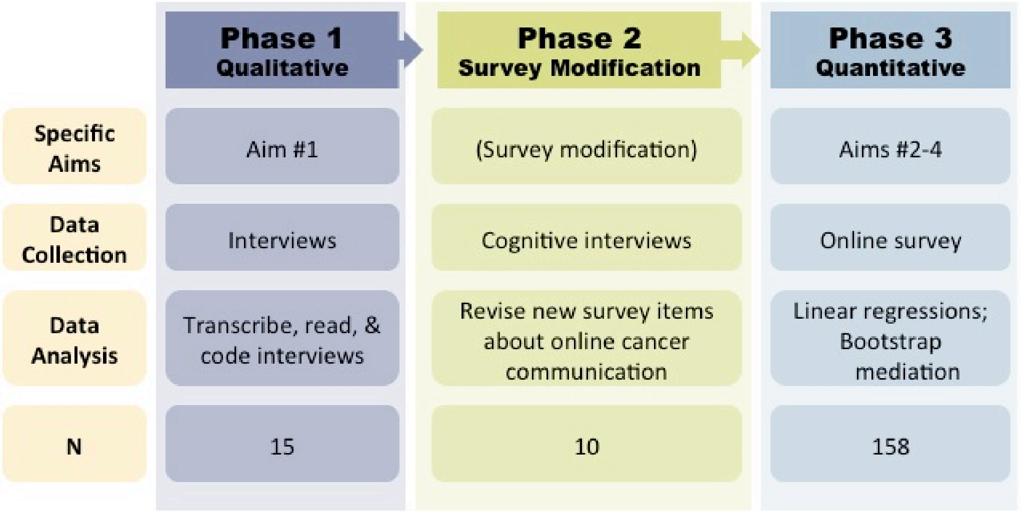
This doctoral research project used a mixed methods approach, which is defined as "the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration" (108) (page 123).

In Phase 1 of the study, the investigator conducted semi-structured interviews with young adult cancer survivors. The main purpose of this qualitative phase was to generate a list of online and in-person social activities through which young adult cancer survivors access support.

In Phase 2 of the study, the investigator used Phase 1 findings to write and pilot new survey questions asking about participation in these online and in-person activities. The investigator conducted cognitive interviews with young adult cancer survivors, which generated feedback that was used to clarify and refine the survey questions.

In Phase 3, the quantitative phase of the study, the investigator incorporated the newly written questions into a cross-sectional online survey that was distributed to a larger sample.

The sequence of study procedures is represented in Figure 2.



	Phase 1 Qualitative	Phase 2 Survey Modification	Phase 3 Quantitative
Specific Aims	Aim #1	(Survey modification)	Aims #2-4
Data Collection	Interviews	Cognitive interviews	Online survey
Data Analysis	Transcribe, read, & code interviews	Revise new survey items about online cancer communication	Linear regressions; Bootstrap mediation
N	15	10	158

Figure 2. Sequence of study phases

GENERAL PROCEDURES

The study was approved by the Institutional Review Board of the Uniformed Services University of the Health Sciences. IRB approval documentation and consent forms are attached in Appendix A.

Participants

In all phases of the study, inclusion criteria were: (1) diagnosis at age 18-38 with any type of cancer, except non-melanoma skin cancer (which is generally excluded in population-based mixed-cancer studies due to its lower severity than other cancers) (96; 113; 155; 192); (2) current age 19-39; (3) completion of primary treatment for cancer, including surgery, chemotherapy, and/or radiation therapy between 1-5 years prior to the study; (4) no diagnosis of any serious psychiatric or neurological co-morbidity (e.g., schizophrenia, dementia), and (5) English speaker (speaking English as a native language or having received an 8th grade education or higher in English). Inclusion and exclusion criteria were determined by completion of a self-report screening questionnaire (Appendix B).

Basic Measures

In all phases of the study, the investigator collected demographic information using questions from the Behavioral Risk Factor Surveillance Survey (39) and the Health Informational National Trends Survey (94) (Appendix C). Participants reported age, sex, marital status, education level, employment status, race, and ethnicity. General health status was assessed using a validated single item from the BRFSS (39). Cancer history was assessed with questions from the National Cancer Institute's Health Information National Trends Survey (HINTS) where available (94) (Appendix C). Participants reported cancer site, stage at diagnosis, year of diagnosis, time since completion of treatment, and type of treatment received (e.g., surgery, chemotherapy, radiation, bone marrow transplant).

Recruitment

In all phases, the investigator disseminated information about the study nationwide through fliers and web-based advertising (Appendix D) in cancer centers, support groups, community-based organizations, and national organizations that serve people diagnosed with cancer, with a particular focus on young adult-specific organizations. Representatives from those organizations published the link to the study on the organizations’ social media sites and email lists. A full list of organizations that assisted with recruitment appears in Appendix E.

PHASE 1: SEMI-STRUCTURED INTERVIEWS

Participants

The investigator used purposive sampling to recruit participants from a variety of settings, including community-based organizations as well as hospitals, with cooperation of representatives of local and national organizations that serve young adult cancer survivors. Potential participants were referred to the researcher, who screened for eligibility, and invited eligible individuals to participate in interviews. Participants were recruited to complete individual interviews until data reached saturation, defined as the lack of new thematic material (i.e. categories of online and in-person support activities) with subsequent interviews. Based on these past studies, the target sample size was 20, with a minimum sample size of 15 participants. Participants were offered a $25 gift certificate to Amazon.com in compensation for their time.

Data Collection

All interviews were conducted by the principal investigator. The first three interviews (one pilot and two regular interviews) were conducted in-person in a private room on the campus of Uniformed Services University of the Health Sciences. After the third interview, the researcher switched to conducting the subsequent 14 interviews by phone, which enabled the investigator to recruit participants from a broader geographic catchment area; include participants who were unable to attend an in-person interview (due to logistical constraints, physical limitations, or other barriers); and avoid having participants, many of whom may be facing infertility, feel inhibited or distressed by the researcher being visibly pregnant at the time.

Written consent was obtained for in-person interviews. In the phone interviews, participants were provided with the consent document (Appendix A) at least 24 hours before the interview. The investigator confirmed consent verbally by asking participants whether they had read the consent document, understood it, had any questions about it, and whether they consented to participate in the study and to be recorded. The investigator transcribed all interviews from the audio recording.

Study Instrument

The investigator conducted semi-structured interviews using an interview guide developed for this study (Appendix F). The interview guide contained a standard list of questions designed to be used flexibly over the course of the interview. The interview guide addressed sources of online and offline support, differences between support from various people (e.g., friends and family vs. other cancer survivors), communication about cancer using social media, and perceived benefits associated with various forms of support (offline, online, from different groups of people). Probes (e.g., "what do you mean by…" "tell me more about…") were used as needed for clarification. Each interview was transcribed from the audio recording.

Data Analytic Plan

The investigator performed qualitative description using a three step thematic analysis, a process described by Braun and Clarke (33). During Step 1, the investigator became immersed in the data by transcribing the interviews verbatim, re-reading the transcripts, and searching for meanings and patterns. Two graduate student assistants (clinical psychology doctoral students with experience in cancer survivorship) also read through all transcripts.

During Step 2, this investigator and the two graduate student assistants generated initial codes. Codes are labels applied to describe the most basic elements of raw data (words, phrases, or sentences), which were used to organize the data into meaningful groups. The graduate student assistants each coded half of the transcripts, so that two researchers (the investigator and one assistant) coded each transcript. Researchers independently read each transcript and created a list of codes describing all online and in-person support activities described in the interview. To create this list, coders did not use any pre-conceived coding categories. In Step 3, the three researchers compared each coder's list of activities in the transcripts and created a consolidated list of online and in-person support activities. The researchers then re-coded all of the transcripts using this consolidated list.

The study used several techniques to validate the qualitative data (143). First, the investigator used a systematic process for data analysis, thematic analysis as described by Braun and Clarke (33), that leaves a written audit trail so that analytic decisions may be followed and scrutinized by others. Second, the investigator worked with the two graduate student assistants to increase interrater reliability (to 96%). The researchers independently coded the transcripts, compared their findings, and resolved any discrepancies (164). Finally, the design deliberately incorporated a range of perspectives by recruiting from a variety of settings (e.g., community organizations, hospitals) and seeking an adequate variety of ages and diagnoses so that the findings are more broadly generalizable to young adult cancer survivors (143).

PHASE 2: SURVEY QUESTION DESIGN AND MODIFICATION

Phase 2 linked the qualitative information gathered in Phase 1 with the survey instrument disseminated in Phase 3. In this phase, the investigator used the list of online and in-person social activities from Phase 1 to design survey questions assessing participants' engagement in these activities.

Participants

To ascertain the comprehensibility of all newly developed or modified questions, the investigator performed cognitive interviews with 10 young adult cancer survivors. Although there are no strict conventions regarding the number of participants required for cognitive interviews, experts in this field have found that as few as five cognitive interviews may reveal important problems in survey questions that would otherwise be undetected (217). General cognitive interviewing guidelines call for 5-15 participants (17). Participants were recruited using the same procedures described for Phase 1.

Data Collection

Cognitive interviews were conducted using the "how to" guide by Willis (216). At least 24 hours before each interview, the investigator sent the participant an electronic copy of the draft survey questions and asked the participant to keep the draft survey questions accessible during the interview. Before beginning the interview, the investigator explained that she is interested in testing the questionnaire to fix items that are difficult to understand, hard to answer, or make little sense. The investigator emphasized that she is seeking feedback on participants' understanding of items and *process* in coming up with an answer rather than the participant's actual answer per se.

The investigator encouraged participants to be as “nitpicky” as possible to make the questions more clear and understandable.

The investigator instructed participants to read each survey question aloud, think about their answer to the survey question, and provide feedback on: (1) Comprehension: What they understood the question to mean, and what specific words or phrases meant, and (2) Retrieval from memory: The strategy they used to recall information to retrieve an answer (59). Participants were also invited to share other suggestions or comments on individual items or overall. The interviewer asked participants to think aloud during their response process and also probed concurrently, i.e., probed participants after reading each individual question. A combination of scripted and spontaneous probes were used to follow-up on unanticipated input from participants. When participants detected a problem with specific survey questions, the interviewer elicited their feedback about different ways of resolving the problematic questions. Interviews were conducted by telephone and were audio-recorded and transcribed. The investigator engaged in an iterative process of conducting cognitive interviews, adjusting the question wording in response to participant feedback, and then testing the revised questions.

Consent was obtained for Phase 2 using the same procedure described above for Phase 1.

PHASE 3: QUANTITATIVE SURVEY

PROCEDURES

Sample size

A minimum sample size of 80 was recruited. Sample size and power calculations were performed using the POWER procedure in SAS version 9.2. Power was calculated based on a multiple linear regression model with 16 independent variables (including demographic and medical variables as well as primary independent variables of interest) that jointly explain 25% of the variance in the dependent variable (R^2=.25). If one primary independent variable (in this study, social support) explains 10% of the variance in the dependent variable, so that the model R^2 with social support excluded is .15, a sample size of 79 observations will have 80% power to detect a significant association between the primary independent variable and each dependent variable (unmet needs and impact of cancer). This calculation further assumes a 5%, two-sided significance level and random distribution of the independent variables, as opposed to investigator-determined.

Estimates of the effect size were chosen based on a limited number of previous studies using this study's dependent variables (impact of cancer, unmet needs) as well as similar variables for which there is a wider body of previous literature available, including posttraumatic growth and quality of life. Previous studies of cancer survivors have found that social support explained between 6-14% of the variance in posttraumatic growth (32; 137; 177), 8% of the variance in the negative impact of cancer, (53), and 17% of variance in quality of life (174). Estimates of the variance in unmet needs and positive impact of cancer explained by social support were unavailable. Based on these previous findings, the investigator calculated sample size using an estimate that the multiple regression model will explain 25% of the variance, of which social support will explain 10%.

A more conservative power analysis based on a multiple linear regression model of 16 independent variables that jointly explain 20% of the variance in the dependent variable (R^2=.20), of which one independent variable explains 5% of the variance, would require a sample size of 146 observations to have 80% power to detect a significant association between the primary independent variable and each dependent variable. Therefore, the minimum sample size required for this study is 80 participants, with a target sample size of 150.

The sample size range produced by these power analyses (80-150) is consistent with the recommended minimum sample size determined to detect a mediated effect using bias-corrected bootstrap. Fritz and MacKinnon (77) performed a simulation which found that the bootstrap could detect a mediated effect with only 71 participants if the A path and the B path of the mediation model were each medium size (β=0.39). Alternatively, if the size of the A path and B path were smaller (β=0.26), a minimum of 148 cases would be needed to detect a mediated effect. Therefore a sample size range of 80-150 is also appropriate for this study's mediation analysis.

Data Collection

The web-based questionnaire (Appendix G) was available on a secure website hosted by surveymonkey.com. Participants completed eligibility screening and indicate informed consent before accessing the survey instrument.

Measures

In addition to demographic and medical information, the following measures were included in the survey:

Social Network (General)

Cohen's Social Network Index (SNI) (45) was used to assess social network diversity (number of social roles). This 12 item measure assesses the participant's number of social roles, defined by having contact at least once every two weeks with a person in each of the following social relationships: spouse/partner, parent, child, child-in-law, close relative, close friend, religious organization member, student, employee, neighbor, volunteer, other group member. The SNI may be scored on a scale of 0-12 to indicate presence or absence of each of the 12 relationship domains. In a sample of women with suspected coronary artery disease, the median value was 6 (173). The SNI appears in Appendix G.

Social Network (Cancer)

Relationships with young adult cancer survivors were assessed with newly developed survey questions from Phase 1 and 2. Participants were asked whether they ever had any of six types of in-person relationships with another cancer patient/survivor including receiving a formal mentor, receiving an informal mentor, serving as a formal mentor, serving as an informal mentor, having an acquaintance, or having an ongoing friendship (Appendix G).

Cancer Support Programs

Participation in cancer support programs was assessed with newly developed survey questions from Phase 1 and 2. Participants were asked if they ever participated in seven types of in-person support activities for cancer patients/survivors. The seven activities included completing a cancer-related athletic event, volunteering for a cancer-related organization or event, attending a camp or retreat, attending a lecture or conference, presenting at a lecture or conference, attending a social event (e.g., meet-up, dinner), and attending an in-person formal support group (Appendix G).

Online Communication (Cancer)

Engagement in online social activities related to cancer was assessed with newly developed survey questions from Phase 1 and 2. Participants were asked if they had ever done eleven types of online activities related to cancer including writing mass emails to family/friends about cancer, posting personal cancer-related updates on Facebook, visiting a Facebook group, posting on a Facebook group, visiting an online forum outside Facebook, posting on an online forum outside Facebook, writing a blog, reading another cancer patient/survivor’s blog or narrative, using Twitter to tweet (post) content, using Twitter to read content, or other cancer-related online activity (Appendix G).

Online Communication (General)

Participants' use of online communication for general (non-cancer) purposes was assessed using items from the Pew Internet & American Life Project (160) (Appendix G).

Social Support

Description of measure: Social support was assessed using the Social Provisions Scale (SPS) (57) (Appendix I). The measure contains 24 items and includes six subscales: attachment/intimacy (emotional support), reliable alliance (tangible support), guidance (informational support), social integration (belonging), reassurance of worth (esteem support), and opportunity for nurturance. The six subscales are based on Weiss' (214) theoretical description of the six functions provided by social relationships. Sample items include, "I feel a strong emotional bond with at least one other person," "There are people I can depend on to help me if I really need it," and "There is a trustworthy person I could turn to for advice if I were having problems."

Each item is rated on a 4-point scale and the total score or subscale scores may be calculated as the mean of the items in the scale.

Reliability and validity: Internal consistency estimates of the subscales are above .60, and the reliability of the total score is .915 (57). Low scores are predictive of loneliness, depression, and poor health status among teachers (172) and predict post-partum depression and low self-efficacy in first-time mothers (55; 58). Social integration, reassurance of worth, and guidance were all predictive of scores on the UCLA Loneliness Scale and accounted for 66% of the variation in loneliness among college students (57). Convergent validity was also established by finding that attachment/intimacy is related to satisfaction with romantic/dating relationships (beta=.547), social integration is related to satisfaction with friendships (beta=.317) (57). The factor structure of the subscales was evaluated through confirmatory factor analysis, which found that all factor loadings were statistically significant and ranged from .55-.99 (57). The investigator contacted one of the authors of the scale to inquire about test-retest reliability information, but he was unable to provide it.

Rationale for this measure: Although several measures of social support are available (Table 1, page 20), the SPS was chosen because, unlike other measures, it captures bidirectional support. It uniquely contains a scale for the opportunity to nurture or provide support *to others*, rather than only the types of support available *from others*. Previous research on online cancer support groups has suggested that bidirectional support (both expressing and receiving empathy) is predictive of reduction of cancer-related concerns over time (88).

Impact of Cancer

Description of measure: The impact of cancer was evaluated using the Impact of Cancer Scale, Version 2 (IOCv2) (52), which assesses the ways in which cancer has a positive and a negative long-term impact on the lives of survivors several years post-diagnosis (Appendix J). The IOCv2 focuses primarily on the problems, issues, and changes that long-term survivors attribute to their cancer history. It includes positive changes such as empathy, awareness of one's health, and sense of direction in life, as well as negative changes such as worry about health, body dissatisfaction, and disruption of life plans (52). The IOCv2 was validated on two samples, including a sample of breast cancer survivors (N=1188) age 34-89 (M=66.3, SD=10.1), who were assessed between 5-10 years post-diagnosis and a registry-based sample of non-Hodgkins lymphoma survivors (N=652) age 25-91 (M=62.7, SD=13.5) (53).

The measure comprises two higher-order subscales, a Positive Impact Scale and a Negative Impact Scale, each consisting of four subscales. The Positive Impact Scale includes subscales for Altruism/Empathy, Health Awareness, Meaning of Cancer, and Positive Self-Evaluation. The Negative Impact Scale includes subscales for Appearance Concerns, Body Change, Life Interferences, and Worry. Sample items from the Positive Impact Scale include "I do not take my body for granted since the cancer," "I have learned something about myself because of having had cancer," and "Having had cancer has given me direction in life." Sample items from the Negative Impact Scale include "I worry about my future," "I feel disfigured," and "Having had cancer keeps me from doing activities I enjoy."

There are additional scales for Employment Concerns ("I worry about being forced to retire or quit work before I am ready") as well as separate measures of Relationship Concerns for survivors who are partnered ("I worry about my spouse/partner leaving me if I were to become ill again") and those who are not partnered ("I worry about not having a spouse, partner, boyfriend, or girlfriend").

The IOCv2 comprises 47 items using a 5-point Likert scale as well as 3 screening questions. Subscale scores and higher-order scale scores are calculated as the mean of the responses for the items comprising that subscale or higher order scale. Therefore scales range from 1 (strongly disagree) to 5 (strongly agree), with 3 being neutral. In samples of breast cancer and non-Hodgkins lymphoma cancer survivors, mean values of higher-order scales were: Positive Impact Scale (3.5-3.7) and Negative Impact Scale (2.2-2.4). Mean values of subscales were: Altruism/Empathy (3.7-4.1), Health Awareness (3.7-3.8), Meaning of Cancer (2.8-3.0), Positive Self-Evaluation (3.9-4.1), Appearance Concerns (1.7-2.7), Body Change (2.5 in all samples), Life Interferences (1.9-2.0), Worry (2.6-2.7), Employment Concerns (2.4-2.7), Relationship Concerns/Not Partnered (1.5-2.0), Relationship Concerns/Partnered (1.4-1.6) (53).

Reliability and validity: The IOCv2 exhibits high factor loadings of the subscales in both domains (0.72-0.83 for subscales in negative impact domain, 0.73-0.80 for subscales in positive impact domain), high internal consistency (Cronbach's α of 0.76-0.89), and total congruence of 0.98 across split samples (52). In a sample of 1188 breast cancer survivors 5-10 years post diagnosis, scores were well distributed with no evidence of floor or ceiling effects (52). Correlation between the Positive Impact Scale and Negative Impact Scale was very low (r=0.19) (52). The measure shows good concurrent validity. The Negative Impact Scale is associated with depression (r=0.40) and breast cancer symptoms (r=0.42) in a sample of breast cancer survivors (52). The Positive Impact Scale is associated with post-traumatic growth (r=0.75) (53).

Rationale for this measure: The investigator chose the Impact of Cancer Scale as an outcome variable because it measures the long term problems (validated on sample 5-10 years post-diagnosis) and changes that cancer survivors experience years after diagnosis (52) that also encompass several of the psychological constructs that are theoretically affected by social support. Social support has been theorized to affect health by influencing appraisals of stressful situations (129), which in this context may include how a cancer survivor appraises the positive or negative impact of cancer on the survivor's life. Social cognitive views of social support theorize that social support is associated with self-esteem and self-efficacy, which parallel the IOCv2's subscales for Meaning of Cancer and Positive Self-Evaluation.

Unmet Needs

Description of measure: Unmet needs was measured by the Short-Form Survivor Unmet Needs Survey (SF-SUNS) (36). The SF-SUNS is a 30 item measure comprising four domains: information, work and financial needs, access and continuity of care, and emotional health & relationships. Sample items from each domain include "finding information about complementary or alternative therapies" (information needs), "worry about earning money" (work and financial needs), "having access to cancer services close to my home" (access and continuity of care), and "dealing with feeling depressed" (emotional health and relationships). Answer choices for each item are: 0 = no unmet need, 1 = low unmet need, 2 = moderate unmet need, 3 = high unmet need, 4 = very high unmet need.

Reliability and validity: The SF-SUNS was validated on a heterogeneous sample of 1,580 cancer survivors age 19 and older, who were between 12 and 60 months post diagnosis (36). Internal consistency is strong, with Cronbach's α for the domains ranging from .85 (information needs) to .95 (emotional health and relationship needs) (36). Because the instrument is new, currently there are no available data on test-retest reliability, predictive validity, or norms. The original SUNS established construct validity by conducting principal component analysis and only retaining items with factor loading greater than .50.

Rationale for this measure: Although unmet needs among young adult cancer survivors are widely documented in qualitative studies (157; 166) and survey studies (19; 115; 225), these survey studies have assessed prevalence of unmet needs in AYA survivors using unvalidated instruments. Review of the literature, as well as consultation with several young adult cancer researchers, revealed only one needs measure developed for and validated on AYA survivors who were diagnosed as adolescents or young adults (42). However, this measure was validated on a sample of only 139 participants, and it did not distinguish between patients undergoing active treatment or survivors post-treatment. The SF-SUNS was chosen because it was validated on a large sample of post-treatment survivors 1-5 years post-diagnosis, has demonstrated reliability and validity, and is shorter and therefore less burdensome than other measures.

Data Analytic Plan

All statistical analyses were conducted using IBM SPSS Statistics version 22 (1). Moderation and mediation analyses were conducted respectively using the PROCESS macro (92)and INDIRECT macro (165) for SPSS. The investigator first screened the data by identifying and handling missing data; identifying univariate and multivariate outliers; checking for multicollinearity by measuring bivariate correlations between main study variables; conducting tests for normality; and reviewing the distribution of variables. The investigator conducted preliminary descriptive statistical analysis to describe the sample's demographic and medical characteristics as well as the main study variables.

The investigator conducted preliminary analyses to determine which of the following demographic or medical variables should be retained as controls in the regression models: gender, education, race, employment, marital status, parenthood, general health status, cancer site, stage at diagnosis, time since diagnosis, time since completion of treatment, and type of treatment received. The investigator conducted separate regressions for each dependent variable of interest (social support, impact of cancer, unmet needs). Demographic and medical variables were retained in final regression models if they were significant at $p<.1$. Age was retained as a variable in all analyses as determined a priori.

The analytic plan for Aims #2-4 are listed below:

Study Aim #2: To determine, through a cross-sectional survey, how online cancer communication and social network involvement are associated with social support.

To test Aim #2, the investigator conducted a hierarchical linear regression analysis with social support as the dependent variable. Demographic and medical variables retained from preliminary analyses at p<.1 were added first to the model, followed by general social network involvement, then cancer social network and online cancer communication. To test an exploratory hypothesis about whether social network involvement moderates the relationship between online cancer communication and social support, moderation analysis was conducted using the PROCESS macro (92).

Study Aim #3: To determine whether social support is associated with impact of cancer and unmet needs.

To test Aim #3, the investigator conducted three separate hierarchical linear regression analyses with positive impact of cancer, negative impact of cancer, and unmet needs as the dependent variables. Independent variables entered into the model included demographic and medical variables retained from preliminary analyses and social support.

Study Aim #4: To determine whether social support mediates the relationship between social activity measures (online cancer communication, social network involvement) and survivorship measures (impact of cancer and unmet needs).

To test Aim #4, the investigator conducted mediation analysis using the bootstrap technique. Bootstrapping was developed by Efron (66) as a statistical technique that can be used on small samples and samples with non-normal distributions, which violate the assumption of theoretical sampling distribution. Mediation analysis estimates whether one variable X can account for a change in variable Y through a change in the mediating variable, M (14). Bootstrapping can be used to test a mediated effect by providing an estimate of the size of the indirect (mediated) effect (91). The mediated effect is calculated as *ab*, which is the product of the path coefficients of Path A (the association from X → M) and Path B (the association from M → Y). Bootstrapping is recommended as a mediation technique because it is more powerful than other methods and can detect a mediated effect using a smaller sample size (77); creates a more accurate confidence interval than other methods (140); and makes no assumptions about the distribution of the variables, unlike other methods (91).

Bootstrapping tests the mediated effect by repeatedly sampling from the obtained study sample of size N by selecting individual cases with replacement until a resampled data set of size N is obtained. In this resampled set, the path coefficients of a and b are calculated, as is the product ab. This process is repeated 5,000 times through computer simulation (165), and the 5,000 estimated products ab are ordered from smallest to largest. A 95% confidence interval is determined from this distribution. The lowest 2.5 percentile constitutes the lower bound of the confidence interval, and the highest 2.5 percentile constitutes the upper bound of the confidence interval. If the confidence interval does not contain zero, then the investigator concludes that there is a statistically significant mediated effect at $p<.05$ (91).

CHAPTER 7: Results

PHASE 1

Participants

Thirty three potential participants contacted the researcher. Ten respondents screened out as ineligible due to age or time post-treatment, and an additional six participants initially expressed interest in the study over email but did not respond to subsequent emails by the researcher. Seventeen interviews were conducted, including one pilot interview. One participant passed the screener but later revealed that she had completed primary treatment within one year of the interview and was therefore ineligible. Fifteen interviews were included in the final analysis.

The sample was mostly female (73%), white non-Hispanic (80%), and all participants had at least a college degree. Mean age was 30 years old at the time of the study. Approximately half (53%) of the participants were married or in a significant relationship. A broad variety of cancer types was represented, including breast, Hodgkins lymphoma, non-Hodgkin lymphoma, brain, sinus, thyroid, rectal, and leukemia. Mean time post-treatment was 33 months or 2.75 years, with a range of 12-58 months. A full description of the sample appears in Table 2.

Table 2. Phase 1 Participant Characteristics

Characteristic	**n = 15**
Gender	
Male	4 (26.7%)
Female	11 (73.3%)
Age	30 (4.72) Range 24-37
Race/ethnicity	
White, non-Hispanic	12 (80%)
African-American	2 (13.3%)
Hispanic	1 (6.67%)

Education	
College graduate	9 (60%)
Postgraduate	6 (40%)
Marital Status	
Married	6 (40%)
Living as married	3 (20%)
Single, never married	6 (40%)
Work Status	
Employed	12 (80%)
Out of work for more than 1 year	2 (13.3%)
Unable to work	1 (6.7%)
Time Post-Treatment	
Months post-treatment	29.2 (15.15) Range 12-58
Cancer Type	
Brain	1 (6.7%)
Breast	5 (33.3%)
Colon/rectum	2 (13.3%)
Leukemia	1 (6.7%)
Lymphoma, Hodgkin's	2 (13.3%)
Lymphoma, non-Hodgkin's	1 (6.7%)
Testicular	1 (6.7%)
Thyroid	1 (6.7%)
Other	1 (6.7%)
General Health	
Excellent	6 (40%)
Very good	4 (26.7%)
Good	4 (26.7%)
Fair	1 (6.7%)
Poor	0
Stage	
I	5 (33.3%)
II	1 (6.7%)
III	4 (26.7%)
IV	2 (13.3%)
Other	3 (20%)
Treatment	
Surgery	13 (86.7%)
Chemotherapy	12 (80%)
Radiation	7 (46.7%)
Bone Marrow Transplant	1 (6.7%)
Other	3 (20%)

Interview Conduct

All participants consented to be audio-recorded. Interviews ranged in duration from 32-97 minutes; median interview length was 57 minutes. As noted earlier, three interviews (including the pilot) were conducted in person and all subsequent interviews were conducted by phone.

Thematic Analysis

In qualitative interviews, YACS discussed how their support needs changed over time, and described the different types of support they receive from family and friends contrasted with support from other YACS, as well as the advantages and disadvantages of online support.

Care Transitions

Survivors described how their needs for support changed through their trajectory from patients in active treatment to post-treatment survivors. The same pattern consistently emerged across participants. During treatment, participants recalled need for intensive tangible support, which came from family and friends who served as caregivers. After completing treatment, participants felt more need to connect with a community of YACS. A female colorectal cancer survivor in her mid-twenties summarized the pattern as follows: “I mean I think while you’re in treatment you need a lot of active support, like making sure you get to your appointments, and just – someone checking up on you, making sure you’re eating, normal things like that, which is I think what usually falls to the caregivers, as far as parents and relatives and significant others. But once you get to the survivorship phase, I feel like it’s just finding that sense of community, and people that have been through similar things. “

After treatment ended, participants described a transition in their relationship with caregivers, in which family and friends expected them to go back to “normal” and did not recognize the long-lasting effect of cancer on the participant’s life. A female Hodgkin’s lymphoma survivor in her mid-thirties said: “Sometimes when I’m experiencing the long-lasting effects or PTSD, it’s kind of hard, because no one wants to hear about my cancer anymore, you know?" Similarly A female breast cancer survivor in her mid-thirties said of the post-treatment transition, "Yeah, that has been a little bit harder, because everybody thinks you're back to normal and you're not." A female non-Hodgkin's lymphoma survivor in her mid-twenties said, "The further you get out from chemo and cancer, the easier it is for people to forget that you had it. But it's harder because the farther out you get, you're like, "When is the next ball going to drop?"

While experiencing the withdrawal of support from family and friends, participants described emerging existential concerns and anxiety. For many survivors, these changes led them to seek connections with other YACS, through any combination of online and/or in-person activity. For example, A female breast cancer survivor in her late twenties described how her emerging needs for emotional support as a post-treatment survivor changed the content of what she posted in online support groups: "It switched from being more of this immediate need to understand what's going on with my body while I'm going though treatment and immediate fears and emotions that come along with that, to more of these further removed emotions about you know, having had cancer and integrating that into my identity, and what does that mean, and how do I go forward with my life, and so yeah, definitely the content of all of my online interactions has seen that shift. " Similarly, A male non-Hodgkin's lymphoma survivor in his early thirties described how his emotional needs in the survivorship period led him to seek out volunteer activities for cancer organizations: "Because then it was the matter of dealing with the anxiety of 'Is it coming back?' Being able to talk with people about that. And you know, just telling my story and using my story as a way to kind of inspire people to get involved, and educate people about what young adult cancer survivors are going through."

YACS Relationships

Participants cited several advantages of connections with other YACS encompassing several types of social support, especially sense of belonging, information/guidance, and nurturance. Participants also described how comparing themselves to other survivors shifted their attitude about their own condition, and also described some problematic aspects of connections with other YACS.

Sense of belonging

Participants described experiencing an instant connection or unspoken bond with other YACS. A female breast cancer survivor in her mid-thirties said, "There's just a connection, there's an immediate—'I know where you are, I know where you've been, I get you' kind of thing." Several participants described how knowing they shared this experience made it easy to feel connected when spending time with other YACS, even when the conversation did not address cancer per se. A female non-Hodgkin's lymphoma survivor in her mid-twenties noted, "We don't have to be judged on who we are. Because some people didn't have their hair, some people have real bad scars. So it was one of those things where, even if we're not talking about cancer, we don't have to worry about what everyone else is thinking. So it made it a lot easier to adjust. It was kind of like, almost an immediate friendship." A female colorectal cancer survivor in her mid-twenties observed that "doing more normal activities is more help than sitting around in a circle and talking about your week or whatever. I can go to my shrink and do that, talk about all that." She and other participants found that spending time with other

YACS in social settings helped them feel “normal” once again, after feeling alienated from their other peers.

Information/Guidance

Participants found it helpful to speak with other YACS for advice and guidance based on their experience. A female breast cancer survivor in her late twenties shared the multiple ways that YACS provide experiential guidance for one another: “People share their real experiences. And even the things that they’ve gone through, that even my doctor didn’t mention. Like, ‘this may be a problem,’ or ‘look out for this.’ Or, ‘your doctor may give you this medicine, but maybe you can try alternative or ask for, because that particular prescription has way more side effects.’ You can get the truth of getting back in the workplace, or the truth of relationships during and after therapy.”

Often guidance was most helpful coming from others with a similar disease profile when it involved decision-making about treatment or learning what to expect during treatment. YACS valued hearing the lived experiences of other YACS, which were more vivid and helpful than health care providers’ textbook descriptions of treatment side effects. Guidance could also be useful when sharing general resources for survivors of various types of cancers, such as financial aid, fertility preservation, or camps and retreats.

Nurturance

Participants spoke positively about their experiences helping other young adults with cancer.   Several participants noted how they were glad to give hope to other young adults diagnosed with cancer. A male brain cancer survivor in his mid-thirties said, “I think it’s very fulfilling. I mean, I came out on the other side of it by all accounts as good as possible. So it's nice to share some positive experience with people and let them know it really can be ok."   Likewise a male head and neck cancer survivor in his late thirties said, "I just enjoy being able to help out and give people the hope that they can get through it. I really enjoy those connections." Many participants described how mentoring other cancer patients created a sense of purpose out of an otherwise senseless experience. A female breast cancer survivor in her mid-thirties noted, "Just to be able to answer [my mentee's] questions and hear her say, 'Oh you sound so positive.' It makes you feel there's a reason all this happened, there's a purpose for it." For participants who had mentored others, this sense of purpose appears to be an important aspect of coping.

Helpful comparisons

Several participants found that seeing other YACS as positive or negative comparisons affected their attitude towards their own cancer. On the one hand, interacting with post-treatment survivors provided reassurance and a sense of hope for participants while they were newly diagnosed or going through treatment. Witnessing others' recovery after cancer provided inspiration and hope. A female breast cancer survivor in her late twenties said, "When I was first diagnosed, I read all these survivor stories online. And you know, it was really encouraging… when I read the survivor stories—'This woman was 25 and she found a lump and 2 years later, she's ok'—that helped me feel really good."

On the other hand, interacting with cancer patients who were worse off (e.g. experiencing a more severe diagnosis, worse treatment effects, worse prognosis) sometimes led to participants experiencing gratitude that their own situation was not as severe. A male testicular cancer survivor in his mid-twenties said:

"The first round of chemo that I had, I met somebody in the doctor's office… And the man told me he had colon cancer. And I didn't know much about colon cancer until I looked it up, and I saw how much more drastic it is, and how much more painful the after-effects of surgery might be…. For me, because thank God I wasn't such a drastic type of cancer, it was like—what's-it-called, it was having a little easier, seeing how hard it could be, and how hard it actually wasn't for me, compared to other situations."

Comparing his own situation to that of another cancer patient made the participant feel that his own condition was less severe and more manageable.

Disadvantages of YACS Relationships

Although every participant described helpful aspects of their connections with other YACS, half of participants mentioned at least one negative aspect of their interactions with other YACS. Difficult or problematic aspects of interactions with other YACS included feeling primarily identified by a cancer diagnosis as opposed to one's achievements, character, or interests; interacting with people who are mired in their cancer and cannot move forward with their own lives; triggering traumatic memories when interacting with other YACS; feeling guilty that one's diagnosis is not as severe as others; and generating anxiety when witnessing others experience recurrence or metastasis. The most painful aspect of friendships with other YACS was summarized by A female leukemia survivor in her mid twenties: "So I do think in some ways it's hard to deal with bad news. You know, people relapsing, people having irreversible side effects, people passing away."

Family/Friend Relationships

Overwhelmingly, participants cited tangible support during treatment as the primary expression of support from family. This support consistently included driving and accompanying the participant to medical appointments, cooking meals, taking care of children, staying overnight or hosting the participant to care for basic day-to-day needs. Only one participant noted that her family did not provide tangible support during treatment. Participants also described how friends provided emotional support and a sense of normalcy.   A female breast cancer survivor in her late twenties said, “They just help me kind of normalize things. They don’t have the same experience and they don’t really know what I went through. But they were there and said, ‘hey let’s watch a movie,’ and made me feel like life was still going on, and that was the support they’ve given.”

However, participants noted that support from family and friends had its limitations as well. The most common limitation cited by participants was that family and friends could not fully relate, having not experienced cancer first-hand. As A female leukemia survivor in her mid twenties summarized: “Even though caregivers are great and awesome and have been there, you go through it, they go through a different experience than having actually gone through it. And of course, depending on who you talk to, they’ll say ‘Oh cancer is terrible,’ and you can tell them what chemotherapy is like. You can tell them what your experience is like, what radiation is like. But they’re not going to fully be able to understand it.”

Several participants described how their cancer diagnosis distressed their family and friends, such that they (the participants) had to reassure and support their family and friends, which became tiresome if participants felt pressured to put up a falsely cheerful front. A female breast cancer survivor in her mid-thirties described: “There’s this strong desire for everything to be normal, and for me to be ok, when you’re talking to family. And there’s a lot of emotional baggage there. Because these are people who you’ve known for a long time, and they’re looking for support from you, and assurance from you. Whereas the breast cancer community, you can be real. You don’t have to put on a front.”

Online Communication

Participants varied widely in their use of online communication about cancer. Some eagerly engaged in a broad range of online activities, including writing blogs, posting about cancer on their own Facebook page, and participating actively in cancer-related Facebook groups and anonymous online forums. Others chose to eschew most online activity related to cancer. Despite these individual differences, common themes emerged regarding the relative advantages and disadvantages of online connection.

Ease of Use

The most commonly cited advantage of online communication was its practical ease of use, including efficiency, accessibility, immediacy, and broad reach. Particularly during treatment, many participants found it easier to disseminate medical updates via a blog or CaringBridge site. A male head and neck cancer survivor in his late thirties described how maintaining a CaringBridge page (a blog used by people with serious illness to inform family and friends of updates) “just made it much easier to get information out. I had a ton of surgeries, there was a lot going on. And there was – in the beginning it was painful because people were demanding to know what was going on, so I felt like that made things much easier.” Beyond just disseminating medical updates, many participants found online communication to be much more efficient overall. A female breast cancer survivor in her mid-thirties said, “I’m able to connect with people in so many different areas more time efficiently… And I think it offers the ability to connect to more people, talk to more people in a faster way.” She added that the efficiency of online communication enabled her to share more intimate details online than she would have been able to in person: “The details, the feelings, the kinds of things that I wrote in my blog—for the majority of people who read it, I wouldn’t have had time to sit down with them and express all that stuff in that much detail. So just the amount of information and the amount of people who are able to get that information, it just wouldn’t happen if it was only in person. I wouldn’t have the opportunity to sit and talk to people in that intimate way that I do in my blog.”

Availability at any time, in any place makes online interaction particularly useful for those who are too ill to leave home or the hospital, or who are too fatigued to engage in extended activity. A female thyroid cancer survivor in her early thirties said, “I do feel like online interactions have their place, especially for someone who is really sick and can’t get out of the hospital room.” The constant availability of online interaction makes it appealing even for those without physical limitations. A female breast cancer survivor in her late twenties described how the immediacy of online connection provided instant gratification as soon as she craved social contact: “If at 9am on a Wednesday I’m feeling [expletive] about once thing or another—excuse my French—then that’s why I would go on Facebook. So with the in-person interactions, I mean, I guess I could call someone at 9am on a Wednesday if I wanted to, but it’s much easier to go on Facebook and post something there. And then you know, inevitably there’s always someone on Facebook at any time if you go on, so someone can give you an immediate response at any time. So it kind of caters to that like immediacy, the need for instant gratification."

Participants also described how communicating online provides access to a very large pool of people, making it easier to find information from others who have been through a similar experience. A male testicular cancer survivor in his mid-twenties said, "If I ask 10 people that I know about cancer, you know, I might not find an answer that I want. But if I ask a forum of 1,000 people, chances are I might get that answer that will make me feel better, or the answer that I'm looking for. "

Emotional and Social Aspects

Participants also described how online communication facilitates emotional expression and overcome inhibitions to social connection. A male brain cancer survivor in his mid-thirties noted, "Maybe somebody is shy and they don't like talking about it, but they can type about it. Some people are not good at talking to people they don't know, face to face. But online, it seems to bridge that gap." Several participants noted how the anonymity of online interaction reduced their inhibitions, making it possible to ask embarrassing questions that they would not have asked in person. A female colorectal cancer survivor in her late twenties said that when she was first diagnosed, "I wasn't sure that what other people were—if they were kind of scared of the same things I was, that you kind of have that anonymity behind your screen. You can ask questions that maybe you wouldn't ask in person. Things that you find embarrassing, or things that you think necessarily aren't questions that you'd want to ask in person. " Some participants also found therapeutic value in expressing themselves online through writing. A female breast cancer survivor in her late twenties said, "I wanted to write about my experience, and I knew that writing would be therapeutic. Writing is a good way to make sense of emotions for me. It just kind of helps to organize things when I can write it out in words. So it's a way of expression and kind of working things out in my head, and turning something from an emotion into something more concrete."

For some participants, writing online created new helpful social interactions. A female breast cancer survivor in her late twenties said, "I've had people comment on my blog and say, 'Oh, I had a double mastectomy as well, and I had complications, and it's nice to know that I'm not alone.' I wrote this one blog about having children, and that's generated a lot of comments actually. And I thought that was really neat, that I started a conversation about something that's important to me and clearly important to other people. Yeah, so it's been good for myself with the ability to express through writing, but also for the interactions that it's brought about."

Drawbacks of Online Communication

Despite the multiple ways in which online communication led to helpful social interactions for participants, participants also identified limitations and downsides of online interactions. One theme was the anxiety generated by online forums: anxiety from misinformation; anxiety from wondering about the consequences of disclosing cancer on Facebook; anxiety generated by reading negative posts by individuals in poor physical or emotional health. A female breast cancer survivor in her mid-thirties described the consequences of reading 'horror stories' online: "And then you have people who have posted absolute horror stories. People who had some kind of terrible adverse reaction to their breast implant and got a terrible infection and had all of these horrible complications post-surgery. That can happen, but it's very rare. I think sometimes when you're looking at those types of blogs or posts that people mean to be helpful, it makes it seem like there's a far greater chance of that happening to you. So it's hard to figure out the scale or scope of some of the things that are discussed online." These drawbacks of online interaction led several participants to limit their use of some online communication tools, such as discussion boards.

Analysis: Identification of Items

Aside from thematic findings addressing the first qualitative aim of the study, the interviews were used to generate items for the Phase 3 survey. After transcribing all interviews, the investigator read and coded all transcripts with the assistance of two additional coders. Together the three coders compared the preliminary list of activities in the transcripts created by each coder and created a consolidated list of online and in-person support activities. The investigator then created a coding guide using the consolidated list of 15 online support activities and 12 in-person support activities, with an operational definition of each activity. The principal investigator re-coded all transcripts and the second coders each coded half of the transcripts using the new coding guide. The principal investigator reviewed discrepancies between coding and met with the other coders to review discrepancies. Initial agreement was 73%. Coders reviewed discrepancies and reached consensus when possible. The new interrater reliability rate was 96%.

The investigator compared the semi-final list of online support activities against survey items created by the Pew Internet Research Project, which "aims to be an authoritative source on the evolution of the internet through surveys that examine how Americans use the internet" (159). After this comparison, the investigator consolidated or eliminated survey items about online activities that did not clearly map onto Pew items. The investigator reviewed the list of semi-final list of survey items with the two additional coders/readers to further address redundancy, unclear wording, question ordering and excessively complicated questions. Tables 3 and 4 display the original list of items together with coding guide, the number of transcripts in which an item appeared, and notes about which items were revised or eliminated in the final draft of survey items.

Table 3. Coding Guide: Online Activities

#	Activity	Definition	# of transcripts with activity	Final Status for Phase 2
1	Created or worked on your own online journal or blog	Writing your own free-standing blog. DOES NOT apply to CaringBridge, Facebook updates, etc.	6	Kept, collapsed with #2. See below.
2	Created or worked on your own CaringBridge site, or had a family member create or work on a CaringBridge site on your behalf (e.g., a personal site hosted by a web service for people experiencing health events such as cancer).	CaringBridge site or a similar service. DOES NOT apply to a general blog or FB.	3	Collapsed together with item #1: Considered to be excessively splitting
3	Read another cancer survivor's stories online (blog, online narrative, etc.)	Applies to any activity involving reading another cancer survivor's individual story online. Can include reading personal blogs, reading narratives or stories posted on a website like LiveStrong or the American Cancer Society, etc.	8	Kept
4	Had your cancer story featured on a cancer-organization's website.	Applies when an organization like a hospital, cancer-related foundation or coalition, etc. featured your cancer story on their website. Can include video and/or written narrative of your story. Also can include having an organization like Stupid Cancer publicize your blog on their website.	4	Eliminated: Considered to be confusing, did not map onto a Pew item.
5	Posted on a Facebook group for people with cancer	Includes posting an update, link, or comment on a FB group. Does NOT include passive activity ("liking" the group, etc.) ***Can be young adult specific (Stupid Cancer, Young Survival Coalition, Ulman, SAM Fund) or not (Breast Friends, Team Fight, FORCE, FACES, Leukemia and Lymphoma Society).	9	Kept
7	"Lurked" (viewed content without posting) on a Facebook group for people with cancer.	Some passive activity (liked the group, member of a private group, viewed content) but did not post new content.	11	Kept
8	Posted a cancer-related content on your own Facebook page	Can include: • Writing a cancer-related status update (e.g., celebrating an anniversary, announcing a clear scan, discussing cancer)	8	Kept

		- Posting pictures of yourself in treatment - Using FB as a platform to fundraise (e.g., posting link to your own Team-in-Training website to raise money for a race) - Posting cancer-related article links		
9	Had individual contact via Facebook with other cancer survivors you met online	Includes: Becoming Facebook friends, exchanging messages via Facebook. Applies to individuals you first MET ONLINE e.g., in an online support group, on Facebook, via email introduction.	5	Collapsed to encompass any one-on-one online contact. Considered too confusing by itself.
10	Had individual contact via Facebook with other cancer survivors you first met in person.	Includes: Becoming Facebook friends, exchanging messages via Facebook. Applies to individuals you first physically met in person BEFORE having online contact.	5	Collapsed to encompass any online contact.
11	Posted on an online discussion board (not through Facebook) for people with cancer	Contributed a post on discussion boards hosted on freestanding websites, NOT groups hosted on Facebook. Can be young adult specific (Planet Cancer) or not (e.g. breastcancer.org).	8	Kept
12	"Lurked" (viewed content without posting) on an online discussion board (not through Facebook) for people with cancer	Applies to passively viewing content without posting. Only discussion boards that are not on Facebook.	8	Kept
13	Used Twitter to view cancer-related content posted by others.	Includes following others on Twitter or otherwise using Twitter to access links, articles, or cancer-related materials.	2	Kept
14	Used Twitter to share cancer-related content.	Includes re-tweeting cancer-related content, posting links to your blog or cancer-related fundraising page.	3	Kept
15	Participated in a private online group for participants in a specific program (e.g., online group for members of Team in Training, alumni of First Descents, patients at a specific hospital)	Has to be private and restricted to people who participated in some kind of offline activity together.	1	Eliminated. Considered to be very confusing, did not map onto a Pew item.

Table 4. Coding Guide: In-Person Relationships and Activities

#	Activity	Definition	# of transcripts with activity	Final Status for Phase 2
1	Informal brief contact with another person with cancer (e.g. patient or survivor)	Includes informal contact. DO NOT count interactions that occur SOLELY over the course of a formal organized support group, program, mentor-mentee relationship, etc. BRIEF means very time-limited isolated contacts (e.g. exchanging one or two emails, going out to coffee once), not an actual extended relationship. This may entail being introduced by a mutual friend/acquaintance because both people had cancer, or sustaining some sporadic contact with another survivor after meeting at a formal event. Contact MUST be two-way. Doesn't count if you send out an email into the abyss without ever getting a response. Contact must be individual (i.e. not just communicating in a group setting) but can include phone, email, text, or in-person contact.	14	Kept
2	Informal relationship with another person with cancer (e.g. patient or survivor)	Includes informal contact. DO NOT count interactions that occur SOLELY over the course of a formal organized support group, program, mentor-mentee relationship, etc. RELATIONSHIP means some kind of continuous contact beyond a single coffee date or one or two emails. Some examples: • Someone you already had a relationship with outside of cancer (like a coworker, friend, classmate) • Someone you were introduced to by a mutual friend/acquaintance just because of cancer • Someone you initially met at a formal cancer-related program or activity, but then became friends afterward Contact must be individual (i.e. not just communicating in a group setting) but can include phone, email, text, or in-person contact.	13	Kept
3	Volunteered as a mentor in a one-on-one cancer patient/survivor matching program (e.g., Imerman Angels)	Includes any kind of formal organized one-to-one matching program. Count this ONLY if the person has actually been matched with a mentee, not if they're just waiting to be matched. Contact may take place in-person, email, phone, text, etc.	3	Kept

4	Requested to receive a mentor in a one-on-one cancer patient/survivor matching program (e.g., Imerman Angels)	Note that this usually a patient in treatment who requests to be matched with a cancer survivor as a mentor/buddy. Contact may take place in-person, email, phone, text, etc.	3	Kept
5	Participated in a cancer-related athletic training program, race, or event.	This can include enrolling in a training program targeted at cancer survivors and/or completing an athletic event (running, biking, triathlon, etc.) that benefits a cancer-related organization. Examples include Ulman's Cancer to 5K, Team in Training, Race for the Cure, Breast Cancer 3-Day Walk etc.	8	Kept
6	Attended or spoke at a cancer-related conference, lecture, workshop, or educational event.	Includes serving on a panel, being a guest speaker at an event, attending a workshop or educational session, attending a conference. May be young adult specific (e.g., Stupid Cancer) or not.	11	Separated into two items (attended vs. spoke) to parallel active vs. passive online items
7	Attended an organized social/recreational outing for cancer survivors (e.g., happy hour, movie, dinner)	Refers to organized social events for young adult cancer survivors. Doesn't need to have a formal facilitator present (in fact they usually don't.) Sometimes participants refer to them as "support groups," but note that these occur in real-world settings like bars, restaurants, theaters, etc.	7	Kept
8	Attended an overnight camp or outdoor/wilderness program for cancer survivors (e.g., First Descents)	The most commonly cited program in these interviews is First Descents, which entails a week of kayaking or rock-climbing. However this could also refer to overnight camps.	5	Kept
9	Attended a formal, in-person professionally facilitated support group for people with cancer	This refers to traditionally structured support groups, generally facilitated by a mental health professional, held on a regular basis (weekly, monthly, etc.) based at a hospital or community support organization.	8	Kept
10	Participated in a wellness program for people with cancer.	This includes yoga, meditation, art therapy, or other wellness activities.	4	Kept
11	Volunteered or worked for a cancer-related organization	Examples: Served on an advisory board, worked for an organization in some capacity not captured by other items. (Don't code this if they signed up to be a mentor, or fundraised for an athletic event).	6	Kept

PHASE 2

Participants

Participants were recruited using the same methods described in Phase 1. Nineteen potential participants expressed interest in participating in Phase 2 of the study. Four potential participants were screened out as ineligible because they were diagnosed earlier than age 18, completed treatment more than five years ago, or were still undergoing treatment. An additional five potential participants initially expressed interest in the study over email but did not respond to subsequent emails by the researcher. One pilot test was conducted with a young adult cancer survivor who is a clinical psychologist with research experience in cancer survivorship.

Ten cognitive interviews were conducted by telephone by the principal investigator. The sample consisted of 9 females and 1 male. Five participated in Phase 1 as well. Average age was 29 years. The large majority of the sample was Caucasian non-Hispanic (9 out of 10), had completed a college degree (9 out of 10), and was married or living as married (8 out of 10). Participants had a broad range of cancer types including breast, colorectal, germ cell, Hodgkin's lymphoma, non-Hodgkin's lymphoma, and thyroid cancer. Average time since treatment was slightly more than 2 years (27 months), with a range of 12-40 months (1-3.3 years) post-treatment. Full sample descriptives appear in Table 5.

Table 5. Phase 2 Participant Characteristics

Characteristic	**n (%) or Mean (SD)**
Gender	
Male	1 (10%)
Female	9 (90%)
Age	29 (4.69) Range 22-39

Race/ethnicity	
White, non-Hispanic	9 (90%)
Hispanic	1 (10%)
Education	
Some college	1 (10%)
College graduate	5 (50%)
Postgraduate	4 (40%)
Marital Status	
Married	6 (60%)
Living as married	2 (20%)
Single, never married	2 (20%)
Work Status	
Employed	6 (60%)
Out of work for more than 1 year	1 (10%)
Unable to work	1 (10%)
Homemaker	1 (10%)
Student	1 (10%)
Time Post-Treatment	
Months post-treatment	26.9 (13.88) Range 12-56
Cancer Type	
Breast	2 (20%)
Colon/rectum	2 (20%)
Germ cell	1 (10%)
Lymphoma, Hodgkin's	1 (10%)
Lymphoma, non-Hodgkin's	1 (10%)
Thyroid	3 (30%)
General Health	
Excellent	2 (20%)
Very good	6 (60%)
Good	1 (10%)
Fair	1 (10%)
Poor	0
Stage	
I	2 (20%)
II	1 (10%)
III	2 (20%)
IV	3 (30%)
Other	2 (20%)
Treatment	
Surgery	10 (100%)
Chemotherapy	7 (70%)
Radiation	5 (50%)
Bone Marrow Transplant	1 (10%)
Other	1 (10%)

Interview

Consent was confirmed verbally on the phone using the same procedure described in the methods for Phase 1. All interviews were audio-recorded. Interviews ranged in duration from 29-86 minutes; average interview length was 52 minutes.

Results

Participant revisions generally addressed clarity, consistency, elimination of redundancy, and inclusion of examples. Other major changes included addition of response category differentiating between three points in time (before finishing treatment, after finishing treatment, and in the last 30 days), and differentiation between individual cancer survivor peer relationships and group activities.

Consistency: Formatting and word choice were made more consistent. The term "cancer patients/survivors" was used uniformly in the final questions. Previous question drafts used a variety of terms such as "survivors," "people with cancer," "young adult with cancer," "cancer patients/survivors." Formatting was made consistent to make questions easier to follow.

Ordering: Question ordering was altered to improve participant comprehension of questions.

Examples: Participants suggested adding specific examples to questions wherever possible to increase clarity.

The full list of original draft survey questions at the start of Phase 2 and final draft survey questions at the end of Phase 2 appear in Tables 6-8.

Table 6. Original and Final Draft Questions About Online Activities

#	Original Question	Final Question	Comments
1	N/A	**Wrote mass email updates about cancer to your family/friends**	Was suggested to be added as an alternative way of communicating via online writing.
2	Posted personal cancer-related content on your own Facebook page (Examples: status about your cancer treatment, link to your cancer-related blog.)	**Posted personal cancer-related updates on your OWN Facebook page** (e.g. status update about your treatment or symptoms, link to your cancer blog)	▪ The word "content" was confusing, so switched to "updates." ▪ OWN was capitalized to visually distinguish from Facebook groups. Examples were clarified.
3	Visited a Facebook group for people with cancer, even if you did not post	**Visited but did NOT post or comment on a Facebook group for cancer patients/survivors** (e.g. Stupid Cancer Facebook group)	▪ Made mutually exclusive with the next question. Provided a specific example.
4	Posted on a Facebook group for people with cancer	**Posted or commented on a Facebook group for cancer patients/survivors** (e.g. Stupid Cancer Facebook group).	▪ Specified "posted or commented" because participants noted the distinction. Provided a specific example.
5	Visited an online discussion board for people with cancer (not through Facebook), even if you did not post	**Visited but did NOT post on an online forum for cancer patients/survivors** (not through Facebook, e.g. Planet Cancer, cancer.org).	▪ Made mutually exclusive with the next question. ▪ Switched "discussion board" to "forum" to be more concise and clear. Provided a specific example.
6	Posted on an online discussion board for people with cancer (not through Facebook)	**Posted or commented on an online forum for cancer patients/survivors** (not through Facebook, e.g. Planet Cancer, cancer.org).	▪ Switched "discussion board" to "forum" to be more concise and clear. ▪ Specified "posted or commented" because participants noted the distinction. Provided a specific example.
7	Created or worked on your own online journal or blog (including sites such as CaringBridge)	**Created or worked on your own online journal or blog about cancer** (including sites such as	Specified that it is about cancer

		CaringBridge).	
8	Read another cancer survivor's stories online. (Examples: Blogs, videos, narratives on cancer websites).	**Read or viewed another cancer patient/survivor's online journal, blog, or narrative**	▪ "Stories" was confusing. Question was moved below the questions about online forums to clarify the distinction.
9	Tweeted cancer-related content	**Used Twitter to tweet about cancer** (e.g. update about your treatment or symptoms, link to your cancer blog).	▪ "Content" was confusing, switched to "about cancer" ▪ Added term "Used Twitter" to be parallel with other items Provided examples
10	Use Twitter to read/view cancer-related content tweeted by others	**Used Twitter to read updates or posts about cancer** (e.g. cancer news stories, cancer-related events)	▪ "Content" was confusing, switched to "read updates or posts about cancer" Provided examples
12	Exchanged individual online communication (such as becoming Facebook friends, exchanged emails) with other cancer survivor(s) you <u>met in person</u>.	**Deleted**	This question was very confusing to participants. It was unclear whether this question included relationships that were first formed online as well as relationships that were first formed in-person. It was also considered redundant with the set of questions about in-person relationships. Therefore it was deleted.
13	Exchanged individual online communication (such as becoming Facebook friends, exchanging emails) with other cancer survivor(s) you <u>met online</u>.	Communicated online one-on-one (e.g. email, gchat, Facebook message)* *See note in right column	▪ This question was confusing to participants because it was clunky and awkwardly worded. Participants also wondered how to classify phone calls or text messages with other survivors whom they met online. ▪ Instead, the researcher created a new separate set of questions asking about individual contact between survivors who met online. ▪ The separate question set gave the prompt, "**Thinking about other cancer survivors you first met online (through email introduction, in an online group, etc.), Please tell me if you've ever talked back and forth more than once in the following ways:"** The items following that prompt were: Communicated online on-one-one (e.g. email, gchat, Facebook message); sent and received phone calls or text messages; met in person
14	Other	**Other online communication about cancer** (e.g. had your story featured on a website; webinar; mobile apps).	▪ Specified ▪ Provided examples.

Table 7. Original and Final Draft Questions About In-Person Relationships

#	Original Question	Final Question	Comments
1	Received a mentor or “buddy” in a one-on-one cancer patient/survivor matching program. (Example: Imerman Angels)	**RECEIVED a formal cancer patient/survivor mentor** (e.g. in a one-on-one matching program like Imerman Angels, YSC SurvivorLink, hospital-based program)	▪ Added “formal” to distinguish from the next question. ▪ Provided more examples.
2	**N/A**	**RECEIVED an informal cancer patient/survivor mentor** (e.g. introduced by a mutual friend)	Added new question because many participants described informal mentoring, were confused about whether to include it in previous item.
3	Volunteered to be a mentor or “buddy” in a one-on-one cancer patient/survivor matching program (Example: Imerman Angels)	**SERVED AS a formal cancer patient/survivor mentor** (e.g. in a one-on-one matching program like Imerman Angels, YSC SurvivorLink, hospital-based program)	▪ Switched “volunteered” to “served as” because many participants signed up but never actually were matched with a mentee. ▪ Added “formal” to distinguish from the next question. ▪ Provided other specific examples.
4	**N/A**	**SERVED AS an informal cancer patient/survivor mentor** (e.g. introduced by a mutual friend)	Added new question because many participants described informal mentoring, were confused about whether to include it in previous item.
5	Aquaintance or friend with another young adult with cancer	**Had other limited in-person informal contact with another cancer patient/survivor(s)** (e.g. went out for coffee once or twice, hung out at an event, just talked)	▪ Separated into two question to break out acquaintances and friendships. ▪ Used the words “limited” and “informal” ▪ Provided examples.
6	**N/A**	**Had an in-person ongoing friendship with another cancer patient/survivor(s)**	▪ Separated from previous question ▪ Added the word “ongoing” friendship to clarify that it did not need to be a new friendship forged in each time period
7	Other (please specify)	**Other connection (please specify)**	▪ Added word “connection”

Table 8. Original and Final Draft Questions About In-Person Activities

#	Original Question	Final Question	Comments
1	Completed a cancer-related athletic event (Examples: training program, fundraising walk, run, triathlon).	**Completed a cancer-related athletic event** (e.g. Team in Training, Relay for Life)	▪ Switched examples to be specific.
2	Volunteered for a cancer-related organization	**Volunteered for a cancer-related organization or event** (e.g. fundraising, staffing a booth at an event)	▪ Added "or event" to include sporadic volunteer activities. ▪ Provided examples.
3	Attended an overnight camp, retreat, or outdoor adventure trip for cancer survivors (Example: First Descents).	**Attended a camp, retreat, or outdoor adventure trip for cancer patients/survivors** (e.g. First Descents)	▪ Eliminated the word "overnight" to include day-time retreats.
4	Attended a cancer-related lecture, conference, workshop, or educational event Attended a wellness program for cancer patients/survivors (e.g., art therapy, yoga, meditation)	**Attended an in-person lecture, conference, workshop, educational event, or wellness program for cancer patients/survivors** (e.g. OMG Summit, Look Good Feel Better, nutrition class)	▪ Combined two questions because participants had difficulty distinguishing between them. ▪ Provided specific examples.
5	Spoke at a cancer-related lecture, conference, workshop, or educational event	**Presented at an in-person cancer-related lecture, conference, workshop, educational event, or wellness program for cancer patients/survivors**	▪ Changed "spoke" to "presented" to clarify
6	Attended a social event for cancer survivors. (Example: Happy hour, dinner, movie).	**Attended a social event for cancer patients/survivors** (e.g. meet-up, happy hour, dinner, movie)	▪ No changes other than formatting
7	Attended a formal support group led by a mental health professional	**Attended an in-person formal support group for cancer patients/survivors led by a facilitator**	▪ Clarified "in-person" and "formal" ▪ Changed "mental health professional" to "facilitator" because some groups are led by participant-leader
8	Other	**Other (please specify, e.g. had friends run a cancer race on your behalf, attended a support group for people with chronic illness in general)**	▪ Provided specific examples.

PHASE 3

Participants

From May 26, 2014 to June 22, 2014, 625 potential participants accessed the study. Of those who accessed the survey, 312 were disqualified, 97 did not complete the survey, and 48 respondents were determined to be fraudulent responses by individuals seeking gift cards. A flow chart of all potential participants, including reasons for non-inclusion, is in Figure 3.

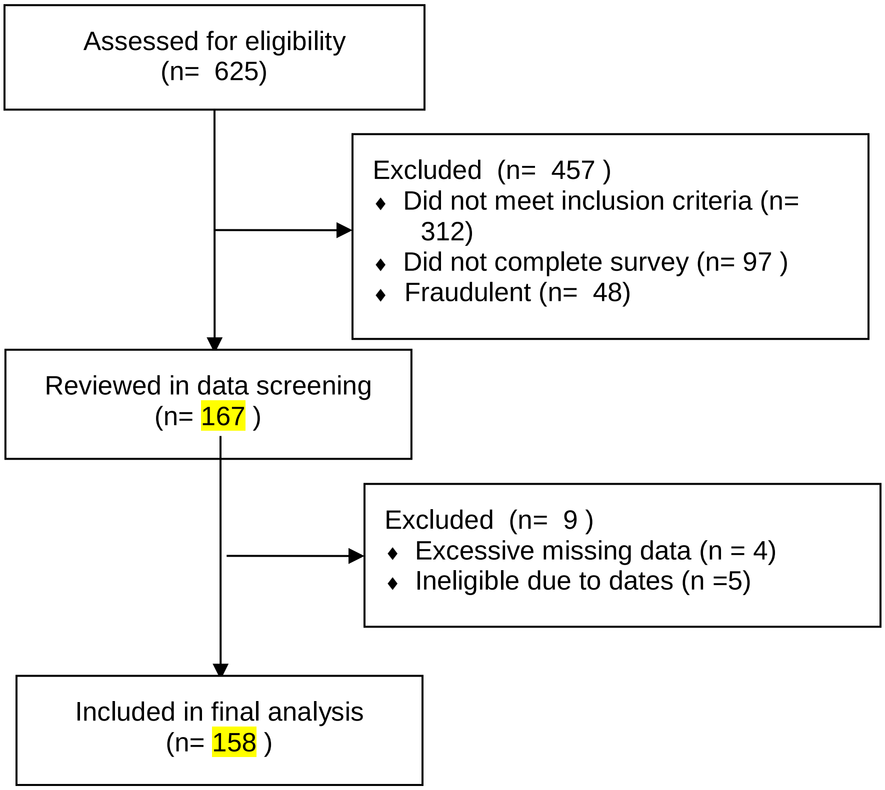


Figure 3. Participant Flow Diagram

Survey

Internal reliability was calculated for the newly created variables of online communication. Cronbach's alpha was .67 for online activities, .70 for cancer social network, and .75 for in-person support activities.

During data cleaning, an additional five respondents were found ineligible due to duration of time post-treatment, and four respondents had excessive missing data (e.g. missing entire measures or the majority of items in a measure). One hundred and fifty-eight participants were included in the final analysis.

The sample was mostly female (85%), white non-Hispanic (89%), and highly educated (73% with at least a college degree). Half of the sample (50%) was married or in a significant relationship, and nearly a third (32%) had children. Over half the sample (53%) was employed full-time and an additional 20% were employed part-time. Mean age was 31 years, and mean time post-completion of primary treatment was 31 months (2.6 years). A wide variety of cancer types were represented, including breast (27%), Hodgkin's lymphoma (15%), thyroid (13%), and leukemia (11%). The distribution of cancer sites approximately matched the distribution of most common cancer sites in the young adult cancer survivor population (105). Complete demographic and medical summaries of the sample are available in Table 9.

Table 9: Phase 3 Participant Characteristics

Characteristic	**n (%) or Mean (SD)**
Gender	
Male	24 (15.2%)
Female	134 (84.8%)
Age	31 (4.97) Range 19-39
Race/ethnicity	
African American	2 (1.3%)
American Indian/Alaska Native	1 (.6%)
Asian	4 (2.5%)
Hispanic	10 (6.3%)

White, non-Hispanic	141 (89.2%)
Education	
8-11 years	2 (1.3%)
12 years or completed high school	7 (4.4%)
Vocational or technical	1 (.6%)
Some college	32 (20.3%)
College graduate	64 (40.5%)
Postgraduate	52 (32.9%)
Marital Status	
Married or in a significant relationship	79 (50.0%)
Single, never married	66 (41.8%)
Divorced	9 (5.7%)
Separated	3 (1.9%)
Widowed	1 (.6%)
Parenthood Status	
Have children	51 (32.3%)
Do not have children	107 (67.7%)
Work Status*	
Employed full time	84 (53.2%)
Employed part time	32 (20.3%)
Out of work for more than 1 year	11 (7.0%)
Out of work for less than 1 year	9 (5.7%)
Unable to work	10 (6.3%)
Homemaker	12 (7.6%)
Student	24 (15.2%)
Other	3 (1.8%)
Time Post-Cancer	
Months post-diagnosis (months)	42.2 (21.8) Range 14-175
Months post-treatment (months)**	30.8 (14.1) Range 12-60
Cancer Type*	
Bone	5 (3.2%)
Brain	7 (4.4%)
Breast	43 (27.2%)
Cervical	2 (1.3%)
Colon/rectum	4 (2.5%)
Germ cell	1 (.6%)
Leukemia	17 (10.8%)
Lymphoma, Hodgkin’s	23 (14.6%)
Lymphoma, non-Hodgkin’s	12 (7.6%)
Melanoma	6 (3.8%)
Ovarian	9 (5.7%)
Soft tissue	3 (1.9%)
Testicular	7 (4.4%)
Thyroid	21 (13.3%)
Uterine	1 (.6%)
Other	11 (6.9%)
General Health	
Excellent	13 (8.2%)
Very good	61 (38.6%)
Good	57 (36.1%)
Fair	25 (15.8%)
Poor	2 (1.3%)
Stage***	
I	33 (20.9%)
II	51 (32.3%)

III	30 (19.0%)
IV	15 (9.5%)
Other	25 (15.8%)
Treatment*	
Surgery	121 (76.6%)
Chemotherapy	119 (75.3%)
Radiation	73 (46.2%)
Bone Marrow Transplant	9 (5.7%)
Other	22 (13.9%)
Cancer History*	
Childhood cancer	4 (2.5%)
Recurrence	18 (11.4%)
Second cancer	9 (5.7%)
Only one cancer diagnosis	132 (83.5%)

*Total exceeds 100% because participants could check multiple work statuses, cancer types, treatment types, or cancer histories
**1 missing, N=157
***4 missing, N=154

For all analyses, demographic variables were dichotomized as follows: white non-Hispanic vs. all other races/ethnicities; less than a college degree vs. college degree or higher; employed vs. not employed; married or in a significant relationship vs. not in a relationship; history of multiple cancer diagnoses (childhood, second cancer, or recurrence) vs. single cancer diagnosis.

Data Screening and Cleaning

The researcher examined the extent and distribution of missing data. Aside from the four respondents who were deleted because of extensive missing data, other missing data was minimal (e.g. one or two items per measure) and widely distributed throughout the sample. To deal with missing data, the researcher used mean imputation. Descriptive data for the study variables are presented in Table 10.

Table 10. Descriptive data for study variables

	Mean	SD	Sample Range	Possible range
Social Network	5.1	1.6	2-9	0-12
Social Support	3.28	.445	2.0-4.0	1-4
Positive Impact of Cancer	3.90	.543	2.0-5.0	1-5
Negative Impact of Cancer	3.60	.676	1.35-4.84	1-5
Unmet Emotional Needs	1.81	1.175	0.0-4.0	0-4
Online cancer activities	7.09	2.42	1-11	0-11

Cancer Social Network	2.77	1.68	0-6	0-6
In-person activities	2.97	2.07	0-7	0-7

Variable distribution was reviewed for normality, linearity, and homoscedasticity. To identify potential confounders and reduce the overall number of variables in the model, the researcher conducted individual regressions with each demographic and medical variable as the independent variables and social support; positive impact of cancer; negative impact of cancer; and unmet emotional needs as the dependent variables. Variables were retained if they were significant at p<.1 (103). The univariate regression results appear in Table 11.

Table 11. Summary of Univariate Regressions

Variable	Social Support			Positive Impact of Cancer			Negative Impact of Cancer			Unmet Needs		
	B	SE B	B	B	SE B	B	B	SE B	β	B	SE B	B
Age	.006	.007	.063	-.005	.009	-.044	.017	.011	.122	.027	.019	.113
Gender	-.065	.099	-.052	.151	.120	.100	-.472	.145	-.252**	-.537	.258	-.165*
Race	-.223	.113	-.156$^{\#}$	-.094	.140	-.054	.034	.174	.015	.348	.301	.092
Education	-.176	.079	-.175*	.188	.097	.153$^{\#}$	.255	.120	.167*	.447	.209	.168*
Work	-.007	.081	-.007	-.072	.099	-.059	-.132	.123	-.086	-.512	.211	-.191*
Marital	.131	.070	.147$^{\#}$	-.091	.086	-.084	.135	.107	.100	.374	.185	.160*
Children	.040	.076	.042	-.047	.093	-.040	.153	.115	.106	.544	.196	.217**
General Health	-.165	.038	-.331***	-.115	.048	-.189*	.364	.053	.481***	.470	.099	.356***
Months post-treatment	.002	.003	.057	.001	.003	.031	.002	.004	.039	.000	.007	.003
Stage at diagnosis	.007	.027	.020	.037	.033	.091	.007	.041	.014	-.081	.071	-.093
Multiple cancer history	.039	.096	.033	-.262	.115	-.179*	.038	.145	.021	-.159	.253	-.050

# p < .1 (threshold for retaining demographic and medical potential confounds in analyses)
*p<.05
**p<.01
*** p<.001

Linear regressions found that education and general health status were significantly associated with social support. Marital status and race were marginally associated with social support (p<.1) so they were also retained as a control variable. Significantly greater positive impact of cancer was associated with having only one cancer diagnosis (as opposed to childhood cancer, recurrence, or second cancer) and better general health. Education was marginally associated with positive impact of cancer. Female gender, lower education level, and worse health status were significantly associated with negative impact of cancer. Factors significantly related to greater unmet emotional needs included female gender, lower education level, not being employed, being married, having children, and being in worse health. Although age was not significant associated with any variables, it was retained for analyses as determined a priori.

Hypothesis 2a: Online cancer communication, general social network roles, cancer social network roles, and participation in in-person cancer support activities are associated with social support.

Hierarchical multiple regression was performed using social support as the dependent variable. Demographic and medical variables (age, race, education, marital status, and general health status) were added first to the model, followed by general social network roles in the second block. Finally, cancer social network roles, in-person cancer support activities, and online cancer communication were added as independent variables in the final block. The full results of the regression are displayed in Table 12.

Table 12. Summary of Hierarchical Regression Analysis Predicting Social Support.

Variable	**Model 1**			**Model 2**			**Model 3**		
	B	SE B	β	B	SE B	Β	B	SE B	Β
Age	.001	.007	.006	.002	.007	.020	-.001	.007	-.010
Race	-.157	.109	-.110	-.154	.107	-.108	-.136	.107	-.095
Education	-.093	.078	-.092	-.106	.077	-.106	-.098	.077	-.097
Marital	.123	.069	.138	.044	.076	.050	.054	.076	.061
General health	-.154	.038	-.307***	-.142	.038	-.284***	-.140	.038	-.280***
General social network				.063	.027	.191*	.054	.027	.166*
Online cancer communication							.003	.014	.018
Cancer social network							.058	.024	.219**
Cancer activities							-.021	.019	-.097
R^2			.156			.184			.218
F			5.599***			5.685***			4.594***

*p<.05
**p<.01
*** p<.001

The results of the regression indicated that the final model with nine predictors explained 21.8% of the variance (R^2 = .218, F(9,148)=4.594, p<.001). In the final model, number of cancer social network roles (β = .219, B = .058, p = .015) and number of general social network roles (β = .166, B = .054, p = .049) were significantly positively associated with social support. General health, measured continuously (β = -.140, B = -.280, p < .001) was also associated with social support. Online cancer communication and in-person cancer support activities were not significantly associated with social support.

Hypothesis 2b: Social network involvement will moderate the relationship between online cancer communication and social support. Online cancer communication will be more strongly associated with social support among those who have low social network involvement than among those who have higher social network involvement.

The PROCESS macro for SPSS, developed by Hayes (92), was used to conduct moderation analysis to determine whether general social network or cancer social network involvement moderated the relationship between online cancer communication and social support. Neither interaction was significant. Exploratory review of graphic output confirmed the absence of an interaction.

Exploratory analyses were also conducted to determine whether social network involvement moderated the relationship between online cancer communication and study outcome measures (positive impact of cancer, negative impact of cancer, unmet emotional needs). A significant interaction was found between cancer social network and online cancer communication for positive impact of cancer only. There was a significant main effect for cancer social network (.061, p = .022) and a significant interaction between cancer social network and online cancer communication (.029, p = .007). The interaction is graphed in Figure 4.

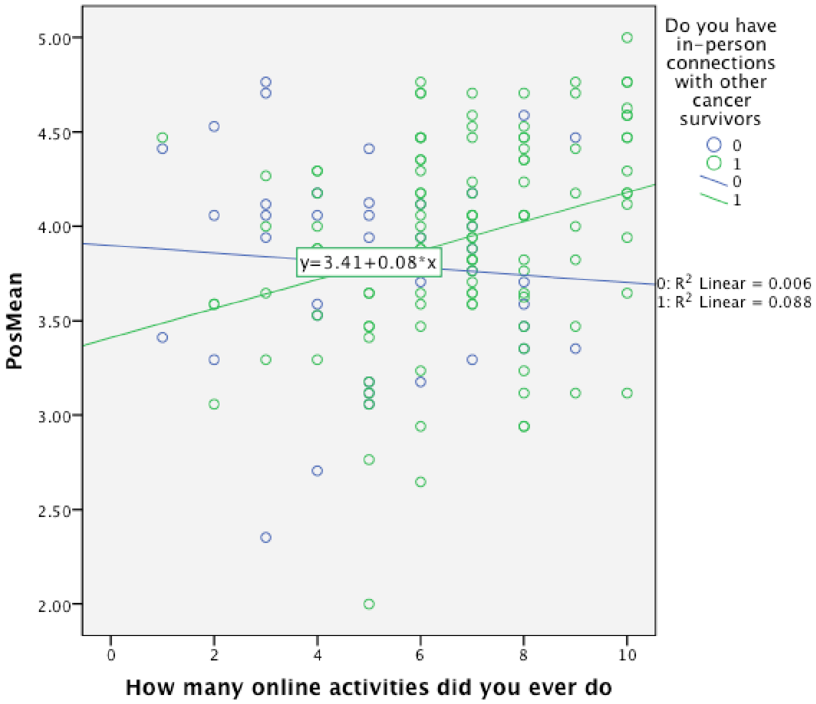


Figure 4. In-person connections with other cancer survivors moderates relationship between online cancer communication and positive impact of cancer

Young adult cancer survivors who are socially isolated from other cancer survivors (i.e., have zero or one type of individual relationship with another cancer survivor) show no relationship between online cancer communication and positive impact of cancer. Among cancer survivors who have multiple in-person connections with other cancer survivors, greater involvement in online cancer communication is associated with reporting greater positive impact of cancer on their lives.

Hypothesis 3a: Social support will be positively associated with positive impact of cancer.

Hierarchical multiple regression was performed with positive impact of cancer as the dependent variable. Age, education, history of multiple cancers (e.g. childhood cancer, recurrence, or second cancer), and general health status were included in the first block of the model. Social support was added in the second block of the model. The results of the regression are displayed in Table 13.

Table 13. Summary of Hierarchical Regression Analysis Predicting Positive Impact of Cancer.

Variable	**Model 1**			**Model 2**		
	B	SE B	β	B	SE B	Β
Age	.001	.008	.006	-.001	.008	-.007
Education	.302	.096	.247**	.342	.093	.279***
Additional diagnosis	-.392	.114	-.269**	-.388	.109	-.266**
General health	-.172	.048	-.283***	-.117	.048	-.192*
Social Support				.358	.094	.294***
R^2		.139			.215	
F		6.186***			8.315***	

*p<.05
**p<.01
*** p<.001

The results of the regression indicated that the model with five predictors explained 21.5% of the variance (R^2 = .215, F(5,152)=8.315, p<.001). Social support (B = .358, p < .001) was significantly positively associated with the positive impact of cancer. Education level (B = .342, β = .279, p < .001), general health status (B = -.117, β = -.192, p = .016), and history of multiple cancers were associated with the positive impact of cancer (B = -.388, β = -.266, p = .001) such that participants with higher education level, better general health, and a history of only one cancer diagnosis (e.g. no childhood cancer or recurrence) reported greater positive impact of cancer.

Hypothesis 3b: Social support will be inversely associated with negative impact of cancer.

Hierarchical multiple regression was performed with negative impact of cancer as the dependent variable. Age, gender, education, and general health status were included as potentially confounding independent variables in the first block, and social support was included as an independent variable in the second block. The results of the regression are displayed in Table 14.

Table 14. Summary of Hierarchical Regression Analysis Predicting Negative Impact of Cancer.

Variable	**Model 1**			**Model 2**		
	B	SE B	β	B	SE B	Β
Age	.015	.009	.110	.016	.009	.119
Gender	-.366	.130	-.195**	-.407	.124	-.217**
Education	.149	.107	.098	.099	.102	.065
General health	.340	.053	.448***	.271	.053	.357***
Social Support				-.435	.105	-.287***
R^2		.294			.366	
F		15.929***			17.516***	

*p<.05
**p<.01
*** p<.001

The results of the regression indicated that the model with five predictors explained 36.6% of the variance (R^2 = .366, F(5,152)=17.516, p<.001). Participants with lower levels of social support (β = -.287, p < .001), female gender (B = -.407, p = .001), and worse general health (β = .357, p < .001) reported greater negative impact of cancer. Neither age nor education was significant.

Hypothesis 3c: Social support will be inversely associated with unmet needs.

Hierarchical multiple regression was performed with unmet emotional needs as the dependent variable. Age, gender, education, work status, marital status, children, and general health status were included as potentially confounding independent variables in the first block, and social support was added in the second block. The results of the regression are displayed in Table 15.

Table 15. Summary of Hierarchical Regression Analysis Predicting Unmet Needs.

Variable	**Model 1**			**Model 2**		
	B	SE B	β	B	SE B	Β
Age	.008	.020	.032	.007	.018	.027
Gender	-.343	.245	-.105	-.422	.230	-.129
Education	.239	.206	.089	.130	.195	.049
Work Status	-.251	.204	-.094	-.333	.191	-.124
Marital status	.200	.192	.085	.305	.181	.130
Children	.299	.214	.119	.304	.200	.121
General health	.405	.101	.307***	.250	.100	.190**
Social Support				-.921	.196	-.349***
R^2		.203			.306	
F		5.424***			8.158***	

*p<.05
**p<.01
*** p<.001

The results of the regression indicated that the model with eight independent variables explained 30.6% of the variance (R^2 = .306, F(8,149)=8.158, p<.001). Better general health (B = .250, β = .190, p = .013), and higher social support (β = -.921, p < .001) were significantly associated with lower unmet emotional needs.

Hypothesis 4: Social support mediates the relationship between social activities (online cancer communication, general social network, cancer social network) and outcome measures (positive impact of cancer, negative impact of cancer, unmet emotional needs).

Mediation models were tested to determine the extent to which social support mediates the association between social activities and outcome measures. Demographic variables that were related to social support and the outcome measures at p<.1 were included as covariates. Bootstrapping was performed to test these models using INDIRECT, a macro for SPSS developed by Preacher and Hayes (165). For each of the three mediation models (one model for each dependent variable), Table 6 shows the effect of each independent variable on the mediator (path a); the effect of the mediator on the outcome (path b); the total effect of the independent variable on the outcome variable (path c); the direct effect of the independent variable on the outcome variable (path c'); and estimates of the mediated effect (a x b). The mediation models are displayed in Figure 5-7.

Positive Impact of Cancer

After adjusting for all other variables in the model, education and history of multiple cancers remained significant, indicating that cancer survivors who have at least a college degree and those who have not experienced multiple diagnoses (e.g., childhood cancer, recurrence, or second cancer) perceive greater positive impact of cancer on their lives.

Online cancer communication (*c* = .033, p = .049), general social network involvement (*c* = .079, p = .019), and cancer social network involvement (*c* = .059, p = .017) each had a significant total effect on positive impact of cancer, after controlling for race, marital status, education, general health status, and multiple cancer history. The mediated effects for general social network involvement (*a x b* = .020, 95% CI: .004, .046) and cancer social network involvement (*a x b* = .016, 95% CI: .001, .040) were positive and significant at p<.05. After adjusting for social support as a mediator, general and cancer- social network involvement were not significantly directly related to positive impact of cancer, suggesting a complete mediation. The mediated effect of online cancer communication on positive impact of cancer was not significant, and after adjusting for social support as a mediator, online activity remained significantly directly related to the positive impact of cancer (c’ = .033, p = .041). The mediation model appears in Figure 5.

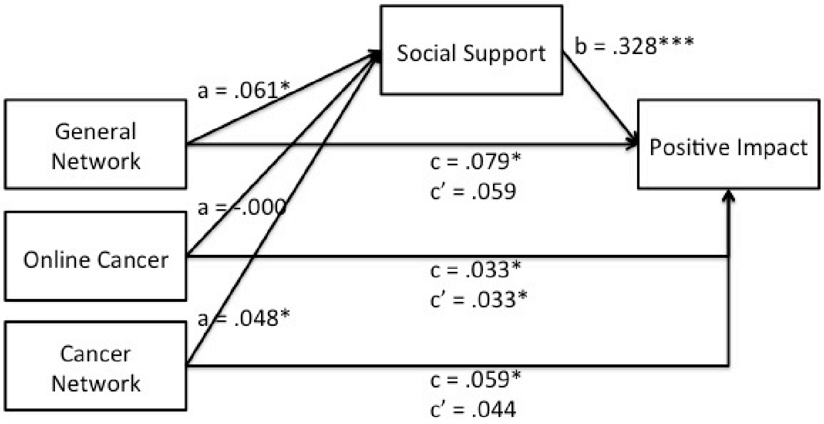


Figure 5. Mediation Model for Positive Impact of Cancer

Negative Impact of Cancer

After adjusting for all other variables in the model, general health status and gender remained significant, showing that females and survivors with fair or poor health report that cancer has a greater negative impact of cancer on their lives.

Of the three social activity measures, only cancer social network involvement (*c* = -.064, p = .037) had a significant total effect on negative impact of cancer after controlling for race, marital status, education, general health, and gender). However, both cancer social network involvement (*a x b* = -.026, 95% CI -.062, -.003) and general social network involvement (*a x b* = -.033, 95% CI: -.069, -.006) showed significant mediated effects at p<.05. After adjusting for social support as a mediator, general and cancer social network were not significantly directly related to negative impact of cancer, suggesting a complete mediation. Online cancer communication was not a significant predictor in the model. The mediation model appears in Figure 6.

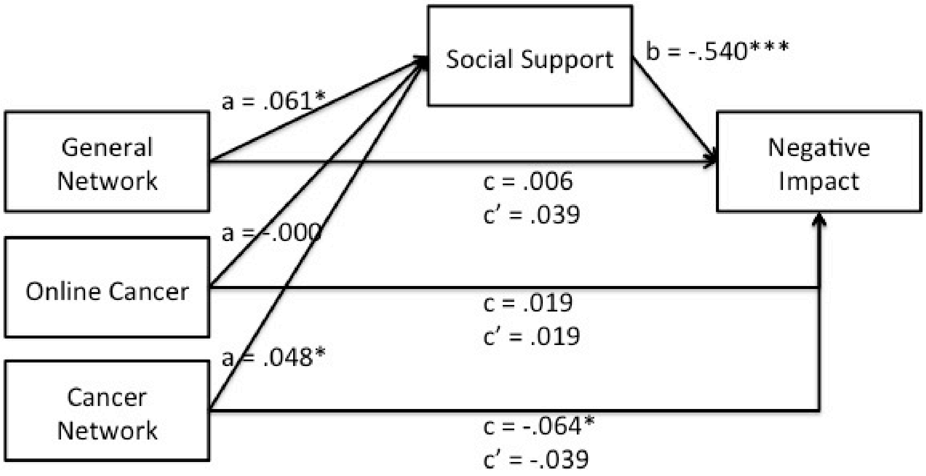


Figure 6. Mediation Model: Negative Impact of Cancer

Unmet Emotional Needs

After adjusting for all other variables in the model, gender, work status, and general health remained significant, showing that females, survivors who are not working, and survivors in fair or poor health have more unmet emotional needs.

Of the three social activity measures, only cancer social network involvement (*c* = -.109, p = .050) had a significant total effect on unmet emotional needs after controlling for race, gender, education, work status, marital status, parenthood status, and general health. The mediated effect for cancer social network (*a x b* = -.047, 95% CI: -.112, -.005) was significant at p<.05. General social network involvement had no significant total effect on unmet emotional needs, but the mediated effect for general social network involvement was significant (*a x b* = -.090, 95% CI: -.172, -.025). Online cancer communication was not a significant predictor in the model. The mediation model appears in Figure 7.

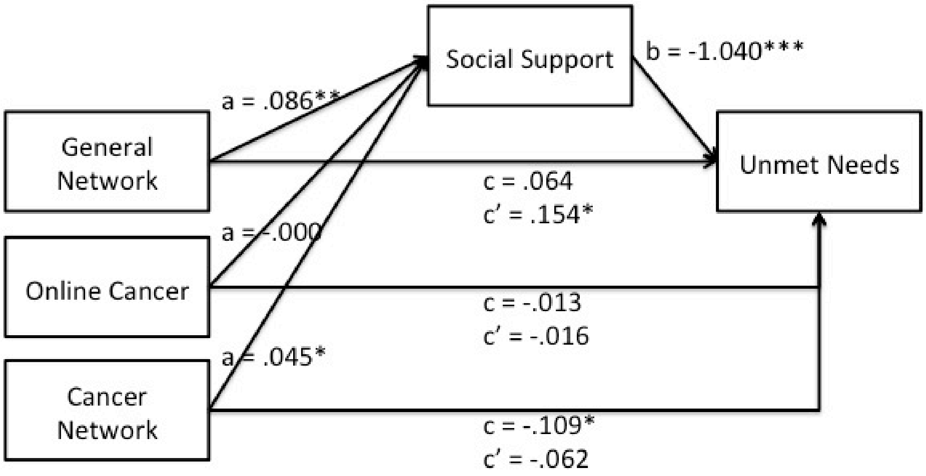


Figure 7. Mediation Model: Unmet Needs

In summary, the survey found that the number of cancer social network roles and general social network roles are associated with social support, and online cancer communication and participation in in-person support programs are not associated with social support. Social support in turn was associated in the expected direction with all three outcome measures: positive impact of cancer, negative impact of cancer, and unmet emotional needs. Social support completely mediates the relationship between general and cancer- social network (predictor variables) and positive impact of cancer, negative impact of cancer, and unmet emotional needs (outcome variables).

CHAPTER 8: Discussion

BRIEF SUMMARY OF FINDINGS

The study found that YACS participate in a wide variety of online and in-person support activities. Having a larger number of general social network roles (such as spouse, friend, co-worker, neighbor) and types of connections with other cancer survivors (such as formal mentor, informal mentor, acquaintance, friend) is associated with higher levels of social support. Social support, in turn, is associated with better long-term adjustment to cancer. Specifically, higher social support is associated with greater perception that cancer impacted YACS' lives in positive ways, lower reports that the cancer impacted survivors' lives in negative ways, as well as lower levels of unmet emotional needs. Having a wider variety of general social network roles and social roles with other cancer survivors indirectly is associated with better long-term adjustment to cancer through a positive association with social support. Participating in more online cancer support activities (such as writing a blog about cancer, posting in a Facebook cancer support group) was not associated with social support. Likewise, participating in a higher number of in-person cancer social activities (such as attending a support group, meet-up, or workshop for cancer patients/survivors) was not associated with social support.

DETAILED REVIEW OF FINDINGS

Participants described a variety of online cancer-related activities and in-person relationships that provided support during and after treatment. These activities included sharing updates about treatment via mass emails; writing blogs and reading blogs or narratives of other survivors; passively lurking and actively posting to support groups on

Facebook; passively lurking and actively posting to anonymous discussion boards; writing about cancer on their own Facebook pages; and sharing and reading cancer news on Twitter. Participants also described several ways of connecting with other young adult cancer survivors in person, including one-on-one relationships (such as formal and informal mentoring relationships, as well as limited casual encounters and ongoing friendships), as well as organized group activities (such as athletic events, conferences, retreats, formal support groups, and meet-ups). The investigator created survey questions out of this list of online and in-person cancer support activities and relationships, and the newly written questions were refined with participant input in Phase 2.

The investigator hypothesized that engaging in various types of social connections—both online and in-person, with cancer survivors and general social network roles—would each be independently associated with social support. The hypothesis was partially supported. Social support was higher among participants who had more social roles in their general social network and more types of connections with other cancer patients/survivors.). This finding is consistent with literature positing that members of an individual's primary group (e.g. family, close friends) provide different aspects of social support than members of an individual's secondary group (e.g. more peripheral contacts) who have experienced the same stressor such as a chronic illness (183; 198). However social support was unrelated to number of online cancer activities. Social support was also higher among those with higher education levels and better general health.

The investigator also hypothesized that social network involvement would moderate the relationship between online cancer activities and social support, such that people who were more socially isolated would turn to the internet for support, and would show a stronger positive association between intensity of cancer-related internet activity and social support. This hypothesis was based on the social compensation model (127), which posits that individuals lacking in in-person connections seek to compensate by accessing social support online. However, social network involvement did not moderate the relationship between online activities and social support. In other words, online activities were unrelated to social support regardless of a person's number of in-person social connections.

However, in an exploratory finding, YACS who have in-person ties to other cancer survivors, participating in more online cancer support activities is associated with greater report that cancer impacted their lives in positive ways. This finding supports the "rich get richer" hypothesis of online interaction, whereby people who are socially connected offline can use online communication to augment and strengthen their social ties (127). However, for YACS who are socially isolated from other cancer survivors, participating in more cancer-related online activities was not associated with any outcomes.

The study also examined long-term adjustment to cancer, including positive impact, negative impact, and unmet emotional needs. Overall, survivors who had higher levels of education, better general health, and had only one cancer diagnosis (as opposed to a history of childhood cancer, recurrence, or a second cancer) reported more strongly that cancer impacted their lives in positive ways. Examples of positive consequences of cancer include greater altruism and empathy, greater health awareness, greater confidence and direction in life, or pride in surviving cancer. In contrast, survivors who were female, who had a lower education level, or who had worse health reported more strongly than cancer affected their lives in negative ways. Examples of negative consequences of cancer include concerns about their appearance, concerns about changes in their bodies, worries, and ways that cancer interfered with their life plans. Survivors who had a lower education level, were not employed, were in worse health, or had children had more unmet emotional needs.

As hypothesized, participants with greater levels of social support reported more positive ways that cancer impacted their lives, fewer negative ways that cancer impacted their lives, and fewer unmet emotional needs. As hypothesized, social support mediates between in-person social activity measures (general social network and cancer social network) and outcomes including positive impact of cancer, negative impact of cancer, and unmet emotional needs. The hypothesized mediation model did not hold true for online cancer activities, which were not related to social support.

Social support from other cancer survivors likely improves long-term adjustment to cancer in a variety of ways. In the Phase 1 interviews, participants described numerous benefits of having connections with other young adult cancer survivors, such as sharing an immediate unspoken bond, reducing loneliness, belonging to a community, being inspired by role models living well after cancer, normalizing and validating each others' concerns, providing reassurance, and sharing guidance based on experience, including word-of-mouth referrals to resources such as financial aid for cancer survivors. These descriptions by participants mirrored previous theoretical and empirical research suggesting that social relationships impact well-being by buffering against the harmful effects of stress and chronic isolation (47); improving coping through positive influences on attitude and behavior (196); providing a sense of mattering to others (195); increasing access to resources (26; 27); and increasing self-efficacy through reassurance, positive feedback, and vicarious learning (e.g. by seeing other succeed) (10).

Importantly, the majority of participants in Phase 1 described feeling a sense of purpose from informally or formally mentoring other YACS. Nurturing others was one of the aspects of social support captured by the measure used in this study. The therapeutic benefits of volunteering and supporting others have been well documented, both in the general population (150), as well as in online cancer support groups (152; 220)

LIMITATIONS AND ALTERNATIVE EXPLANATIONS OF FINDINGS

The generalizability of this study is limited because of its sampling. This study used a convenience sample, which was overwhelmingly educated, female, and Caucasian. By the very nature of the recruitment, most of which was conducted via social media, participants were highly engaged in online activity. It is unknown how well the study's findings generalize to YACS who are less highly educated, male survivors, cancer survivors with other races and ethnicities, and survivors who are less engaged in online activities. Also, the study recruited a heterogeneous sample of participants with different cancer types, which could have masked important differences between participants with specific types of cancer. This mixed sample also included participants with and without recurrence, and some participants with a history of childhood cancer (in addition to their diagnosis as a young adult).

A limitation of phone interviews in Phases 1 and 2 is that interviews were unable to capture facial expressions and other non-verbal behaviors. Further, the study is cross-sectional, and can therefore only show associations rather than determine cause and effect. Although this study was predicated on previous theoretical models proposing that social support leads to greater well-being (47; 198), it is also easy to envision a cyclical relationship between social support and long-term adjustment to cancer. Survivors who display more positivity by showing greater altruism, empathy, confidence, and pride might be more successful in their social relationships, and therefore more easily muster social support. Survivors who are experiencing more disruptive long-term effects of cancer might become more withdrawn and isolated, and therefore have more difficulty maintaining relationships that provide social support.

Another limitation is the use of unvalidated measures for online cancer activity, cancer survivor social network, and in-person cancer support activities. For these constructs, no known validated instruments previously existed and therefore this study used newly developed survey questions without previously known psychometric properties. However, the three newly created variables (online cancer communication, cancer social network, and in-person cancer support activities) all had Cronbach's alphas around the threshold for acceptability (.67, .70, and .74 respectively).

The failure to find significance for online cancer activity can be explained in many ways. First, the measure of online cancer activity in this study was very crude. It summed the number of online cancer support activities a person ever engaged in, without taking into account timing (e.g. current use vs. past use), frequency of use (e.g. multiple times per day or per week vs. once or twice ever), level of engagement (e.g. passively browsing vs. posting one's own content), or purpose of use (e.g. to seek support for oneself vs. provide support for others). Timing is likely a critical variable to consider. It is quite possible that individuals who are currently heavy users of online support activities might have the poorest adjustment, because of the selection bias inherent in online support use. Many participants noted in Phase 1 interviews that individuals who are struggling the most tend to be the most vocal in online cancer support groups. This observation is consistent with literature documenting that online support use is higher among cancer patients/survivors who have weaker offline support (88; 90; 147). Therefore it would be important to investigate other dimensions of online support (e.g. timing, frequency of use, intensity of use) and to study whether online support activity at one point in time predicts better adjustment in the future. Purpose of online cancer activity (e.g. seeking support for oneself vs. providing support for someone else) is another important variable to consider, because providing online support may be more beneficial than receiving online support (152).

Second, the lack of significant findings on online cancer activity may be due to the omission of other potential moderators between online cancer activity and outcomes. Coping styles and emotional expression are two potential moderators that were not examined in this study. One recent study on breast cancer patients participating in an online support system found that users high in emotional expression and users with active coping styles are more likely to benefit (have lower depression and fewer breast cancer-related concerns) from using online support systems than users who are low in emotional expression and users with avoidant coping styles (16).

Alternatively, it is also possible that use of online cancer activities is truly unrelated to social support and adjustment outcomes in young adult cancer survivors. Despite the many advantages of online connections in terms of accessibility, convenience, efficiency, and ease of use, participants in Phase 1 described the limitations of online cancer activity as well. The overwhelming majority of participants described how the physical presence of another person provides warmth and human touch—through eye contact, facial expressions, body language, hugs—that reduce emotional distress and ease loneliness in a way that online connections cannot do. Several also described how in-person bonds with other cancer survivors also tend to feel deeper and more authentic than online connections. Although social media may be an ideal medium for disseminating educational information to cancer survivors, it may be that online cancer-related social connections are simply not as effective at providing support as in-person connections for young adult cancer survivors. This needs further study.

In an unanticipated Phase 1 finding, several participants differentiated between online contacts and in-person contacts by noting that online conversations with other cancer patients/survivors tend to be very cancer-focused, whereas in-person connections tend to stimulate conversations about more aspects of the survivor's life beyond cancer (e.g. occupational interests, leisure activities, family). In online cancer groups, whether on Facebook or anonymous forums, participants introduce themselves by their disease characteristics and discuss topics solely related to cancer. This exclusive focus on cancer can be highly anxiety provoking and can make participants feel trapped by their cancer identity. In contrast, participants noted that through in-person contact with other cancer survivors, the conversation may start with cancer but often ranges freely to other topics, enabling survivors to get to know each other as people beyond their cancer experience. Sharing in social activities or conversations about relationships, careers, and other aspects of life may help young survivors' psychological recovery from cancer.

Another limitation of online cancer activity is in its group-focused nature. Indeed, in Phase 1 participants described how online cancer activities are appealing largely because of their usefulness in communicating to many people at once. For example, participants used online platforms to broadcast information to a large number of people (such as when providing updates to friends/family on treatment status), "crowdsource" information needs (i.e. seek the wisdom of the crowd to address questions), and find others with a similar medical profile in a large, geographically dispersed pool of people. As several participants noted, anyone can sign into Facebook at any time of day and communicate with other cancer survivors. Although this group-based communication can be useful when seeking information or a sense of community, it may be that online connections simply cannot provide the one-on-one emotional connections that underlie many aspects of social support.

Organized in-person cancer support activities, such as support groups, conferences, and workshops, may be similarly limited in their ability to foster long-lasting social support. Like online activities, participation in in-person support activities was not related to social support in this study. In-person support activities are also group focused in nature. Simply attending a group program may or may not help foster connections with other participants in the program. It is possible that merely attending more types of in-person support activities may only foster social support insofar as they facilitate the formation of individual relationships.

STRENGTHS

Major strengths of this study include its innovative design combined with methodological rigor. This study used a mixed methods approach, which used a rigorous qualitative process to develop new survey items, refine them, and then incorporate them in a survey. This mixed methods approach also enabled the investigator to use qualitative findings from Phase 1 to help explain quantitative findings in Phase 3.

The study's measurement of online and in-person activities has ecological validity by drawing from survivors' real descriptions of different types of support that they used. In contrast with the majority of previous studies on online social support for cancer survivors, which historically focused exclusively on online forums, this study comprehensively considered a wide variety of online activities such as Facebook groups, individual Facebook pages, blogs, and Twitter. The study also took a more comprehensive look at sources of in-person social support for cancer survivors. Using findings from Phase 1, the study measured use of cancer peer support in a variety of ways including many types of relationships with other cancer survivors, such as acquaintances, friends, and formal and informal mentoring, as well as participation in a wide variety of traditional and non-traditional in-person support activities.

This study focused on a population that has historically been overlooked in the literature yet has poorer functioning and greater unmet needs than other cancer survivors. This study's focus on online activity is especially applicable given the high penetration of Internet access and social media use in this age group. Study findings are highly relevant to the design and delivery of support services for this underserved population.

IMPLICATIONS AND APPLICATIONS

This study developed from the puzzle of how to bolster social support in order to optimize long-term adjustment in young adult cancer survivors. Underlying this challenge were questions about who provided support for YACS, through what media

YACS accessed support, and what benefits were associated with social support for YACS. This study provides four key take-home messages: (1) Social support matters for long-term adjustment to cancer; (2) both cancer and non-cancer connections matter for social support; (3) supportive relationships involve giving and receiving; and (4) relationships, not activities, were directly linked to social support in this study, but more research is needed on online activities.

Social Support Matters

YACS with higher social support report more favorable long-term adjustment to cancer. The higher survivors' levels of social support, the more they reported that cancer had a positive impact on their lives (such as by increasing their confidence, pride, empathy toward others, awareness of their health, and/or sense of direction in life), the less they reported that cancer had a negative impact on their lives (such as by disrupting life plans, causing dissatisfaction with their bodies, or increasing their worries about health), and the less they reported unmet emotional needs (such as needs to deal with feeling depressed, tired, stressed, or not being able to feel 'normal'). Although in a cross-sectional study like this, it is impossible to conclude whether social support *causes* better adjustment, the strong relationship between social support and long-term adjustment suggests that increasing social support for young adult cancer survivors may be an important component of professional and/or self-care.

Cancer and Non-Cancer Connections

It can be helpful for YACS to have many types of social connections, both in their general lives and with other cancer survivors. The more types of connections YACS had with other cancer survivors, the higher their level of social support, regardless of their number of general social network relationships, and vice versa. In other words, both cancer- and non-cancer social connections are independently associated with social support and thereby are associated with better long-term adjustment.

Being socially engaged is not necessarily easy. Some YACS are uprooted from their social network roles over the course of diagnosis and treatment: jobs may be stalled or lost, friends may fade away, and medical appointments and symptoms may interfere with participation in work, school, or leisure activities. After the unusual experience of having cancer at a young age, YACS may feel distanced from peers. However, resuming or increasing involvement in a broad social network can help survivors regain a sense of normalcy, move toward their personal and professional goals, and show themselves that they can live their lives fully after cancer.

Connections with other cancer patients or survivors can also help in ways that family and friends simply cannot. Relationships between YACS can provide a deep unspoken bond, a therapeutic sense of shared experience. As one breast cancer survivor stated, “There’s just a connection, there’s an immediate—‘I know where you are, I know where you’ve been, I get you’ kind of thing.” This immediate sense of connection between cancer survivors was described in nearly all interviews. A colorectal survivor described the importance of in-person one-on-one relationships between survivors by saying, “I feel that if a survivor is there to kind of help you through, not only do you see that there are other survivors, you’re in the same place in the world, but you have someone that understands what you’re thinking, feeling, hearing. And you have almost a lifeline that isn’t going to judge you or isn’t going to question you, and you know that is there and cares enough to be there and will help you in any way that they can.” The shared bond and common understanding between survivors can help shift survivors' perspectives and share coping strategies. This participant's statement parallels the observation by Thoits that the empathic understanding between people who have shared a similar adverse life experience provides validation and facilitates ventilating distressing thoughts and emotions, without fear of criticism (198)

Importantly, this study shows that the number of *types* of social roles (such as being a parent, friend, co-worker, religious community member, acquaintance of another cancer survivor, informal mentor of a cancer patient), rather than the sheer number of people in a survivors' network, is associated with better social support and thereby better adjustment outcomes. In other words, cultivating different kinds of connections with a relatively few people can help survivors. YACS can deepen their general social network involvement by volunteering, attending religious services, taking classes, joining sports leagues, or participating in other common interest groups. Because cancer is relatively rare among young adults, many YACS do not know other young adults with cancer in their naturally existing social network. But many of the participants interviewed described meeting other YACS through organizations and structured programs, including social meet-ups, outdoor adventure trips, mentoring programs, in-person support groups, and online groups.

Giving and Receiving

Social support is not just something that survivors receive unilaterally. It also develops through giving to others and engaging in give-and-take relationships. Many of the social roles measured in this study offer opportunities to nurture and lead others, such as volunteering, supervising work subordinates, parenting a child, or serving as a formal or informal mentor for other people diagnosed with cancer. Other types of relationships, such as familial ties, work colleagues, and friendships with people who have or have not had cancer, offer the opportunity to exchange reciprocal support.

The survey’s finding about the benefit of engaging in a variety of relationships, including those that focus on providing support to others, is once again consistent with the survivor interviews. A brain cancer survivor described why he enjoys providing support to other cancer patients: “it’s nice to share some positive experience with people and let them know it really can be ok.” Similarly, a breast cancer survivor stated, “I’ve mentored a lot of women I met through [a breast cancer support organization] during their treatment, you know, and I find that to be very helpful and therapeutic. And it makes me feel like, you know, there’s some reason that this happened to me. That I have some purpose tied to my diagnosis.” This sense of purpose from mentoring other cancer patients can help YACS make meaning out of a senseless life experience and reshape their personal narrative about the positive and negative ways that cancer impacted their lives.

Relationships, Not Activities

Unlike the direct link between having more types of social relationships and reporting higher levels of social support, this study found no relationship between participation in online (or in-person) activities and social support. The cross-sectional study design makes it difficult to draw any clear implications about this finding. The effect of online activities on survivors’ outcomes is likely complex and depends on many external variables. It would be inaccurate to conclude that online activities do not help increase social support in YACS. Much more nuanced research is needed to determine how and when online activities can be supportive or unsupportive.

Throughout participant interviews, many survivors described the advantages of online support. For many, online support provided a convenient outlet that enabled 24/7 access to other cancer survivors when they were physically isolated and unable to access any other connections to other YACS. For some participants, online activities served as a bridge that eventually led to the cultivation of in-person friendships or engagement in meaningful support activities. For others, writing about their thoughts, feelings, and experiences online enabled them to express themselves to family and friends in ways that facilitated the flow of information and also proved therapeutic. As one Hodgkin's lymphoma survivor stated, posting about her cancer experience online "benefited me because it helped me—it helped my transition from feeling pitiful and weak and sad and unlucky, to strong, given courage, tough, and accomplished, I guess. So it helped me—it gave me an outlet to be confident and optimistic about my treatment and what was going on after my treatment."

Despite the many advantages of online communication, survivors described several distinct disadvantages of online communication, particularly online support groups. These downsides included the cold and impersonal nature of online communication; the proliferation of anxiety-provoking "scare stories" in online forums; the selection bias whereby the most distressed people post most frequently in online support groups, creating a negative and depressing tone; and the tendency for discussion to be limited to cancer, making it difficult to get to know other cancer survivors in more well-rounded ways.

FUTURE DIRECTIONS

To control for selection bias whereby some people seek out online activity because they are more distressed and need greater support, longitudinal studies are needed to determine whether online activity at baseline predicts later outcomes. Interventional studies could reveal differences between the effects of various types of online interventions (e.g., writing a blog, lurking in a group, posting in a group). Longitudinal studies would also enable further testing of the social compensation hypothesis. In other words, longitudinal studies could examine whether participants with low social support and few in-person social relationships at baseline subsequently engage in more online activity, and whether online activity predicts a greater improvement in social support at follow-up.

Further research could also replicate this study in more homogeneous groups of participants with particular cancer histories, e.g. specific cancer types, or participants without a history of recurrence or second cancer.

Future research should also examine the impact of engaging in different types of online activities, such as actively posting/writing versus passively reading/viewing content (87); seeking support from others versus expressing support to others (152); and communicating with friends and family (e.g. by posting on a personal Facebook page) versus communicating with other cancer survivors (such as posting in online forums and Facebook groups). Qualitative interviews in this study suggest that writing emails, blogs, and engaging in one-on-one online communication may have mostly positive effects on survivors, whereas participating in online support groups can have more negative as well as positive effects. It would be interesting to ascertain whether participation in online support groups has a curvilinear relationship with outcomes. Perhaps at lower frequency or intensity of use, engagement in online support groups can be beneficial, but at higher frequency, increased participation can have negative effects.

Future research should also consider coping style, emotional expression, and emotional competence as moderators of online activity. It may be that online activities are helpful for YACS who use them to problem-solve and express emotions (16) and that YACS with high emotional competence show the greatest benefit from giving and receiving support online (220). Future studies may also consider a variety of outcomes measures including variables related to physical health (e.g., health-related behaviors, physical symptoms), as well as other psychological outcomes, including empowerment (13) and self-efficacy (10).

Since cancer survivors' levels of social support and perspectives about the impact of cancer may change over time, future research could examine those temporal changes. Repeated assessments of social support, which could entail ecological momentary assessment, could reveal those temporal patterns and clarify how levels of social support and perspectives about cancer change during the trajectory from patient, to short-term survivor, to longer-term survivor.

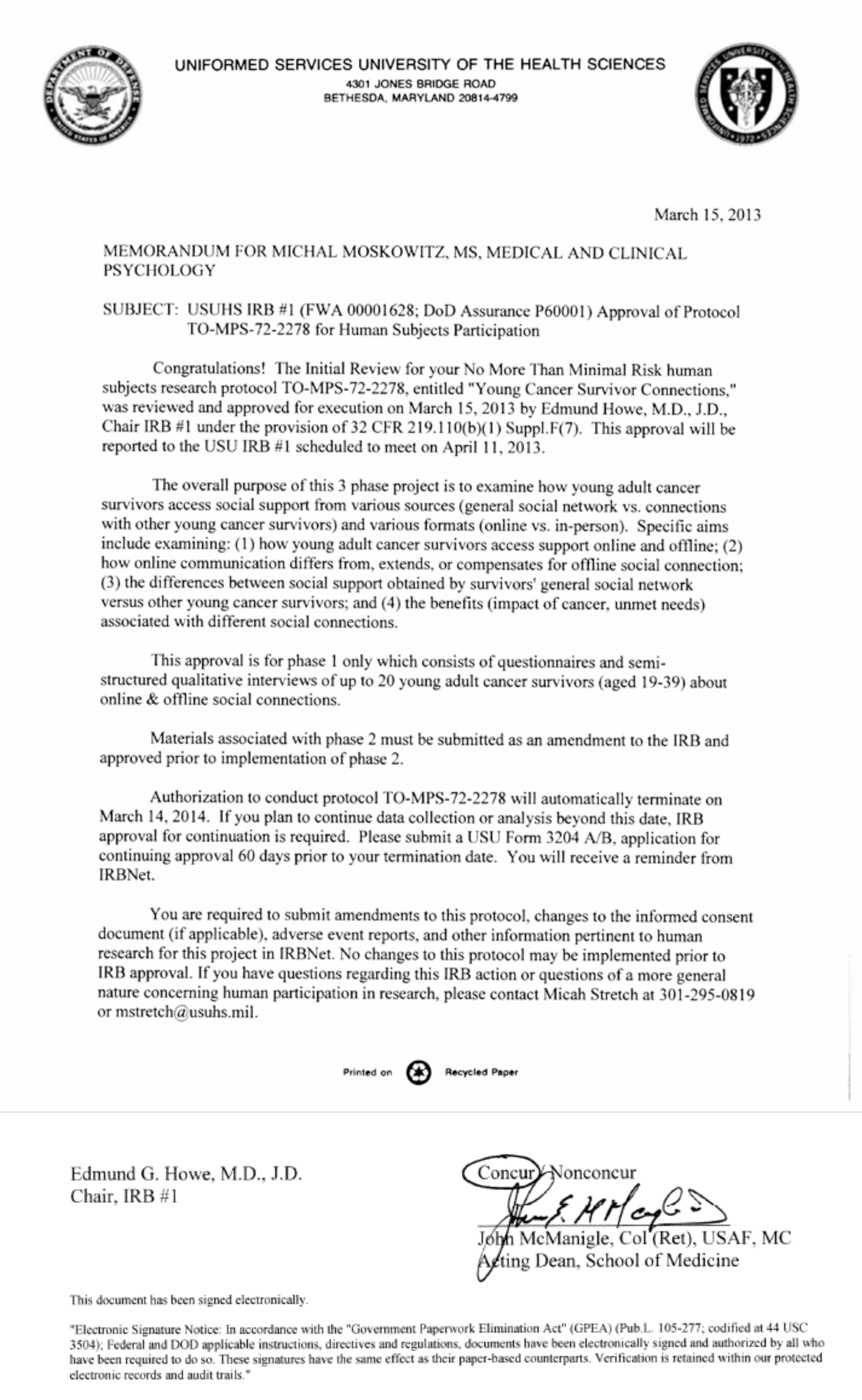
In addition, future research can distinguish between the different types of social connections that foster different aspects of social support, and how activity at different points in time is associated with different types of support. For example, we might expect that participation in online and in-person groups during treatment is associated with more informational support (guidance), whereas participation in these groups after completion of treatment is associated with greater sense of belonging. Mentoring and posting in online groups after completion of treatment also may provide opportunity for nurturance, another aspect of social support. We would expect that tangible support is the least relevant to online activity and relationships with other YACS, but is a major component of support from family or friends serving as caregivers. Future extensions of this research could further investigate YACS' changing relationships with caregivers over time; the ways YACS express their support needs to and receive support from caregivers; as well as caregivers' need for and means of accessing support.

CONCLUSION

This study provides four key take-home messages: First, social support matters for long-term adjustment to cancer. Second, YACS with more types of social relationships, including cancer connections and general social network ties, have higher levels of social support. Third, YACS may benefit from having a variety of supportive relationships that involve a combination of receiving support from others as well as giving to others (e.g. by volunteering, mentoring, or exchanging support with friends). Fourth, simply participating in more online activities was not directly linked to social support in this study, but more research is needed to investigate the nuances of online activity and social support.

APPENDICES

APPENDIX A: IRB APPROVAL AND CONSENT FORMS



UNIFORMED SERVICES UNIVERSITY OF THE HEALTH SCIENCES
4301 JONES BRIDGE ROAD
BETHESDA, MARYLAND 20814-4799

March 15, 2013

MEMORANDUM FOR MICHAL MOSKOWITZ, MS, MEDICAL AND CLINICAL PSYCHOLOGY

SUBJECT: USUHS IRB #1 (FWA 00001628; DoD Assurance P60001) Approval of Protocol TO-MPS-72-2278 for Human Subjects Participation

Congratulations! The Initial Review for your No More Than Minimal Risk human subjects research protocol TO-MPS-72-2278, entitled "Young Cancer Survivor Connections," was reviewed and approved for execution on March 15, 2013 by Edmund Howe, M.D., J.D., Chair IRB #1 under the provision of 32 CFR 219.110(b)(1) Suppl.F(7). This approval will be reported to the USU IRB #1 scheduled to meet on April 11, 2013.

The overall purpose of this 3 phase project is to examine how young adult cancer survivors access social support from various sources (general social network vs. connections with other young cancer survivors) and various formats (online vs. in-person). Specific aims include examining: (1) how young adult cancer survivors access support online and offline; (2) how online communication differs from, extends, or compensates for offline social connection; (3) the differences between social support obtained by survivors' general social network versus other young cancer survivors; and (4) the benefits (impact of cancer, unmet needs) associated with different social connections.

This approval is for phase 1 only which consists of questionnaires and semi-structured qualitative interviews of up to 20 young adult cancer survivors (aged 19-39) about online & offline social connections.

Materials associated with phase 2 must be submitted as an amendment to the IRB and approved prior to implementation of phase 2.

Authorization to conduct protocol TO-MPS-72-2278 will automatically terminate on March 14, 2014. If you plan to continue data collection or analysis beyond this date, IRB approval for continuation is required. Please submit a USU Form 3204 A/B, application for continuing approval 60 days prior to your termination date. You will receive a reminder from IRBNet.

You are required to submit amendments to this protocol, changes to the informed consent document (if applicable), adverse event reports, and other information pertinent to human research for this project in IRBNet. No changes to this protocol may be implemented prior to IRB approval. If you have questions regarding this IRB action or questions of a more general nature concerning human participation in research, please contact Micah Stretch at 301-295-0819 or mstretch@usuhs.mil.

Printed on Recycled Paper

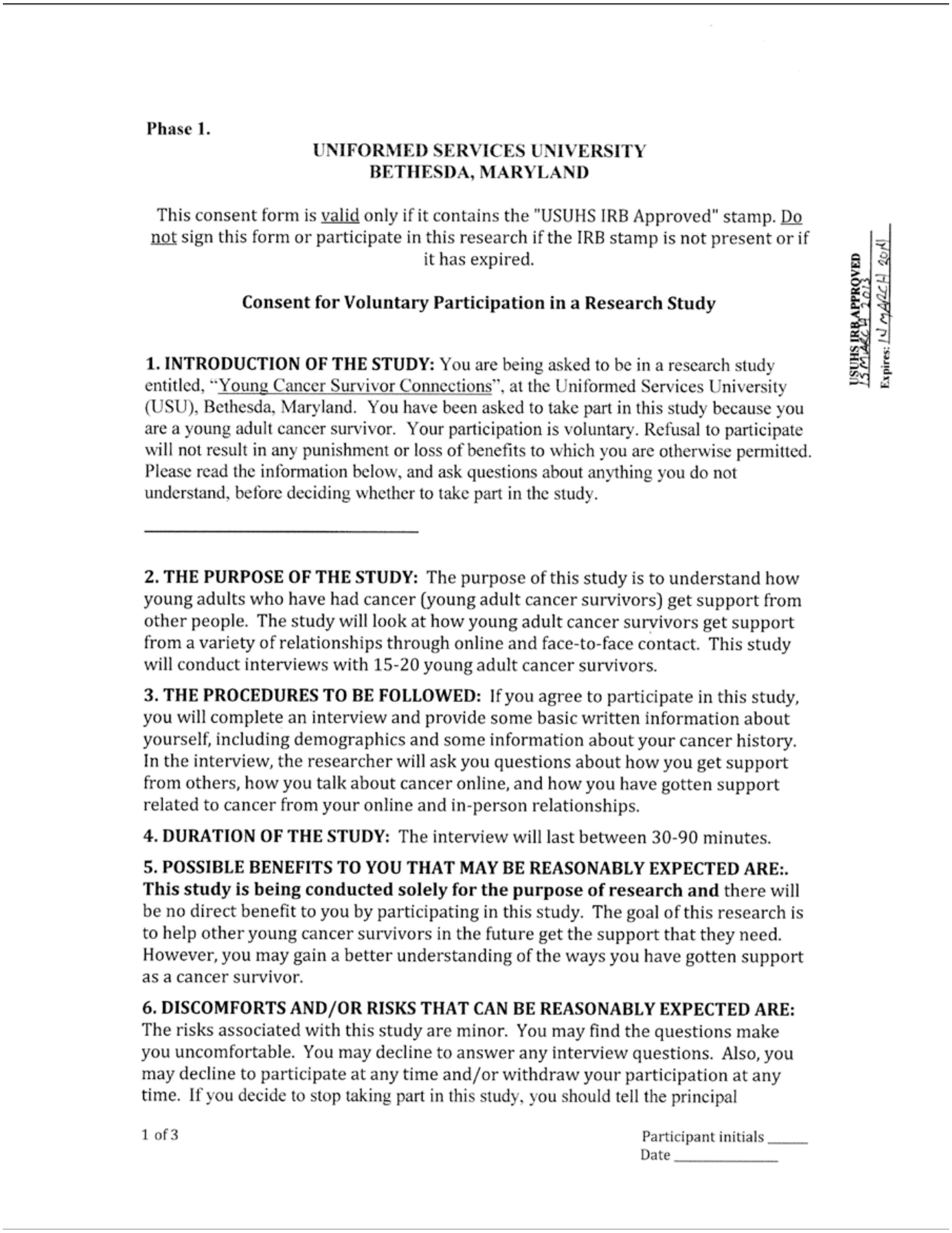
Edmund G. Howe, M.D., J.D.
Chair, IRB #1

[✓ Concur] / Nonconcur

John McManigle, Col (Ret), USAF, MC
Acting Dean, School of Medicine

This document has been signed electronically.

"Electronic Signature Notice: In accordance with the "Government Paperwork Elimination Act" (GPEA) (Pub.L. 105-277; codified at 44 USC 3504); Federal and DOD applicable instructions, directives and regulations, documents have been electronically signed and authorized by all who have been required to do so. These signatures have the same effect as their paper-based counterparts. Verification is retained within our protected electronic records and audit trails."



Phase 1.

UNIFORMED SERVICES UNIVERSITY
BETHESDA, MARYLAND

This consent form is valid only if it contains the "USUHS IRB Approved" stamp. Do not sign this form or participate in this research if the IRB stamp is not present or if it has expired.

USUHS IRB APPROVED
15 MARCH 2013
Expires: 14 MARCH 2014

Consent for Voluntary Participation in a Research Study

1. INTRODUCTION OF THE STUDY: You are being asked to be in a research study entitled, "Young Cancer Survivor Connections", at the Uniformed Services University (USU), Bethesda, Maryland. You have been asked to take part in this study because you are a young adult cancer survivor. Your participation is voluntary. Refusal to participate will not result in any punishment or loss of benefits to which you are otherwise permitted. Please read the information below, and ask questions about anything you do not understand, before deciding whether to take part in the study.

2. THE PURPOSE OF THE STUDY: The purpose of this study is to understand how young adults who have had cancer (young adult cancer survivors) get support from other people. The study will look at how young adult cancer survivors get support from a variety of relationships through online and face-to-face contact. This study will conduct interviews with 15-20 young adult cancer survivors.

3. THE PROCEDURES TO BE FOLLOWED: If you agree to participate in this study, you will complete an interview and provide some basic written information about yourself, including demographics and some information about your cancer history. In the interview, the researcher will ask you questions about how you get support from others, how you talk about cancer online, and how you have gotten support related to cancer from your online and in-person relationships.

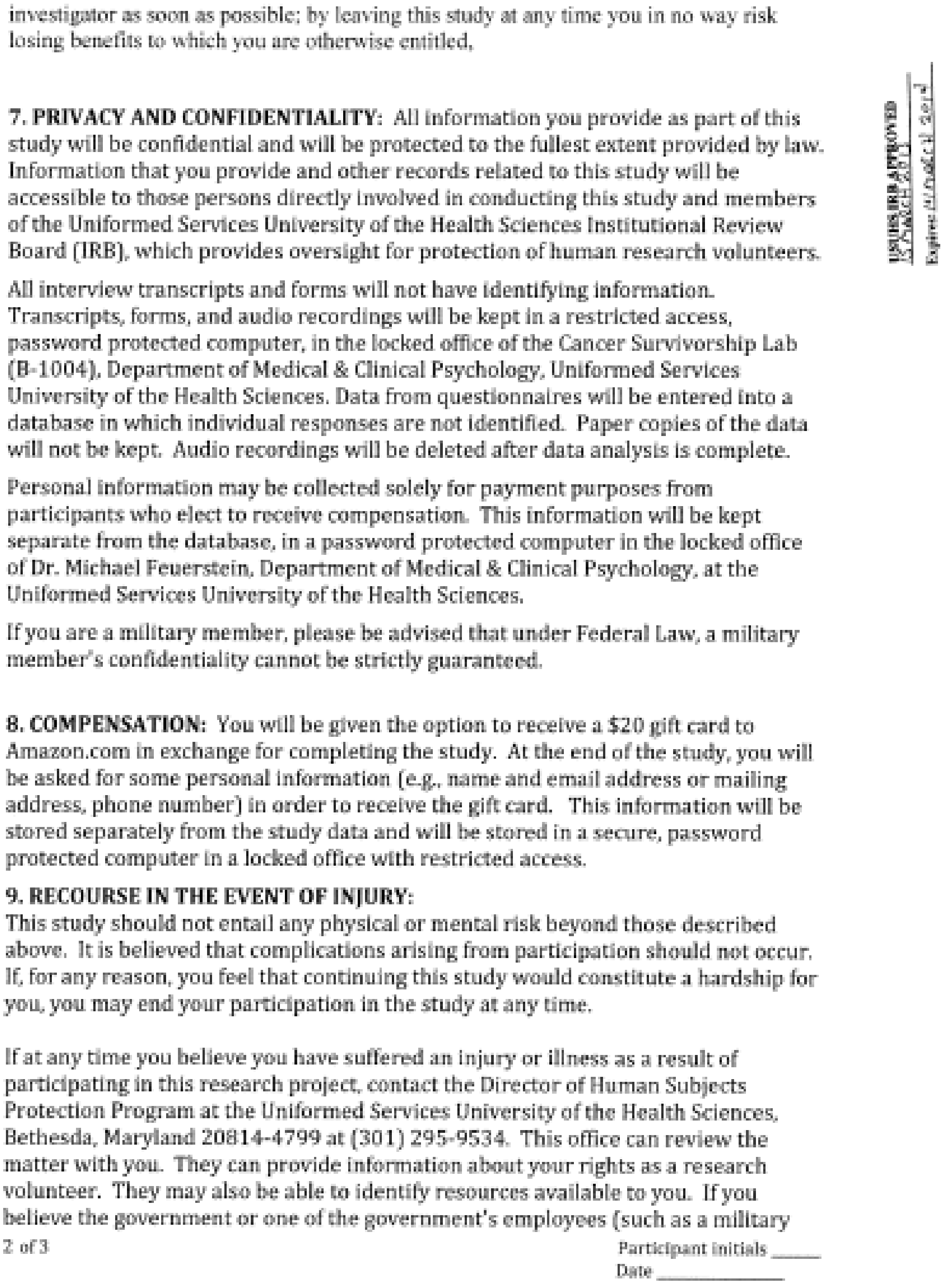
4. DURATION OF THE STUDY: The interview will last between 30-90 minutes.

5. POSSIBLE BENEFITS TO YOU THAT MAY BE REASONABLY EXPECTED ARE:. This study is being conducted solely for the purpose of research and there will be no direct benefit to you by participating in this study. The goal of this research is to help other young cancer survivors in the future get the support that they need. However, you may gain a better understanding of the ways you have gotten support as a cancer survivor.

6. DISCOMFORTS AND/OR RISKS THAT CAN BE REASONABLY EXPECTED ARE: The risks associated with this study are minor. You may find the questions make you uncomfortable. You may decline to answer any interview questions. Also, you may decline to participate at any time and/or withdraw your participation at any time. If you decide to stop taking part in this study, you should tell the principal

1 of 3

Participant initials _____
Date _____________



investigator as soon as possible; by leaving this study at any time you in no way risk losing benefits to which you are otherwise entitled,

USUHS IRB APPROVED
[illegible] MARCH 2013
Expires [illegible]

7. PRIVACY AND CONFIDENTIALITY: All information you provide as part of this study will be confidential and will be protected to the fullest extent provided by law. Information that you provide and other records related to this study will be accessible to those persons directly involved in conducting this study and members of the Uniformed Services University of the Health Sciences Institutional Review Board (IRB), which provides oversight for protection of human research volunteers.

All interview transcripts and forms will not have identifying information. Transcripts, forms, and audio recordings will be kept in a restricted access, password protected computer, in the locked office of the Cancer Survivorship Lab (B-1004), Department of Medical & Clinical Psychology, Uniformed Services University of the Health Sciences. Data from questionnaires will be entered into a database in which individual responses are not identified. Paper copies of the data will not be kept. Audio recordings will be deleted after data analysis is complete.

Personal information may be collected solely for payment purposes from participants who elect to receive compensation. This information will be kept separate from the database, in a password protected computer in the locked office of Dr. Michael Feuerstein, Department of Medical & Clinical Psychology, at the Uniformed Services University of the Health Sciences.

If you are a military member, please be advised that under Federal Law, a military member's confidentiality cannot be strictly guaranteed.

8. COMPENSATION: You will be given the option to receive a $20 gift card to Amazon.com in exchange for completing the study. At the end of the study, you will be asked for some personal information (e.g., name and email address or mailing address, phone number) in order to receive the gift card. This information will be stored separately from the study data and will be stored in a secure, password protected computer in a locked office with restricted access.

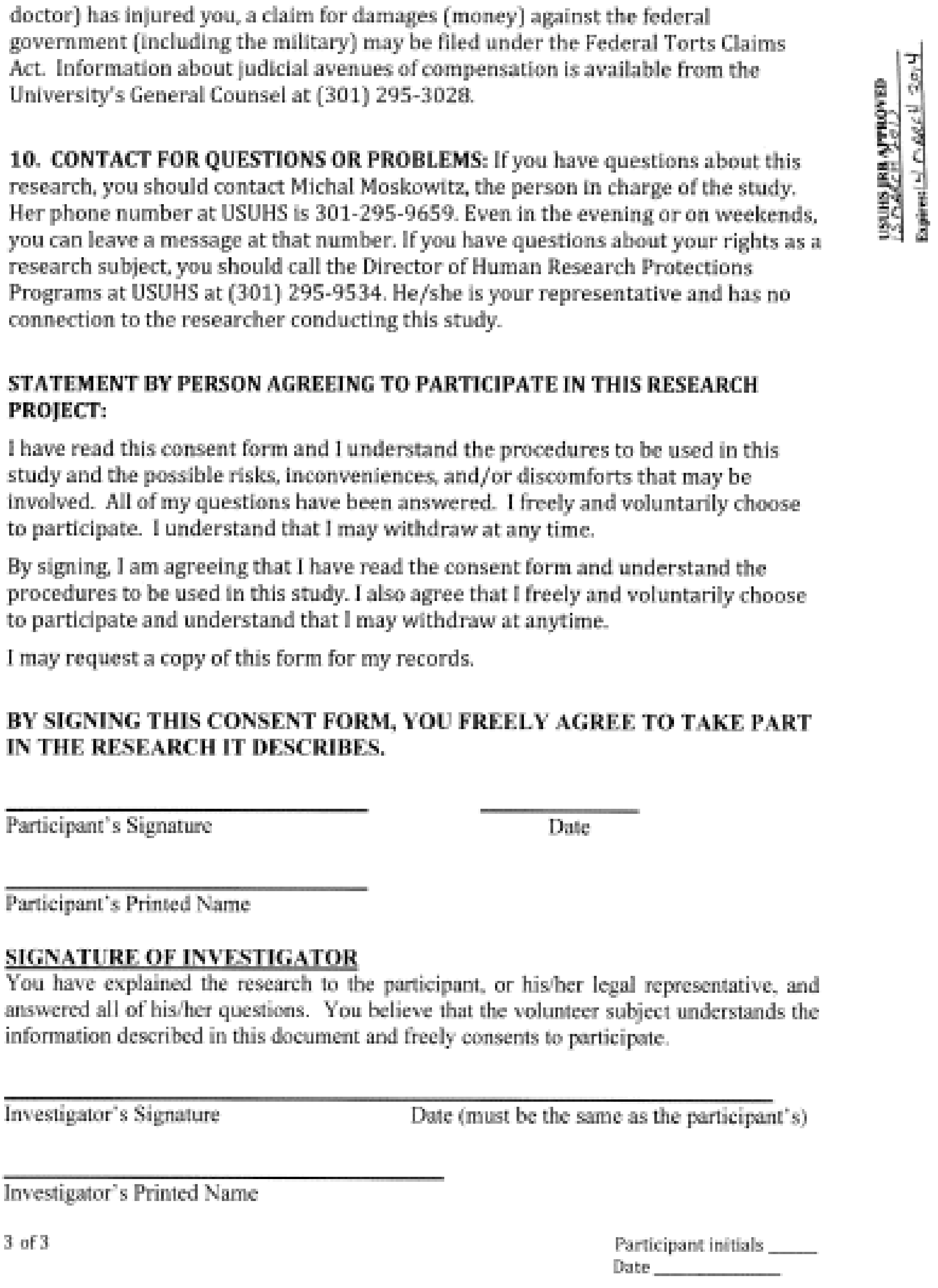
9. RECOURSE IN THE EVENT OF INJURY:

This study should not entail any physical or mental risk beyond those described above. It is believed that complications arising from participation should not occur. If, for any reason, you feel that continuing this study would constitute a hardship for you, you may end your participation in the study at any time.

If at any time you believe you have suffered an injury or illness as a result of participating in this research project, contact the Director of Human Subjects Protection Program at the Uniformed Services University of the Health Sciences, Bethesda, Maryland 20814-4799 at (301) 295-9534. This office can review the matter with you. They can provide information about your rights as a research volunteer. They may also be able to identify resources available to you. If you believe the government or one of the government's employees (such as a military

2 of 3

Participant initials ______
Date ______________



doctor) has injured you, a claim for damages (money) against the federal government (including the military) may be filed under the Federal Torts Claims Act. Information about judicial avenues of compensation is available from the University's General Counsel at (301) 295-3028.

USUHS IRB APPROVED
15 March 2013
Expires: 14 March 2014

10. CONTACT FOR QUESTIONS OR PROBLEMS: If you have questions about this research, you should contact Michal Moskowitz, the person in charge of the study. Her phone number at USUHS is 301-295-9659. Even in the evening or on weekends, you can leave a message at that number. If you have questions about your rights as a research subject, you should call the Director of Human Research Protections Programs at USUHS at (301) 295-9534. He/she is your representative and has no connection to the researcher conducting this study.

STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS RESEARCH PROJECT:

I have read this consent form and I understand the procedures to be used in this study and the possible risks, inconveniences, and/or discomforts that may be involved. All of my questions have been answered. I freely and voluntarily choose to participate. I understand that I may withdraw at any time.

By signing, I am agreeing that I have read the consent form and understand the procedures to be used in this study. I also agree that I freely and voluntarily choose to participate and understand that I may withdraw at anytime.

I may request a copy of this form for my records.

BY SIGNING THIS CONSENT FORM, YOU FREELY AGREE TO TAKE PART IN THE RESEARCH IT DESCRIBES.

_______________________________ _____________
Participant's Signature Date

____
Participant's Printed Name

SIGNATURE OF INVESTIGATOR

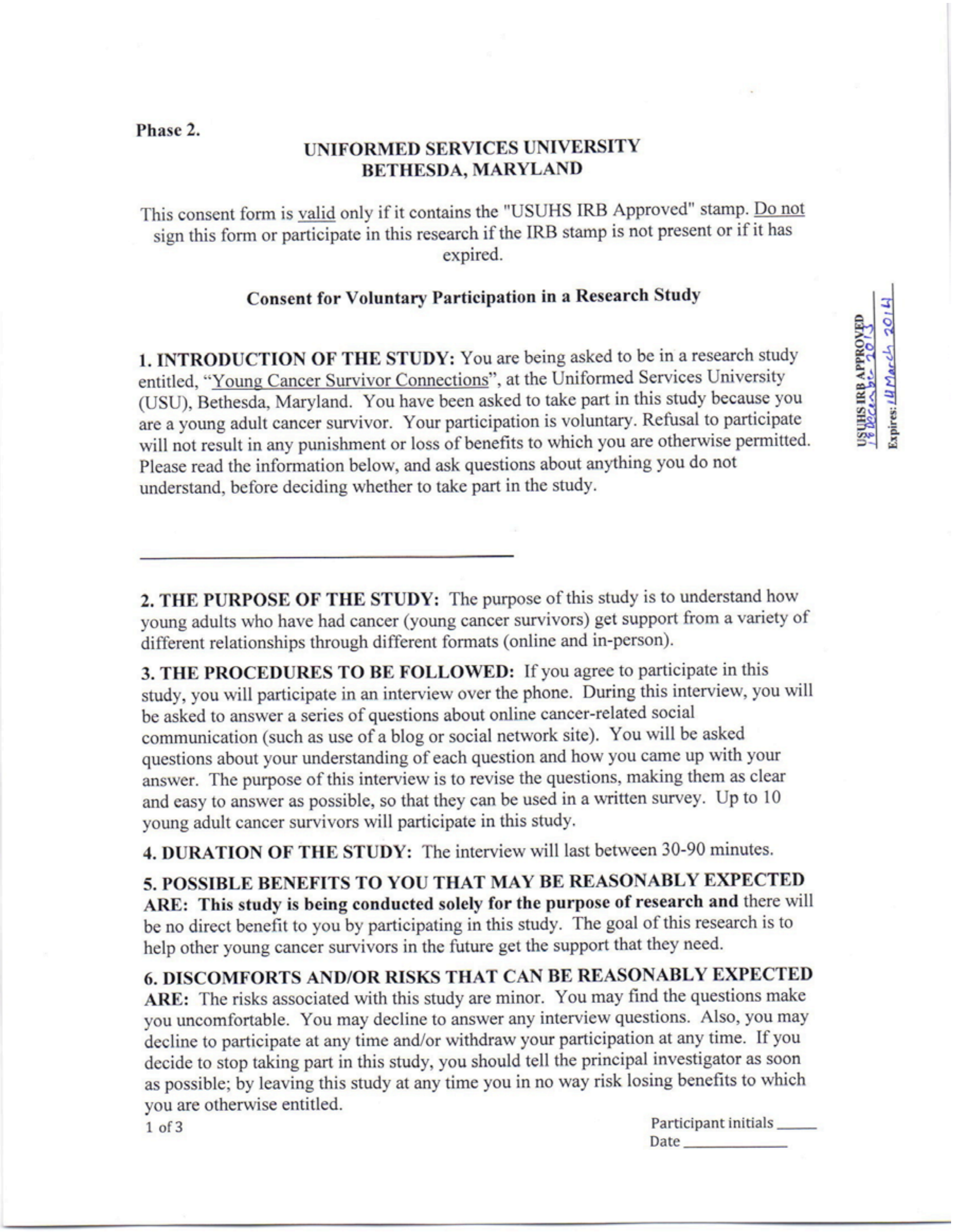
You have explained the research to the participant, or his/her legal representative, and answered all of his/her questions. You believe that the volunteer subject understands the information described in this document and freely consents to participate.

____
Investigator's Signature Date (must be the same as the participant's)

____
Investigator's Printed Name

3 of 3

Participant initials _____
Date ____________



Phase 2.

UNIFORMED SERVICES UNIVERSITY
BETHESDA, MARYLAND

This consent form is valid only if it contains the "USUHS IRB Approved" stamp. Do not sign this form or participate in this research if the IRB stamp is not present or if it has expired.

Consent for Voluntary Participation in a Research Study

1. INTRODUCTION OF THE STUDY: You are being asked to be in a research study entitled, "Young Cancer Survivor Connections", at the Uniformed Services University (USU), Bethesda, Maryland. You have been asked to take part in this study because you are a young adult cancer survivor. Your participation is voluntary. Refusal to participate will not result in any punishment or loss of benefits to which you are otherwise permitted. Please read the information below, and ask questions about anything you do not understand, before deciding whether to take part in the study.

USUHS IRB APPROVED 18 December 2013
Expires: 14 March 2014

---

2. THE PURPOSE OF THE STUDY: The purpose of this study is to understand how young adults who have had cancer (young cancer survivors) get support from a variety of different relationships through different formats (online and in-person).

3. THE PROCEDURES TO BE FOLLOWED: If you agree to participate in this study, you will participate in an interview over the phone. During this interview, you will be asked to answer a series of questions about online cancer-related social communication (such as use of a blog or social network site). You will be asked questions about your understanding of each question and how you came up with your answer. The purpose of this interview is to revise the questions, making them as clear and easy to answer as possible, so that they can be used in a written survey. Up to 10 young adult cancer survivors will participate in this study.

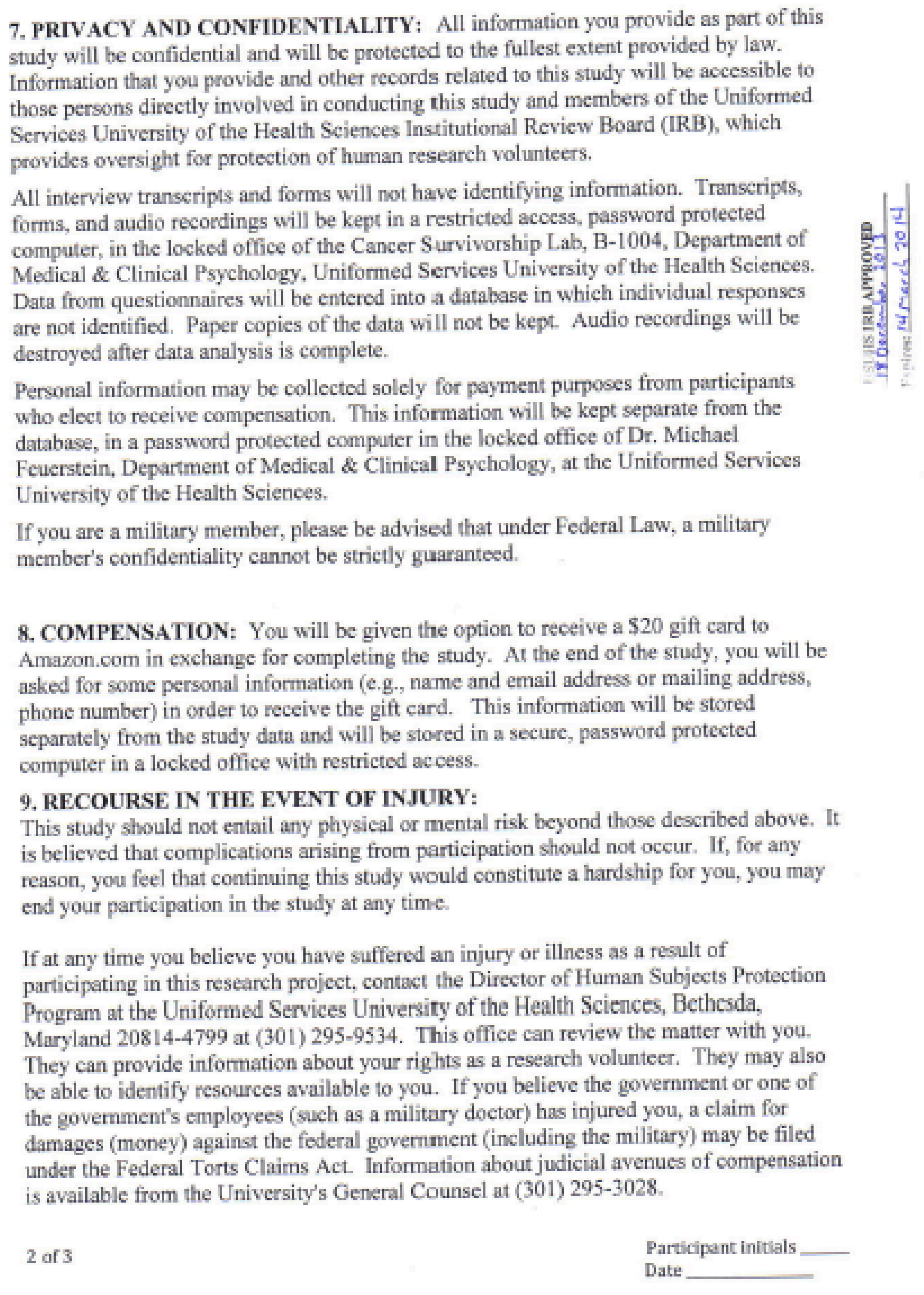
4. DURATION OF THE STUDY: The interview will last between 30-90 minutes.

5. POSSIBLE BENEFITS TO YOU THAT MAY BE REASONABLY EXPECTED ARE: This study is being conducted solely for the purpose of research and there will be no direct benefit to you by participating in this study. The goal of this research is to help other young cancer survivors in the future get the support that they need.

6. DISCOMFORTS AND/OR RISKS THAT CAN BE REASONABLY EXPECTED ARE: The risks associated with this study are minor. You may find the questions make you uncomfortable. You may decline to answer any interview questions. Also, you may decline to participate at any time and/or withdraw your participation at any time. If you decide to stop taking part in this study, you should tell the principal investigator as soon as possible; by leaving this study at any time you in no way risk losing benefits to which you are otherwise entitled.

1 of 3

Participant initials _____
Date ____________



7. PRIVACY AND CONFIDENTIALITY: All information you provide as part of this study will be confidential and will be protected to the fullest extent provided by law. Information that you provide and other records related to this study will be accessible to those persons directly involved in conducting this study and members of the Uniformed Services University of the Health Sciences Institutional Review Board (IRB), which provides oversight for protection of human research volunteers.

All interview transcripts and forms will not have identifying information. Transcripts, forms, and audio recordings will be kept in a restricted access, password protected computer, in the locked office of the Cancer Survivorship Lab, B-1004, Department of Medical & Clinical Psychology, Uniformed Services University of the Health Sciences. Data from questionnaires will be entered into a database in which individual responses are not identified. Paper copies of the data will not be kept. Audio recordings will be destroyed after data analysis is complete.

USUHS IRB APPROVED 18 December 2013
Expires 14 March 2014

Personal information may be collected solely for payment purposes from participants who elect to receive compensation. This information will be kept separate from the database, in a password protected computer in the locked office of Dr. Michael Feuerstein, Department of Medical & Clinical Psychology, at the Uniformed Services University of the Health Sciences.

If you are a military member, please be advised that under Federal Law, a military member's confidentiality cannot be strictly guaranteed.

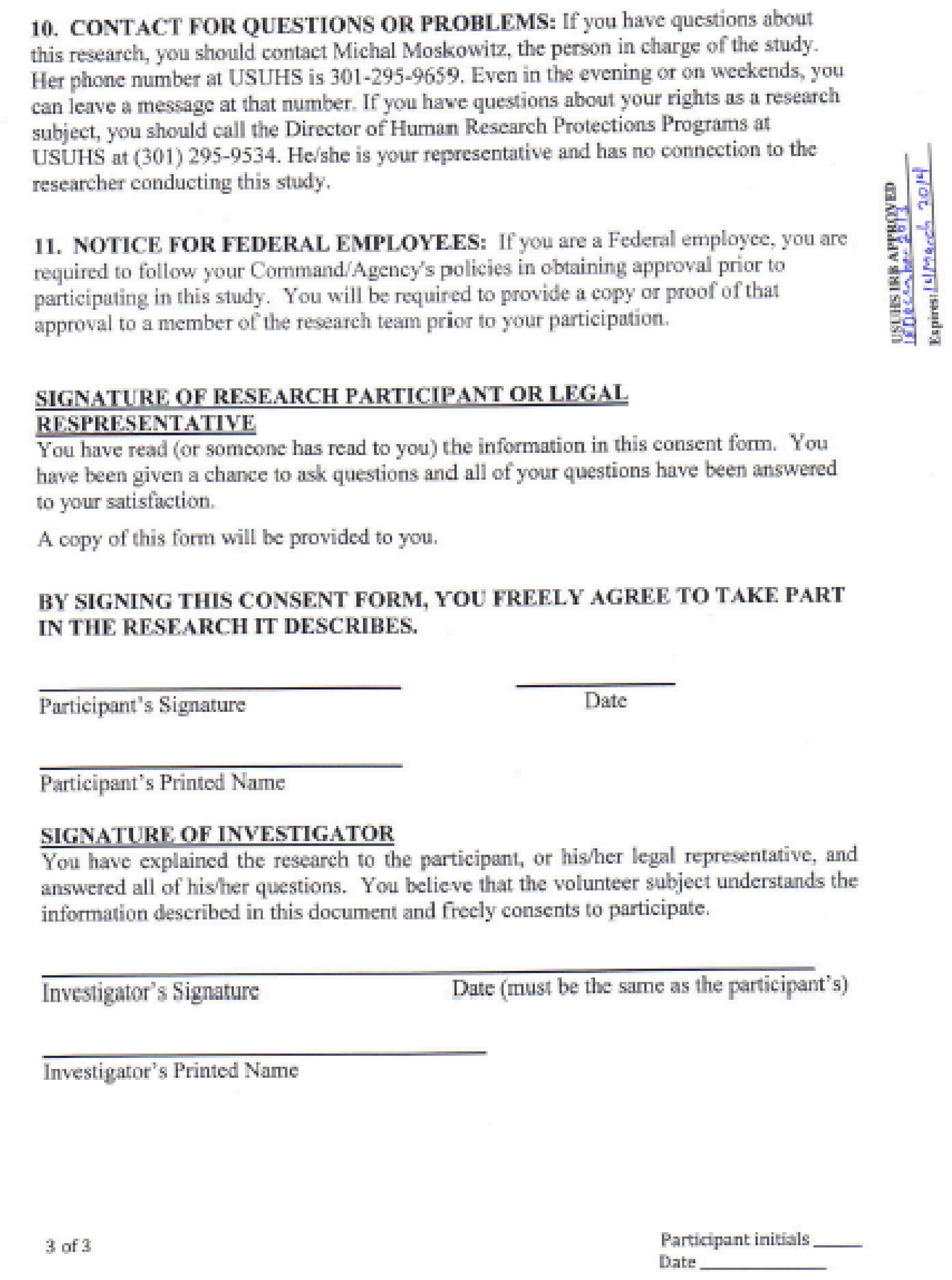
8. COMPENSATION: You will be given the option to receive a $20 gift card to Amazon.com in exchange for completing the study. At the end of the study, you will be asked for some personal information (e.g., name and email address or mailing address, phone number) in order to receive the gift card. This information will be stored separately from the study data and will be stored in a secure, password protected computer in a locked office with restricted access.

9. RECOURSE IN THE EVENT OF INJURY:
This study should not entail any physical or mental risk beyond those described above. It is believed that complications arising from participation should not occur. If, for any reason, you feel that continuing this study would constitute a hardship for you, you may end your participation in the study at any time.

If at any time you believe you have suffered an injury or illness as a result of participating in this research project, contact the Director of Human Subjects Protection Program at the Uniformed Services University of the Health Sciences, Bethesda, Maryland 20814-4799 at (301) 295-9534. This office can review the matter with you. They can provide information about your rights as a research volunteer. They may also be able to identify resources available to you. If you believe the government or one of the government's employees (such as a military doctor) has injured you, a claim for damages (money) against the federal government (including the military) may be filed under the Federal Torts Claims Act. Information about judicial avenues of compensation is available from the University's General Counsel at (301) 295-3028.

2 of 3

Participant initials ______
Date ____________



10. CONTACT FOR QUESTIONS OR PROBLEMS: If you have questions about this research, you should contact Michal Moskowitz, the person in charge of the study. Her phone number at USUHS is 301-295-9659. Even in the evening or on weekends, you can leave a message at that number. If you have questions about your rights as a research subject, you should call the Director of Human Research Protections Programs at USUHS at (301) 295-9534. He/she is your representative and has no connection to the researcher conducting this study.

11. NOTICE FOR FEDERAL EMPLOYEES: If you are a Federal employee, you are required to follow your Command/Agency's policies in obtaining approval prior to participating in this study. You will be required to provide a copy or proof of that approval to a member of the research team prior to your participation.

USUHS IRB APPROVED 18 December 2013
Expires: 11 March 2014

SIGNATURE OF RESEARCH PARTICIPANT OR LEGAL RESPRESENTATIVE

You have read (or someone has read to you) the information in this consent form. You have been given a chance to ask questions and all of your questions have been answered to your satisfaction.

A copy of this form will be provided to you.

BY SIGNING THIS CONSENT FORM, YOU FREELY AGREE TO TAKE PART IN THE RESEARCH IT DESCRIBES.

Participant's Signature ______________ Date ______________

Participant's Printed Name ______________

SIGNATURE OF INVESTIGATOR

You have explained the research to the participant, or his/her legal representative, and answered all of his/her questions. You believe that the volunteer subject understands the information described in this document and freely consents to participate.

Investigator's Signature ______________ Date (must be the same as the participant's)

Investigator's Printed Name ______________

3 of 3

Participant initials ______
Date ______________

Phase 3. [CONSENT FORM PRESENTED ON SPLASH PAGE OF ONLINE SURVEY]

UNIFORMED SERVICES UNIVERSITY
BETHESDA, MARYLAND

Consent for Voluntary Participation in a Research Study

1. INTRODUCTION OF THE STUDY: You are being asked to be in a research study entitled, "Young Cancer Survivor Connections", at the Uniformed Services University (USU), Bethesda, Maryland. You have been asked to take part in this study because you are a young adult cancer survivor. Your participation is voluntary. Refusal to participate will not result in any punishment or loss of benefits to which you are otherwise permitted. Please read the information below, and ask questions about anything you do not understand, before deciding whether to take part in the study.

---

2. THE PURPOSE OF THE STUDY: The purpose of this study is to understand how young adults who have had cancer (young cancer survivors) get support from a variety of different relationships through different formats (online and in-person). Between 80-150 young adult cancer survivors will complete this study.

3. THE PROCEDURES TO BE FOLLOWED: If you agree to participate in this study, you will complete an online survey. The survey will ask you questions about demographic and basic medical information, your social relationships, your perspective on cancer, and your needs.

4. DURATION OF THE STUDY: The questionnaire should take between 20-40 minutes to complete.

5. POSSIBLE BENEFITS TO YOU THAT MAY BE REASONABLY EXPECTED ARE:. This study is being conducted solely for the purpose of research and there will be no direct benefit to you by participating in this study. The goal of this research is to help other young cancer survivors in the future get the support that they need. However, you may gain a better understanding of the ways you have gotten support as a cancer survivor.

6. DISCOMFORTS AND/OR RISKS THAT CAN BE REASONABLY EXPECTED ARE: The risks associated with this study are minor. You may find the questions make you uncomfortable. You may skip any questions. Also, you may decline to participate at any time and/or withdraw your participation at any time. If you decide to stop taking part in this study, you should tell the principal investigator as soon as possible; by leaving this study at any time you in no way risk losing benefits to which you are otherwise entitled,

8. PRIVACY AND CONFIDENTIALITY: All information you provide as part of this study will be confidential and will be protected to the fullest extent provided by law. Information that you provide and other records related to this study will be accessible to those persons directly involved in conducting this study and members of the Uniformed Services University of the Health Sciences Institutional Review Board (IRB), which provides oversight for protection of human research volunteers.

All survey data will not have identifying information and will be kept in a restricted access, password protected computer, in the locked office of the Cancer Survivorship Lab, B-1004, Department of Medical & Clinical Psychology, Uniformed Services University of the Health Sciences. Anonymous data will be kept until data analysis is complete.

Personal information may be collected solely for payment purposes from participants who elect to receive compensation. This information will be kept separate from the database, in a password protected computer in the locked office of Dr. Michael Feuerstein, Department of Medical & Clinical Psychology at the Uniformed Services University of the Health Sciences.

If you are a military member, please be advised that under Federal Law, a military member's confidentiality cannot be strictly guaranteed.

9. COMPENSATION: You will be given the option to receive a $20 gift card in exchange for completing the study. At the end of the study, you will be asked for some personal information (e.g., name and email address, mailing address, phone number) in order to receive the gift card. This information will be stored separately from the study data and will be stored in a secure, password protected computer in a locked office with restricted access.

10. RECOURSE IN THE EVENT OF INJURY:

This study should not entail any physical or mental risk beyond those described above. It is believed that complications arising from participation should not occur. If, for any reason, you feel that continuing this study would constitute a hardship for you, you may end your participation in the study at any time.

If at any time you believe you have suffered an injury or illness as a result of participating in this research project, contact the Director of Human Subjects Protection Program at the Uniformed Services University of the Health Sciences, Bethesda, Maryland 20814-4799 at (301) 295-9534. This office can review the matter with you. They can provide information about your rights as a research volunteer. They may also be able to identify resources available to you. If you believe the government or one of the government's employees (such as a military doctor) has injured you, a claim for damages (money) against the federal government (including the military) may be filed under the Federal Torts Claims Act. Information about judicial avenues of compensation is available from the University's General Counsel at (301) 295-3028.

11. CONTACT FOR QUESTIONS OR PROBLEMS: If you have questions about this research, you should contact Michal Moskowitz, the person in charge of the study. Her phone number at USUHS is 301-295-9659. Even in the evening or on weekends, you can leave a message at that number. If you have questions about your rights as a research subject, you should call the Director of Human Research Protections Programs at USUHS at (301) 295-9534. He/she is your representative and has no connection to the researcher conducting this study.

STATEMENT BY PERSON AGREEING TO PARTICIPATE IN THIS RESEARCH PROJECT:

I have read this consent form and I understand the procedures to be used in this study and the possible risks, inconveniences, and/or discomforts that may be involved. All of my questions have been answered. I freely and voluntarily choose to participate. I understand that I may withdraw at any time.

By signing, I am agreeing that I have read the consent form and understand the procedures to be used in this study. I also agree that I freely and voluntarily choose to participate and understand that I may withdraw at anytime.

I may request a copy of this form for my records.

BY CHECKING "YES," YOU FREELY AGREE TO TAKE PART IN THE RESEARCH IT DESCRIBED.

__ Yes, I consent to participate
__ No, I do not consent to participate

APPENDIX B: SCREENING QUESTIONNAIRE (ALL PHASES)

1. Are you currently between ages 19-39?
   - ○ Yes
   - ○ No
2. Have you ever been diagnosed as having cancer?
   - ○ Yes
   - ○ No
3. What type of cancer did you have?
   - ○ Non-melanoma skin cancer (e.g., squamous cell, basal cell)
   - ○ Any other cancer, including melanoma
4. Were you diagnosed at age 18 or later?
   - ○ Yes
   - ○ No
5. Have you completed primary treatment for cancer (defined as surgery, radiation, chemotherapy, and/or bone marrow transplant)?
   - ○ Yes
   - ○ No
6. Did you complete primary treatment for cancer between 12 months - 5 years ago?
   - ○ Yes
   - ○ No
7. Have you ever been diagnosed with schizophrenia, a psychotic disorder, or dementia?
   - ○ Yes
   - ○ No
8. Is English your native language?
   - ○ Yes
   - ○ No
9. If English is NOT your native language, did you complete an 8th grade education or higher in English?
   - ○ Yes
   - ○ No
   - ○ N/A

APPENDIX C: DEMOGRAPHIC QUESTIONNAIRE (ALL PHASES)

1. What is your age? ________

2. Are you:

○ Male
○ Female

3. Are you Hispanic or Latino?

○ Yes
○ No

4. Which one or more of the following would you say is your race?

○ White
○ Black or African American
○ Asian
○ Native Hawaiian or Other Pacific Islander
○ American Indian or Alaska Native
○ Other (specify)

6. What is the highest grade or year of school you completed?

○ Never attended school or only attended kindergarten
○ Grades 1 through 8 (Elementary)
○ Grades 9 through 11 (Some high school)
○ Grade 12 or GED (High school graduate)
○ College 1 year to 3 years (Some college or technical school)
○ College 4 years or more (College graduate)
○ Postgraduate

7. Are you currently…?

○ Employed for wages
○ Self-employed
○ Out of work for more than 1 year
○ Out of work for less than 1 year
○ A Homemaker
○ A Student
○ Retired
○ Unable to work
○ Other (specify)

8. What is your marital status?

○ Married
○ Living as married
○ Divorced
○ Widowed
○ Separated
○ Single, never married

9. What type of cancer did you have?

o Bone (including osteosarcoma, chondrosarcoma, Ewing's sarcoma)
o Brain/Central nervous system
o Breast
o Cervical
o Colon and Rectum
o Germ cell (non-gonadal, i.e. not testicular or ovarian)
o Leukemia
o Lymphoma (Hodgkin's)
o Lymphoma (non-Hodgkin's)
o Melanoma
o Ovarian
o Soft tissue (including liposarcoma, leiomyosarcoma, Kaposi sarcoma)
o Testicular
o Thyroid
o Uterine
o Other (specify)_________________

10. Would you say that in general your health is…?

o Excellent
o Very good
o Good
o Fair
o Poor
o Not sure

11. What stage was your cancer at diagnosis?

o I
o II
o III
o IV
o Other (specify)

12. In what year were you first told that you had cancer? _________

13. Did you ever receive any treatment for cancer?

o Yes
o No

14. What type of treatment did you receive? (check all that apply)

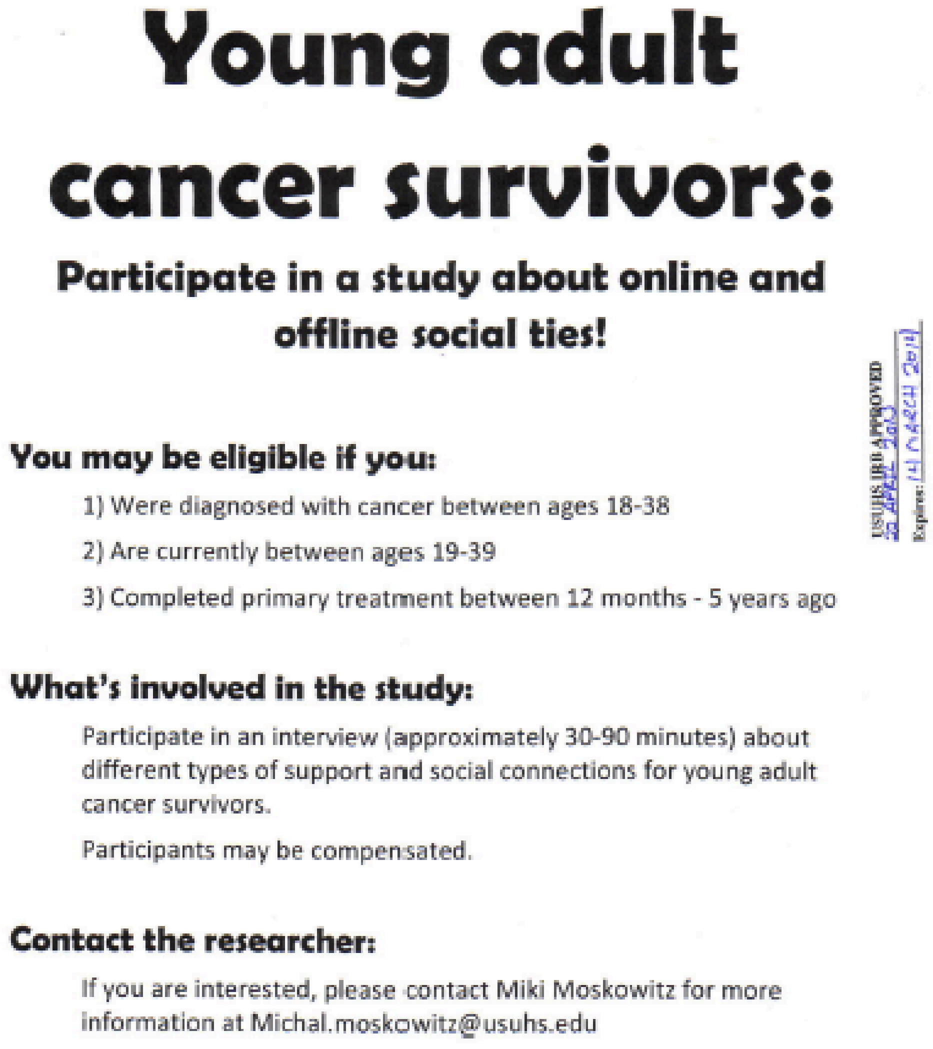
o Surgery
o Chemotherapy
o Radiation
o Bone marrow transplant
o Other (specify)

15. How long ago did you finish your most recent cancer treatment?

Years ____
Months ____

APPENDIX D: FLIERS

Phase 1 & 2 Fliers



Young adult cancer survivors:

Participate in a study about online and offline social ties!

USUHS IRB APPROVED
30 APRIL 2013
Expires: 14 MARCH 2014

You may be eligible if you:

1) Were diagnosed with cancer between ages 18-38
2) Are currently between ages 19-39
3) Completed primary treatment between 12 months - 5 years ago

What's involved in the study:

Participate in an interview (approximately 30-90 minutes) about different types of support and social connections for young adult cancer survivors.

Participants may be compensated.

Contact the researcher:

If you are interested, please contact Miki Moskowitz for more information at Michal.moskowitz@usuhs.edu

Phase 3 Flier:

Acancer

OR

Contact the researcher, Miki Moskowitz, at Michal.moskowitz@usuhs.edu

USUHS IRB APPROVED 22 APRIL 2013
Expires: 14 MARCH 2014

APPENDIX E: ORGANIZATIONS CONTACTED TO ASSIST WITH RECRUITMENT

ALAS Wings
American Cancer Society
Asian American Cancer Support Network
Athletes4Cancer
Bright Pink
Cuck Fancer
First Descents
George Washington Cancer Institute
Hope Connections for Cancer Support
Imerman Angels
Leukemia and Lymphoma Society
Life with Cancer
Light of Life Foundation for Thyroid Cancer
Nueva Vida
SamFund
Sarcoma Alliance
Sisters Network
Smith Center for Healing and the Arts
Stupid Cancer
ThyCa: Thyroid Cancer Survivors' Association
Ulman Cancer Fund for Young Adults
Young Survival Coalition

APPENDIX F: PHASE 1 INTERVIEW GUIDE

Interview Guide

This is a study about how young adults who've had cancer, like you, get the support they need from other people. Support can mean a lot of different things, such as:

- Emotional support: listening to you when you need to talk, making you feel loved, just "being there" for you
- Informational support: Giving you information, guidance, or advice about a problem
- Tangible support: Helping you out with practical things like giving you a ride somewhere, cooking you dinner
- Esteem support: Making you feel good about yourself, making you feel valued or competent
- Belonging support: Making you feel you belong to a group or community
- Opportunity for nurturance: Giving you the opportunity to give back or take care or someone else

Support can come from many types of people in your life, such as friends, family, co-workers, other cancer survivors, etc. It can take place in many different ways, such as in person, over the phone, online, from books or podcasts. I am going to ask about the different ways you feel that you access support as a cancer survivor.

1. Tell me about the support that is available to you from other people in your life.
    - *Follow-up, as needed*: Tell me about who provides you with support. Tell me what support looks like to you. How has that changed over time? (*differences between during treatment vs. immediate post-treatment vs. later post-treatment).*
2. Tell me about opportunities to interact with other young adults who have been diagnosed with cancer.
    - *Follow up, as needed*: What is that like for you? How did you find those opportunities? How is that supportive to you? How is it NOT supportive? What kind of formal support opportunities have you had available to you (such as through your treatment facility or other organizations)? Tell me about your decision about engaging in those opportunities.
    - *If they have not interacted with other young cancer survivors*: Would you like to have more opportunities to meet other young adults who have had cancer? What makes you say that? What would that look like to you?
3. Tell me about using the Internet to communicate about your cancer. That includes writing/posting your own content OR reading/watching/listening to content posted by other individuals or organizations.

- *Follow up, as needed:* Tell me about the places you go online to read, watch, or post your own content about cancer. What led you to these places? What kinds of sites do you use? What do you do online to communicate about cancer? What is most helpful about these places? What is least helpful about these places? How has your online communication about cancer changed over time?
- *For those who post content (such as on blogs or social network sites):* Tell me about your target audience. Who are you trying to reach? What do you want them to take away from reading/watching what you post?
- *For those who do not engage in online cancer communication*: Tell me about your decision not to do that. What do you think about communicating with others about cancer online? What made you choose not to communicate about cancer online? What do you think about doing it in the future?

4. Tell me about how support from others has affected you as a cancer survivor.

   - *Follow up, as needed:* Tell me about the most valuable support you have received as a cancer survivor.
   - What are best parts of support you get online? What are the worst parts of getting support online? Tell me about the differences between online vs. in-person support. Which way do you feel most supported?
   - What are the best parts of getting support from family or friends in person? What are the worst parts about getting support from family and friends in person?
   - Tell me about the differences between support from friends and family vs. other young adult cancer survivors. How do they each help you?

5. What else do you think researchers or clinicians should know about how young adult cancer survivors get support?

6. If you were in charge of making sure that young adult cancer survivors got good support, what would you do?

   - *Follow up, as needed:* Do you feel there are any avenues of support that you wish you had access to but don't? Tell me about those. What has gotten in your way of accessing those?

APPENDIX G: PHASE 3 ONLINE QUESTIONNAIRE

Social Network Index

This questionnaire is concerned with how many people you see or talk to on a regular basis including family, friends, workmates, neighbors, etc. Please read and answer each question carefully. Answer follow-up questions where appropriate.

1. Which of the following best describes your marital status?
____ (1) currently married & living together, or living with someone in marital-like relationship
____ (2) never married & never lived with someone in a marital-like relationship
____ (3) separated
____ (4) divorced or formerly lived with someone in a marital-like relationship
____ (5) widowed

2. How many children do you have? (If you don't have any children, check '0' and skip to question 3.)
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

2a. How many of your children do you see or talk to on the phone at least once every 2 weeks?
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

3. Are either of your parents living? (If neither is living, check '0' and skip to question 4.)
____ (0) neither ____ (1) mother only ____ (2) father only ____ (3) both

3a. Do you see or talk on the phone to either of your parents at least once every 2 weeks?
____ (0) neither ____ (1) mother only ____ (2) father only ____ (3) both

4. Are either of your in-laws (or partner's parents) living? (If you have none, check the appropriate space and skip to question 5.)
____ (0) neither ____ (1) mother only ____ (2) father only ____ (3) both ____ (4) not applicable

4a. Do you see or talk on the phone to either of your partner's parents at least once every 2 weeks?
_____ (0) neither _____ (1) mother only _____ (2) father only ____ (3) both

5. How many other relatives (other than your spouse, parents & children) do you feel close to? (If '0', check that space and skip to question 6.)
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

5a. How many of these relatives do you see or talk to on the phone at least once every 2 weeks?
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

6. How many close friends do you have? (meaning people that you feel at ease with, can talk to about private matters, and can call on for help)
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

6a. How many of these friends do you see or talk to at least once every 2 weeks?
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

7. Do you belong to a church, temple, or other religious group? (If not, check 'no' and skip to question 8.)
_____ no _____ yes

7a. How many members of your church or religious group do you talk to at least once every 2 weeks? (This includes at group meetings and services.)
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

8. Do you attend any classes (school, university, technical training, or adult education) on a regular basis? (If not, check 'no' and skip to question 9.)
_____ no _____ yes

8a. How many fellow students or teachers do you talk to at least once every 2 weeks? (This includes at class meetings.)
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

9. Are you currently employed either full or part-time? (If not, check 'no' and skip to question 10.)
____ (0) no _____ (1) yes, self-employed _____ (2) yes, employed by others

9a. How many people do you supervise?
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

9b. How many people at work (other than those you supervise) do you talk to at least once every 2 weeks?
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

10. How many of your neighbors do you visit or talk to at least once every 2 weeks?
_____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

11. Are you currently involved in regular volunteer work? (If not, check 'no,' skip to question 12.)
_____ no _____ yes

11a. How many people involved in this volunteer work do you talk to about volunteering-related issues at least once every 2 weeks?
____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

12. Do you belong to any groups in which you talk to one or more members of the group about group-related issues at least once every 2 weeks? Examples include social clubs, recreational groups, trade unions, commercial groups, professional organizations, groups concerned with children like the PTA or Boy Scouts, groups concerned with community service, etc. (If you don't belong to any such groups, check 'no' and skip the section below.)
_____ no _____ yes

Consider those groups in which you talk to a fellow group member at least once every 2 weeks. Please provide the following information for each such group: the name or type of group and the total number of members in that group that you talk to at least once every 2 weeks.
Name or type of group:
Number of members in the group that you talk to at least every 2 weeks:

13. How many other adolescents or young adults do you know who have, or have had, cancer (young cancer survivors)?
_____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

13a. How many of these young cancer survivors do you see or talk to at least once every two weeks?
_____0 ____1 ____2 ____3 ____4 ____5 ____6 ____7 or more

General Online Activities

Please tell me if you ever use the Internet to do any of the following.

Do you ever:

	Several times a day	About once a day	3-5 days a week	1-2 days a week	Every few weeks	Less often	Never
Send or receive email							
Use Facebook							
Visit an online forum or discussion board, even if you do not post (not through Facebook)							
Create or work on your own online journal or blog (including sites such as CaringBridge)							
Read someone else's online journal or blog							
Use Twitter							

Online Cancer Support Activities

The following questions ask about activities you did in these time periods since you learned you had cancer:

1) **Before** you finished primary treatment for cancer (e.g. chemo, radiation, surgery). *Continuing hormone therapy like tamoxifen does not count as primary treatment.*
2) **After** you finished primary treatment for cancer (e.g. chemo, radiation, surgery)
3) In the last **30 days**

Have you done any of the following since you learned you had cancer? Check all that apply.

	Never	Before you finished primary treatment	After you finished primary treatment	In the last 30 days
Wrote mass email updates about cancer to your family/friends				
Posted personal cancer-related updates on your OWN Facebook page (e.g. status update about your treatment or symptoms, link to your cancer blog)				
Visited but did NOT post or comment on a Facebook group for cancer patients/survivors (e.g. Stupid Cancer Facebook group)				
Posted or commented on a Facebook group for cancer patients/survivors (e.g. Stupid Cancer Facebook group).				
Visited but did NOT post on an online forum for cancer patients/survivors (not through Facebook, e.g. Planet Cancer, cancer.org).				
Posted or commented on an online forum for cancer patients/survivors (not through Facebook, e.g. Planet Cancer, cancer.org).				
Created or worked on your own online journal or blog about cancer (including sites such as CaringBridge).				
Read or viewed another cancer patient/survivor's online journal, blog, or narrative				
Used Twitter to tweet about cancer (e.g. update about your treatment or symptoms, link to your cancer blog).				
Used Twitter to read updates or posts about cancer (e.g. cancer news stories, cancer-related events)				
Communicated online one-on-one (e.g. email, gchat, Facebook message)				
Other online communication about cancer (e.g. had your story featured on a website; webinar; mobile apps).				

Cancer Social Network Relationships

The following questions ask about connections you had with others in these time periods since you learned you had cancer:

1) **Before** you finished primary treatment for cancer (e.g. chemo, radiation, surgery). *Continuing hormone therapy like tamoxifen does not count as primary treatment.*
2) **After** you finished primary treatment for cancer (e.g. chemo, radiation, surgery)
3) In the last **30 days**

Have you had any of the following connections since you learned you had cancer? Check all that apply.

	Never	Before you finished primary treatment	After you finished primary treatment	In the last 30 days
RECEIVED a formal cancer patient/survivor mentor **(e.g. in a one-on-one matching program like Imerman Angels, YSC SurvivorLink, hospital-based program)**				
RECEIVED an informal cancer patient/survivor mentor **(e.g. introduced by a mutual friend)**				
SERVED AS a formal cancer patient/survivor mentor **(e.g. in a one-on-one matching program like Imerman Angels, YSC SurvivorLink, hospital-based program)**				
SERVED AS an informal cancer patient/survivor mentor **(e.g. introduced by a mutual friend)**				
Had other limited in-person informal contact with another cancer patient/survivor(s) **(e.g. went out for coffee once or twice, hung out at an event, just talked)**				
Had an in-person ongoing friendship with another cancer patient/survivor(s)				
Other connection (please specify)				

Cancer In-Person Support Activities

Have you done any of these activities since you learned you had cancer? Check all that apply.

	Never	Before you finished primary treatment	After you finished primary treatment	In the last 30 days
Completed a cancer-related athletic event (e.g. Team in Training, Relay for Life)				
Volunteered for a cancer-related organization or event (e.g. fundraising, staffing a booth at an event)				
Attended a camp, retreat, or outdoor adventure trip for cancer patients/survivors (e.g. First Descents)				
Attended an in-person lecture, conference, workshop, educational event, or wellness program for cancer patients/survivors (e.g. OMG Summit, Look Good Feel Better, nutrition class)				
Presented at an in-person cancer-related lecture, conference, workshop, educational event, or wellness program for cancer patients/survivors				
Attended a social event for cancer patients/survivors (e.g. meet-up, happy hour, dinner, movie)				
Attended an in-person formal support group for cancer patients/survivors led by a facilitator				
Other (please specify, e.g. had friends run a cancer race on your behalf, attended a support group for people with chronic illness in general)				

Social Provisions Scale

In answering the next set of questions I am going to ask you, I want you to think about your current relationship with friends, family members, coworkers, community members, and so on. Please tell me to what extent you agree that each statement describes your current relationships with other people. Use the following scale to give me your opinion.

Strongly Disagree	*Disagree*	*Agree*	*Strongly Agree*
1	*2*	*3*	*4*

1. There are people I can depend on to help me if I really need it. _____
2. I feel that I do not have close personal relationships with other people. _____
3. There is no one I can turn to for guidance in times of stress. _____
4. There are people who depend on me for help. _____
5. There are people who enjoy the same social activities I do. _____
6. Other people do not view me as competent. _____
7. I feel personally responsible for the well-being of another person. _____
8. I feel part of a group of people who share my attitudes and beliefs. _____
9. I do not think other people respect my skills and abilities. _____
10. If something went wrong, no one would come to my assistance. _____
11. I have close relationships that provide me with a sense of emotional security and well-being. _____
12. There is someone I could talk to about important decisions in my life. _____
13. I have relationships where my competence and skills are recognized. _____
14. There is no one who shares my interests and concerns. _____
15. There is no one who really relies on me for their well-being. _____
16. There is a trustworthy person I could turn to for advice if I were having problems. _____
17. I feel a strong emotional bond with at least one other person. _____
18. There is no one I can depend on for aid if I really need it. _____
19. There is no one I feel comfortable talking about problems with. _____
20. There are people who admire my talents and abilities. _____
21. I lack a feeling of intimacy with another person. _____
22. There is no one who likes to do the things I do. _____
23. There are people I can count on in an emergency. _____
24. No one needs me to care for them. _____

Impact of Cancer Scale

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I do not take my body for granted since the cancer………	1	2	3	4	5
2. Having had cancer has made me more concerned about my health....	1	2	3	4	5
3. I am more aware of physical problems or changes in my body since having had cancer	1	2	3	4	5
4. Having had cancer has made me take better care of myself (my health)……………………..	1	2	3	4	5
5. I consider myself to be a cancer survivor…….	1	2	3	4	5
6. I feel a sense of pride or accomplishment from having survived cancer…………………..	1	2	3	4	5
7. I learned something about myself because of having had cancer………………………………	1	2	3	4	5
8. I feel that I am a role model to other people with cancer………..	1	2	3	4	5
9. Having had cancer makes me feel unsure about my future…	1	2	3	4	5
10. I feel like time in my life is running out...........	1	2	3	4	5
11. I worry about the cancer coming back or about getting another cancer…………………..	1	2	3	4	5
12. Having had cancer makes me feel uncertain about my health……………………………….	1	2	3	4	5
13. I worry about my future.………...	1	2	3	4	5
14. New symptoms (aches, pains, getting sick or the flu) make me worry about the cancer coming back…………………………….	1	2	3	4	5
15. I worry about my health………..	1	2	3	4	5
16. I am concerned that my energy has not returned to what it was before I had cancer…	1	2	3	4	5
17. I am bothered that my body cannot do what it could before having had cancer……………..	1	2	3	4	5
18. Having had cancer has made me feel old……	1	2	3	4	5
19. I worry about how my body looks………	1	2	3	4	5
20. I feel disfigured…………………	1	2	3	4	5
21. I sometimes wear clothing to cover up parts of my body I do not want others to see………	1	2	3	4	5
22. I feel a special bond with people with cancer..	1	2	3	4	5
23. Because I had cancer I am more understanding of what other people may feel when they are seriously ill……………………..	1	2	3	4	5
24. Having had cancer has made me more willing to help others………	1	2	3	4	5
25. I feel that I should give something back to others because I survived cancer…….	1	2	3	4	5
26. I feel guilty today for not having been available to my family when I had cancer……	1	2	3	4	5
27. I feel like cancer runs my life…	1	2	3	4	5
28. Having had cancer has made me feel alone...	1	2	3	4	5

29. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me…………..	1	2	3	4	5
30. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school)	1	2	3	4	5
31. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family)……..	1	2	3	4	5
32. On-going cancer-related or treatment-related symptoms (for example, bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause, lack of energy, impotence/sexual problems, aches, pain or physical discomfort) interfere with my life……………………	1	2	3	4	5
33. Having had cancer turned into a reason to make changes in my life……………………..	1	2	3	4	5
34. Because of cancer I have become better about expressing what I want…………………	1	2	3	4	5
35. Because of cancer I have more confidence in myself…	1	2	3	4	5
36. Having had cancer has given me direction in life…………	1	2	3	4	5
37. Because of having had cancer I feel that I have more control of my life…………………	1	2	3	4	5

38. Are you currently married, living together as married, or in a significant relationship?
___ 1 Yes → Please skip to question 42 on the next page
___ 2 No
↓
Please answer questions 39-41 only if you are not currently married, living together as married, or in a significant relationship.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
39. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship…….	1	2	3	4	5
40. I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer…………………………………….	1	2	3	4	5
41. I worry about not having a spouse, partner, boyfriend or girlfriend………………………..	1	2	3	4	5

Please skip to question 46.

Answer questions 42-45 only if you are currently married, living together as married, or in a significant relationship. Otherwise, please skip to question 46.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
42. I am open and willing to discuss my cancer with my spouse/ partner………..	1	2	3	4	5
43. My spouse/partner is open and willing to discuss my cancer with me……….	1	2	3	4	5

44. Uncertainty about my health has created problems in my relationship with my spouse/partner…………	1	2	3	4	5
45. I worry about my spouse/ partner leaving me if I were to become ill again……	1	2	3	4	5

46. Are you fully retired from paid employment?

___ 1 Yes → Thank you, you have now completed the IOCv2 questionnaire.
___ 2 No
↓

47. Were you employed and earning income at some time during the last 12 months?

___ 0 No → Thank you, you have now completed the IOCv2 questionnaire.
___ 1 Yes
↓

Please answer questions 48-50 **only** if you were employed and earning income at some time during the last 12 months.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
48. I am concerned about not being able to work if I were to become ill again……………………	1	2	3	4	5
49. Concerns about losing health insurance keep me in the job I have now………………………..	1	2	3	4	5
50. I worry about being forced to retire or quit work before I am ready…………………….....	1	2	3	4	5

Unmet Coping, Sharing, and Emotional Needs

This part of the survey is about unmet needs that relate to your relationships with others and your emotional health IN THE LAST MONTH.

For each statement, circle the choice that best describes your level of unmet need.

	No unmet need	**Low unmet need**	**Moderate unmet need**	**High unmet need**	**Very high unmet need**
Telling others how I was feeling emotionally	0	1	2	3	4
Finding someone to talk to who understands and has been through a similar experience	0	1	2	3	4
Dealing with people who expect me to be "back to normal"	0	1	2	3	4
Dealing with people accepting that having cancer has changed me as a person	0	1	2	3	4
Dealing with reduced support from others when treatment has ended	0	1	2	3	4
Dealing with feeling depressed	0	1	2	3	4
Dealing with feeling tired	0	1	2	3	4
Dealing with feeling stressed	0	1	2	3	4
Dealing with feeling lonely	0	1	2	3	4
Dealing with not being able to feel "normal"	0	1	2	3	4
Trying to stay positive	0	1	2	3	4
Coping with having a bad memory or lack of focus	0	1	2	3	4
Dealing with changes in how my body appears	0	1	2	3	4

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