I'M TOO YOUNG FOR THIS: ADOLESCENT AND YOUNG ADULT CANCER SURVIVORSHIP

A Dissertation

by

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ABSTRACT

As of January 1, 2012, an estimated 13.7 million cancer survivors were alive in the United States. The number of cancer survivors is expected to reach 18 million by the year 2022. Adolescent and Young Adult (AYA) cancer survivors, ages 15-39, are a population that experiences disparities in care, including a lack of evidence for increased survival.

This thesis presents three papers, each using different methods. The first, an analysis of AYA breast cancer survivors' risk factors including access to clinical trials, uses geographic information systems to map patients' distance to trials and logistic regression to analyze demographic and clinical risk factors. The second paper applies quantitative and qualitative analyses in an evaluation of a public and professional education project on AYA survivorship. The third paper uses qualitative methods and a theory-based taxonomy to assess the use of behavior change theories in mobile health (mHealth) applications for cancer survivorship.

The results demonstrate the multifactorial elements that impact AYA cancer survivorship, and suggest the need for interventions and expanded research. Additional research is needed to understand the unique physical and biological characteristics of AYAs, in particular those of AYA breast cancer survivors. The thesis illuminates the challenges AYA survivors experience with late effects—physical, psychosocial and financial—and the need for ongoing education for healthcare professionals. In considering the potential of mHealth applications for health behaviors change among

AYAs and other cancer survivors, the study articulates concerns about the limited use of theory in the majority of mHealth apps, and suggests the need for intervention designers to reflect more deeply on theoretical models.

This thesis contributes to the field of AYA survivorship research in its evidence assessing risk factors including distance to cancer trials for AYA breast cancer patients, by identifying ongoing educational needs for both survivors and providers and by assessing lack of theory and potential for improvement among mHealth interventions. It offers suggestions for future research, policies, and program changes, including the use of emerging mobile technology and sensors to engage AYA survivors both as participants and designers of research that could improve their quality of life and wellbeing.

DEDICATION

This dissertation is dedicated to the adolescent and young adult (AYA) cancer survivors, their caregivers and healthcare professionals who have so generously shared their experiences and ideas with me. And most especially, to my cousin Jimmy Shrite and our family friend, the potter, Dan Bastine, both AYA survivors who were too young for this.

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I. INTRODUCTION AND LITERATURE REVIEW

Cancer Survivorship Chronology and Background

Cancer survivorship is a distinct part of the cancer continuum. Despite the relative newness of the concept of cancer survivorship, we now have nearly 30 years of experience with advocacy, research, and care directed generally at cancer survivorship, and specifically at cancer survivors at different ages. Table 1.1 provides a brief chronology of major defining events in cancer survivorship.

Table 1.1 Brief Chronology of Cancer Survivorship in the United States (U.S.)

Year	Activity	Areas of Importance
1937	National Cancer Act	Established the National Cancer Institute (NCI)
1971	National Cancer Act	"War on Cancer" launched. Number of cancer survivors estimated at 3 million
1973	Surveillance Epidemiology and End Results Program (SEER)	Initiated annual collection of cancer incidence and mortality data
1982	Susan G. Komen Foundation	Breast cancer advocacy group representing the largest number of survivors of a specific disease
1986	National Coalition for Cancer Survivorship	Instituted term "cancer survivor"
1995	First National Congress on Cancer Survivorship	Beginning of national advocacy movement
1996	NCI established the National Office of Cancer Survivorship	Office of Cancer Survivorship works with SEER to establish data on national cancer incidence and prevalence.
2004	LIVESTRONG Foundation	Founded in 1987, LIVESTRONG and Nike's yellow arm bands make survivorship make survivorship a global grass roots advocacy effort

Table 1.1 Continued

Year	Activity	Areas of Importance
2005	Institute of Medicine (IOM)"*From Cancer Patient to Cancer Survivor: Lost in Translation"*	Raised awareness of late effects of cancer treatment; call to action for Survivorship Care Plans; and defined quality healthcare systems and policies to support survivors
2007	IOM "*Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*"	Identified failure of healthcare community to meet the psychosocial needs of cancer patients and survivors
2010	American College of Surgeon's Commission on Cancer Standards	Issued first-ever survivor-centered Accreditation Standards for cancer clinics-requiring survivorship plans, psychosocial assessments and patient navigation
2014	American Society of Clinical Oncologists (ASCO) issues clinical practice guidelines	First three of a planned series for evidence-based clinical guidelines for cancer survivorship care for neuropathy, depression and anxiety

When twenty-three leaders in cancer research and advocacy joined to form the National Coalition for Cancer Survivorship (NCCS) in 1986, one of their priority efforts was to find an alternative to the phrase "cancer victim." The NCCS is credited with creating the definition for cancer survivor that we use today: "from the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor" [1]. The First National Congress on Cancer Survivorship was in 1995, and led to the National Cancer Institute's (NCI) creation of an Office of Cancer Survivorship. In September 1998, 250,000 citizens gathered on the National Mall in Washington, DC to call for increased funding for cancer research. They were joined by over a million people

attending over 200 events in all 50 states. Such efforts helped bring about a substantial increase in national research funding with a 16% increase of congressional appropriations to the National Cancer Institute.

With funding from the NCI and the creation of an Office of Survivorship came increased scientific interest and research to document the physical, psychosocial, and economic effects of cancer and its treatment on cancer survivors' quality of life and functional health. The Institute of Medicine (IOM published a number of reports on cancer care, including *From Cancer Patient to Cancer Survivor: Lost in Transition* [2], *Childhood Cancer Survivorship: Improving Care and Quality of Life* [3], and *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* [4].

The "Lost in Transition" report became the touchstone document for cancer survivorship among providers, advocates, and patients. By describing the shortfalls in U.S. survivorship care, and the lack of an evidence base for quality care of survivors, the report served as a research agenda. Most importantly, the IOM report recommended that every cancer survivor should receive a "survivorship care plan" (SCP). The description of the ideal SCP included information on diagnosis, surgery, and treatment, including chemotherapy and radiation dosages. As a shared tool between survivor and patient, there were recommendations for the SCP to include tailored screening and surveillance for late effects and cancer recurrence. The SCP would also include tailored lifestyle risks and tips for healthy living and information on access to psychosocial supportive care. The recommendations for the SCP extended into systems and policy changes, with information on survivors' legal, insurance, and employment rights [2].

In the years from 2004 to 2006, cancer survivorship awareness became a worldwide phenomenon, with the iconic yellow wristband distributed and sold by the LIVESTRONG Foundation. As a major grassroots cancer survivorship advocacy organization, the LIVESTRONG Foundation, founded in 1997, helped give rise to a global awareness of cancer survivorship through the sales and distribution, in partnership with NIKE, of over 87 million yellow plastic bracelets. As of 2012, LIVESTRONG Foundation had raised over $500 million in donations, with approximately 84% going into programmatic efforts including $12.5 million for cancer control research grants to communities, cancer centers, and academic medical institutions [5].

In 2010, the Commission on Cancer of the American College of Surgeons issued the first-ever survivor-centered accreditation standards requiring SCPs, psychosocial assessments, and patient navigators. The SCP accreditation requirement, along with standards for patient navigation and distress monitoring were structured as phased-in requirements, with full standards of care to be evaluated in the 2014 accreditation processes. However, the path for clinics and clinicians to provide SCPs faces significant barriers including the lack of reimbursement under most health insurance policies and the challenges of pulling data from new systems for electronic medical records. And, for the most part, SCPs are required to be delivered only to survivors currently in treatment. Significant barriers exist for the development and delivery of quality care plans to post treatment and longer term survivors [6].

Most recently, in April 2014, the American College of Surgical Oncologists (ASCO) issued three evidence-based clinical practice guidelines for care issues of cancer

survivors including neuropathy, fatigue and depression, and anxiety. The guidelines are the first in a planned series of ASCO guidelines on survivorship care that will reinforce among physicians and healthcare professionals the importance of caring for both physical and psychological needs of cancer survivors [7-9].

Despite the increasing awareness of cancer survivorship in the United States and globally, it took until 2012 for the American Cancer Society to publish the first estimates and forecasts of the numbers of U.S. cancer survivors. An estimated 13.7 million U.S. cancer survivors were alive on January 1, 2012, and the number is expected to reach 18 million by 2022 [10].

Taking stock of nearly thirty years of history, I conclude that there has been significant progress in cancer survivorship, including a growing research and evidence-base, the emergence of survivorship as a professional healthcare discipline, and ongoing efforts in public education, advocacy, and outreach. Yet, there are a number of outstanding areas of concern that remain to be addressed.

Minding the Gap

Prior to the 1970s, a diagnosis of cancer in childhood was nearly always fatal. The relative five-year survival rates among children diagnosed with cancer have improved from 58% in 1976 and 1977, to over 82% between 1999 and 2006. For adults over 50, the relative five-year survival rates are 59%, reflecting a 22.2% decline in the number of deaths due to cancer from 1990 to 2007 [10]. These improvements in survivorship are a combined result of great strides in cancer treatment and care, as well as improvements in diagnostic and screening rates. But, there is a significant gap in these

improvements. Rates of overall survival for adolescent and young adults (AYAs), ages 15-39, diagnosed with cancer have not improved significantly for over 30 years, and until recently, they were a relatively neglected population group. So much so, that in the first Surveillance, Epidemiology and End Results (SEER) monograph and study of AYA cancer epidemiology in 2006, AYAs were considered a population that experienced significant disparities in care [10].

One of the reasons for relative neglect is the size of the AYA population. Only a small number, roughly 5%, of those diagnosed with cancer are young adults. This equates to just over 70,000 AYA patients per year. Over the past 10 years, the gap in survival for AYAs in comparison to older and younger cancer patients has become a focus for both U.S. and international research, including detailed reports from the NCI on AYA cancer incidence and epidemiology. Seminal AYA survivorship and care reports include two NCI Progress Review Groups, one in 2006 and a second in 2012, and a set of National Comprehensive Cancer Center Network Guidelines [10-13]. Most recently, the IOM collaborated with the LIVESTRONG Foundation in a report, *Identifying and Addressing the Needs of Adolescents and Young Adults with Cancer: A Workshop Report* [14].

While it is reassuring to note recent progress in some of the AYA cancers, including acute leukemias, breast cancer, and malignant melanoma, there is a lack of statistically significant evidence for increased survival among the majority of cancer types occurring in AYAs. Researchers speculate that the lack of improvement in AYA survival may be due to a combination of factors including: 1) lack of available clinical

trials for this age group and low enrollments; 2) lack of medical insurance; 3) poor access to medical care both at initial diagnosis and follow on; and 4) attitudes and behaviors of young adults including a sense of invincibility, being too busy with work and education, and risk taking behaviors [15-17].

While more than 80% of AYA survivors will live beyond the first five years after treatment, they are also likely to develop serious morbidities, or will die prematurely. Cancer continues to be the leading cause of disease related death for AYAs, after accidental death and suicide [18,19]. AYA cancer survivors who were diagnosed during adolescence have an increased risk of death beyond five years as compared with other cancer survivor populations. This excess mortality is caused by cancer recurrence, subsequent neoplasms, and cardiovascular and lung disease that are the results of the original cancer treatment. Racial, ethnic, and socio-demographic factors, including geographic location and distance from cancer care and clinical trials, and lack of insurance also impact AYAs survivorship [20, 22].

One of the reasons AYA cancer survivors are an important group to study is that they, as well as childhood cancer survivors, live longer past treatment and thus, the specter of late effects looms larger. Oeffinger et al. reported that by 30 years past initial diagnosis and treatment, the incidence of chronic health conditions among AYA survivors was 73%, with a cumulative incidence of 42% for severe, disabling life-threatening conditions or death [16]. These severe late effects of treatment include breast cancer, male and female after chest radiation, and cardiomyopathy after anthracycline chemotherapy [21, 22].

AYA Cancer Care and Survivorship Interventions

The 2013 IOM/LIVESTRONG workshop report on AYA oncology notes, especially, the lack of information regarding research and the need for an evidence base to guide policies and practice in order to determine what surveillance for cancer among AYAs and AYA survivors is appropriate and needed [15]. This includes the need to identify characteristics that distinguish the unique biological and genetic characteristics of certain AYA cancers, including breast cancer, which may warrant increased support for inclusion of AYAs into cancer research trials. Chapter II in this dissertation addresses this concern by examining demographic and diagnostic risks associated with later diagnosis among Texas AYA breast cancer patients, including distance to breast cancer clinical trials appropriate to their stage of diagnosis. An initial comparison is made between national and Texas populations' AYA breast cancer incidence by race and ethnicity. I used the SEER database and the Texas Limited Use database, both of which reside on the SEER system. Texas Cancer Registry (TCR) data was requested for individual AYA breast cancer patients' diagnostic and demographic information, including the latitude and longitude of their residence at time of diagnosis. This data was used to explore risk factors for AYA breast cancer patients being diagnosed at later versus earlier stages. The study is innovative in that it includes distance from breast cancer trials for which the patients would be eligible as a possible risk factor.

Chapter III considers the need for increased professional and patient education as well as focused education and engagement with AYA survivorship advocacy efforts through a mixed methods evaluation. Cancer survivorship is increasingly seen as a

chronic condition that requires attention for surveillance and screening, not only for physical late effects but also psychosocial late effects. Education and training for self-management of cancer survivorship as a chronic disease is needed for survivors, family members, and caretakers. Because of the high incidence of late effects among AYA cancer survivors, the knowledge sharing and communications that need to occur during the transition period from cancer care into community care is especially important. Not only are AYA survivors likely to need developmentally appropriate psychosocial care, they also need extensive follow-on surveillance by a physician who is educated and aware of the likely chronic conditions and late effects that may occur in these patients.

There are numerous barriers for AYA survivors receiving adequate follow-up care including lack of insurance and funds, lack of awareness of the specifics of their treatments, and lack of relationships with community providers. On the provider side, many community healthcare professionals, both nurses and physicans, lack the knowledge and experience to take on the care of AYA cancer survivors, many of whom are medically complex. In some cases, there may be unwillingness to care for AYA survivors, both as a result of lack of knowledge and the stress of fitting them and their needs into the tight schedules of a busy community-based practice or clinic. This evaluation considers the perceptions of the benefits, value, and sustainability of a grant-funded effort to provide AYA cancer survivorship education among healthcare professionals, cancer advocates, and AYA survivors.

AYA cancer survivors, as is true of all cancer survivors, can benefit from lifestyle and behaviour changes (e.g., not smoking, increasing physical activity, and

improving their diet and nutrition intake) linked to improved health related quality of life. Interventions to support behaviour changes among AYA survivors include the use of Internet and mobile technologies to increase engagement and social support. In addition to health behaviour change interventions, mobile applications offer opportunities to provide increased access to education and tools for AYAs to be aware of late effects of their care and treatment. There are now many mobile applications associated with cancer care, treatment, and survivorship, both for professionals and patients. While less than a handful of mobile applications for cancer survivors are specifically focused on AYAs, these tools may provide cost effective and easily adaptable interventions to support behaviour change and improved quality of life for AYAs and other cancer survivors. Unfortunately, while there are an increasing number of mobile apps for cancer, the theoretical basis used in the apps design and development is frequently unknown. Chapter IV provides an assessment of cancer survivor apps with a focus on the extent to which they are designed and developed based in health and communication theories.

Research Contribution to Public Health and Practice

Recognizing the need to better understand the specific needs and risks of AYA cancer survivors, and developing interventions tailored to address the health disparities that affect this group is a worthy challenge. Over the past few years, progress has been made in closing the gaps in AYA care and survivorship, but many challenges remain in making improvements in the care and outcomes of this unique group of cancer survivors. Much of the effort in AYA research has been on understanding their specific biological

and psychosocial risks and needs. To date, few researchers or healthcare practitioners have taken the steps to translate AYA research into theory and evidence-based interventions. Table 1.2 provides a schema of my research questions, methods, and analytical strategies. I begin in Chapter II with an innovative approach to clarify the risks and barriers faced by AYA breast cancer patients in Texas, including distance to appropriate cancer clinical trials. In Chapter III, I move from risk assessment into an evaluation of professional and patient education programming for AYAs. This mixed methods evaluation is a theory-based, primarily qualitative analyses of the value, benefits, and ongoing barriers in delivering educational programming and health behaviour based interventions to AYA survivors, community healthcare providers, and cancer advocates. In the final study, in Chapter IV, I examine a range of cancer survivorship-related mobile apps to determine the extent to which they incorporate health behaviour change and communication theory elements.

Table 1.2 AYA Survivorship Research Questions, Approaches and Analytical Strategies

Research Question	Population and Setting	Methods/Analytical Strategies
Chapter II What are the demographic and diagnostic risks associated with later versus earlier stage at diagnosis for Texas' AYA breast cancer patients? Does distance to breast cancer clinical trials matter?	SEER and Texas AYA breast cancer population (2005-2009) 4153 Texas breast cancer patients, ages 15-39 (2005-2009)	SEER*Stat for Breast Cancer Rate Incidence by Race and Ethnicity ESRI ArcGIS 10.1 for Mapping and Network Analysis Logistic Regression for Odds Ratios of Risk Factors using Stata 10.1
Chapter III To what extent did the ACCESS AYA educational program for healthcare professionals, AYA cancer survivors and cancer advocates increase health literacy, communications and understanding of AYA survivors? What common barriers do AYA survivors experience? What opportunities and challenges exist for sustaining and expanding AYA survivorship education programs?	Telephone surveys of 19 stakeholder participants in the ACCESS AYA project using semi-structured interview guides.	Brief survey analysis, First and Second Cycle Coding of Stakeholder Interviews based on a theoretical framework. Atlas.ti used for coding by two independent coders.
Chapter IV Are health behavior change theories and behavior change frameworks being used in mHealth apps? What theories should app designers draw upon in designing apps for cancer survivors? What behavior change techniques may be effective in delivering mHealth mobile interventions?	mHealth apps for cancer survivorship for IOS platform apps found on the Apple App store and Android apps found on Google Play web store.	Qualitative analysis based on the taxonomy of health behavior change theories and frameworks by Mitchie et al. [23].

Cancer survivorship is a relatively young field of research. The growing evidence base and research on improvements in care and practices that support improvements among this relatively small population has the potential to provide benefits and value to the larger and ever growing population of older cancer survivors. In this dissertation, I contribute to the expanding research base of understanding the risks and barriers to healthy survivorship among AYA cancer survivors. I further identify innovative practices for survivor and healthcare professional education including use of mHealth applications that have implications for all cancer survivors as well as for self-management of other chronic diseases. I also identify research and intervention challenges and opportunities to support practice, system, and policy changes to improve the quality of life and care for this unique population of young cancer survivors.

II. AYA BREAST CANCER IN TEXAS: RISK FACTORS FOR DELAYED DIAGNOSIS

Background

Breast cancer is one of the most commonly diagnosed cancers among adolescent and young adult (AYA) females, ages 15-39 years of age [24]. In the U.S., approximately 14% of all AYA cancers diagnosed in females are breast cancer. Despite their small numbers, AYAs represent approximately 7% of all female breast cancer diagnoses [24, 25].

Younger women are more likely to be diagnosed at later stages and higher grades of breast cancer, due, in part, to cancer being unexpected at younger ages and screening norms that begin at age 40 or older. Breast cancer in younger women is considered aggressive, and just being younger is considered a negative predictor for survival. Being diagnosed at a younger age has a high correlation with breast cancer recurrence and being diagnosed with both local and distant recurrence, including contralateral breast cancer recurrence [26].

Recent research suggests that AYA breast cancer may be distinctly different from that of older women, clinically, etiologically, and genetically [27]. AYA women diagnosed with breast cancer have larger proportions of cancers with lower estrogen receptor (ER) positivity and overexpression of human epidermal growth factor receptor 2 (HER2) and triple negative subtypes (24, 27).

Family history and genetics may also be factors in younger women's diagnoses. A woman under age 35 has a 9.4% likelihood of having BRCA1/2 genetic mutation as compared to the population average of 0.2% [28]. These statistics suggest the need for increased surveillance for young women diagnosed with breast cancer, and strong consideration for increased research and enrollment of young women diagnosed at both early and later stages of breast cancer into breast cancer research trials.

The documented lack of improvement in overall AYA cancer survival is attributed to a combination of factors. In addition to biological and genetic factors, other issues have been identified including lack of access to care and underinsurance. Further, lack of social support and the unique stage of life issues of entering adulthood, and starting jobs and families are risk factors that need to be taken into consideration when considering cancer care and survivorship among the AYA population [29].

Additionally, the lack of AYA enrollment and participation in clinical trials has been cited as critical factors in making progress in AYA cancer research [29]. Yet, relatively few AYAs are enrolled in clinical trials, in part due to the unique socio-demographic and psychosocial characteristics of young adults, but also because diagnosing physicians seldom refer these patients to trials [30]. In the U.S., clinical trial enrollment among pediatric cancer patients is generally high, near, or at 50%, but enrollments fall as age increases, with approximately 10% of patients ages 15 to 19 years, and only 1% to 2% of patients ages 20 to 39 years enrolling in clinical trials [31]. In order to better understand the factors associated with survivorship among AYAs diagnosed with breast cancer, I wanted to examine the importance of access to care and

clinical trials among AYAs. Texas is an ideal area to examine these questions because of its diverse racial and ethnic population, with a median age of 33 for both sexes [32]. While the actual number of breast cancer trials open and accruing may change on a daily basis, Texas generally ranks among the top three states (i.e., California, New York, and Texas) with the largest number of breast cancer trials [33]. The purpose of this research study was to explore risk factors that may affect Texas' AYA breast cancer patients being diagnosed at early versus later stages of cancer, including the distance to breast cancer clinical trials. By doing so, I hope to add to growing research on AYA cancer care and survivorship and to support efforts to improve access to clinical trials for AYA breast cancer and other AYA cancer patients.

Data and Methods

Data Sources and Population

To assess Texas' AYA breast cancer incidence and comparisons to national data, I used the National Cancer Institute's SEER data [34] and the epidemiological analysis computer program, SEER*STAT [35].

The analyses covered the period from January 1, 2005, through December 31, 2009. I accessed the SEER 18-Registry database, which includes cancer statistics on approximately 28% of the U.S. population. I was granted permission from the Texas Cancer Registry (TCR) to use the Texas Limited-Use Database, also available on through the data sets for SEER*STAT [35].

In addition to the Limited-Use Database for Texas, we obtained individual patient incidence and mortality data from the TCR for 82,643 AYAs diagnosed in Texas

from 1995-2009 (36). From this data, I selected 4,630 breast cancer patients, 15-39 years of age during the period from January 1, 2005 through December 31, 2009. Included are all female residents diagnosed with in situ and invasive breast cancer (International Classification of Disease for Oncology, 3rd Edition, ICD-0-3) for site codes C500 through C509. The data was requested under an approved Institutional Review Board Protocol (IRB) 13-022 from the Texas Department of State Health Services and IRB Protocol 2013-0233M from Texas A&M University. Individual consent was not obtained, as the data used was acquired under Texas' state-mandated cancer registry data process.

Measures

For each breast cancer case, we requested information routinely gathered by clinical cancer registrars from the patient's medical record including sex, age at diagnosis, race/ethnicity, and payer at diagnosis. The TCR patients' tumors stage at diagnosis was recorded by the TCR using the SEER Summary Stage coding (0=in situ; 1=localized; 2=regional by direct extension only; 3=regional to regional lymph nodes only; 4=regional direct extension and regional lymph nodes; 5=regional, not otherwise specified; 7=distant Metastasis; 8=not applicable; 9=unstaged, unknown or unspecified (note that there is no stage 6). Tumors that were in situ and localized stages 0 and I were considered "Local" while tumors diagnosed at stages II through V were considered "Regional" and those diagnosed at stage 7 were classed as "Metastatic." The grades of cancer were based on the ICD-03 system and were classed as follows: 1=Well

differentiated; 2=Moderately differentiated; 3=Poorly differentiated; 4=Undifferentiated, 5-8 = Cell types; and 9=Unknown/Undetermined.

The TCR patient data request included items routinely added to the patient data during inclusion into the registry as a cancer patient. These are fields that have been developed and submitted to the National Program of Cancer Registries and/or the North American Association of Central Cancer Registries to ensure that any data released by TCR has met a protocol of quality standards. The TCR constructed data fields requested included 5- year age groups, Rural/Urban Beale continuum codes (categorized as Metro-1 for Codes 0-3 and Non-Metro=0 for Codes 4-9), patient residence latitude and longitude, vital status at last contact (e.g., dead=0, alive=1), and SEER specific cause of death.

The SEER summary stage classification was selected as a binary dependent variable in our logistic regression analysis with the patients diagnosed at local stages coded as "0" and the combined group of patients coded as regional or metastatic as "1." On this basis, 472 cases for which the patient's summary stage was unknown were excluded from the total of 4,630 breast cancer patient records. All patient geocoding was done by the TCR, and the database received from TCR included the latitude and longitude for each patient. Five cases had to be excluded from the database during the Geographic Information Systems (GIS) Network analyses due to problems with addresses or lack of direct roadway access (e.g., the patient lived on an unpaved road). The resulting study population included 4,153 women, ages 15-39 diagnosed with breast cancer in Texas during the study period 2005 to 2009. Due to the low numbers of

metastatic patients (n=275, 6.62%) in the summary stage groups, this group was combined with patients diagnosed at regional stages. As a result, the dependent variable, summary stage, was defined in two categories: “Early Stage” for patients staged as in situ and local (n=2,238) and “Later Stage” for patients staged as regional and metastatic (n=1,915).

BreastCancerTrials.org, a non-profit foundation that provides patient matching services for breast cancer trials, located at University of California at San Francisco provided data, including latitude and longitude, for 23 trials that were open and accruing Early Stage breast cancer trials at 67 locations in Texas. There were 52 Late Stage Trials open at 93 locations in Texas. Only treatment trials were included, no supportive care trials were provided for matching. The 2,238 patients classified as Early Stage would most likely have been eligible for trials with inclusion criteria for ductal carcinoma in situ, neoadjuvant trials for drugs given prior to surgery, biological therapies, types of radiation therapy, or new surgical techniques. The 1,915 patients classified as Late Stage were matched to Late Stage trials with a range of inclusion criteria, some similar to the early stage, such as biological therapies and radiation therapy. Many of the later stage trials inclusion criteria specified histologically confirmed diagnoses of breast cancer based on pathology report of primary, regional or metastatic breast cancer. Both lists of trials and their locations are provided in Appendix A. The breast cancer trials were situated at various types of locations including American College of Surgeons accredited breast centers, community oncologist offices and academic and National Cancer Institute

designated cancer centers. The trials were geocoded based on the trial site cancer center or clinic physical address and the geocoding-match rate for both sets of trials was 100%.

In order to assess the distance to open and accruing breast cancer trials ESRI ArcGIS software (Version 10.1) Network Analyst was used to provide spatial analysis for the closest facility by either travel time or roadway distance [37]. For each patient in the database, roadway miles were mapped to the nearest breast cancer trial for which the patient would most likely be eligible. The Network Analyst tool created an estimated shortest distance to the nearest facility with an appropriate trial for each patient. For each patient classified as Early Stage, the shortest distance to an Early Stage trial for which they would most likely meet inclusion requirements was calculated. Similarly, the distances in roadway miles required for patients classified as Late Stage were mapped to the closest Late Stage trial location. One Early Stage trial was open at the Brooks Army Medical Facility in San Antonio, Texas, and The Audie L. Murphy VA Hospital, also in San Antonio, offered one Late Stage trial. These trials were only open to members of the military and veterans with military insurance (i.e., Tricare or Military insurance). There were 32 patients classified as Early Stage with Tricare or Military insurance who matched to the Early Stage Trial at Brooks Army Medical Facility in San Antonio, Texas. There were 20 patients classified as Late Stage whose payer at diagnosis was listed as military or Tricare. These Late Stage patients were matched to the trial at Audie L. Murphy VA Hospital in San Antonio, Texas. Once the miles to breast centers and trials were calculated for each patient, the mileage data for each patient was included into the database by matching each patient's geo-unique number from the TCR dataset to

the results from the network analysis. The geo-unique number is associated with the patient data when the patient's address is geocoded at the TCR.

Statistical Methods

For the SEER*Stat analyses of AYA breast cancer incidence rate, I accessed both the SEER 18-Registry database, which includes cancer statistics on approximately 28% of the U.S. population, and the TCR Texas Limited-Use Database. The incidence rates for both data sets were run using the SEER*Stat rate analysis system for the following selections:

- Age at Diagnosis for age groups 15-19 years, 20-24 years, 25-29 years, 30-34 years, and 35-39 year olds;
- Sex was designated as "Female only;"
- Years of Diagnosis -2005-2009;
- Race and Ethnicity as specified; and
- Site and Morphology Site Recode from the 1CD-03/World Health Organization 2008 for "Breast."

In preparing for the individual patient analyses, the data were summarized for descriptive statistics using frequencies and percentages. Bivariate analyses were conducted for patient demographic characteristics and clinical characteristics and associated distance to clinical trials distance as categorized (e.g., 0-<45 miles, 45 -100 miles, 101-200 miles, and >200 miles). This range of distances were calculated based on the mean distance to clinical trials for the majority (73.87% of the AYAs were living within 45 miles of a trial when diagnosed) of the AYA subject population, using 45.5

miles as the base line. The second distance level extending beyond 45 miles to 100 miles takes into consideration the significant distances between major population centers in Texas, and the assumption that many Texans routinely drive between 100-200 miles between major cities. The Pearson's chi-square goodness of fit test was used to test whether the observed proportions for categorical variables differed from hypothesized proportions. Additionally, in preparation for the logistic regression, each variable was tested as an independent variable in separate logistic models using binary dependent variable for summary stage. A likelihood ratio test was computed to assess overall significance of multiple variables. We used the cut point of a *p*-value <. 25 to determine which variables would be included in the analyses.

In order to evaluate differences in the summary stages (i.e., Early Stage as compared to Late Stage) by the clinical and demographic predictor variables, logistical regression was used to calculate Odds Ratios (OR) at the associated 95% confidence intervals (CI). The final fitted model included vital statistics, type of insurance payer at diagnosis, Non-Hispanic/Hispanic ethnicity, grade of cancer, and the patient's distance to the appropriate associated stage of breast cancer trials (e.g., Early Stage or Late Stage Trials). The model was checked and tested for normality among the residuals. Model testing included tests for homoscedasticity, link testing for model specification, goodness of fit, overdispersion, skewness and kurtosis, Variance Inflation Factor (VIF), and influential observations. We made no adjustments to our final fitted model as it displayed no issues for either homoscedasticity or goodness of fit tests and there was no skewness or kurtosis. The VIF score, which was not considered severe with a score

under 10 (i.e., 1.05), was used to test for issues of multicollinearity in the models. Also, there were no significant influential observations according to a Cook's D test. All model tests were conducted using Stata version 12.1 (Stata Corporation, College Station, TX).

Results

To begin the exploration into AYA breast cancer, it is helpful to compare Texas AYA breast cancer incidence rates to U.S. national incidence rates, including differences by race and ethnicity. This information is useful in understanding and interpreting the risks associated with being classified at Early Stage versus Later Stage. Table 2.1 provides a comparison of Texas' AYA cancer incidence to U.S. AYA cancer incidence by race, including comparisons of White, African American, Native American and Alaskan Natives, and Asian American/Pacific Islanders. Non-Hispanic and Hispanic/Latina/Spanish ethnicity cancer incidence rates are also shown.

Table 2.1. Comparison of U.S. and Texas' AYA Breast Cancer Incidence (2005-2009)

Population Characteristic	Sample Size	Age-Adjusted Incidence Rate	95% Confidence Interval
Race			
U.S. AYAs (SEER)	14,074	20.8	20.4-21.1
TX AYAs	4,445	22.6	21.9-23.2
U.S. White	10,175	20.6	20.2-21.0
TX White	3431	21.7	21.0-22.5
U.S. Black	2,215	24.6	23.6-25.7
TX Black	722	27.4	22.8-26.6

Table 2.1. Continued

Population Characteristic	Sample Size	Age-Adjusted Incidence Rate	95% Confidence Interval
American Indian/ Alaska Native	92	8.6	6.9-10.5
TX America Indian/Alaska Native	23	11.2	7.1-16.8
U.S. Asian/Pacific Islander	1,469	18.0	17.1-18.9
TX Asian/Pacific Islander	172	16.3	14.0-19.0
Ethnicity			
U.S. Non-Hispanic White	11,457	22.2	21.8-22.6
TX Non-Hispanic White	3017	24.9	24.0-25.8
U.S. Hispanic/Latino	2617	16.8	15.5-16.8
TX Hispanic/Latino	1428	18.7	17.8-19.7

Note: Rates are per 100,000 and age-adjusted to the U.S. Standard Population (19 age groups Census P25-1130) Confidence Intervals (Tiwari mod) are 95% for rates. Rates for unknown race/ethnicity not calculated.

In considering the comparisons of Texas AYA breast cancer population with the SEER U.S. data, the overall Texas AYA population age-adjusted incidence rate of 22.6 (CI 21.9,23.2) is slightly higher. The Texas Black/African American AYA breast cancer incidence rate is higher at 27.4 (CI 22.8,26.6) as compared to the SEER U.S. Black/African American incidence rate of 24.6 (CI 23.6, 25.7). The Texas Hispanic Latino numbers are more than half (55%) the size of the SEER US. Hispanic/Latino population, which represents 28% of the U.S. population. The Texas Latino/Hispanic AYA breast cancer incidence rate is 18.7 (CI 17.8,19.7) as compared to the SEER Latino Hispanic AYA breast cancer incidence of 16.8 (CI 15.5,16.8). Descriptive statistics from

the TCR dataset for Texas AYA cancer patients from 2005-2009, are shown in Table 2.2.

Table 2.2. Descriptive Statistics for Texas' AYA Breast Cancer Patients (2005-2009)

Variable/Descriptor	Number of Observations	Mean	Percentage/ Frequency
Age at Diagnosis	4,153	34.9 years	N/A
Vital Statistics	3,656		88.03%
Alive			
Dead	497		11.97%
Beale Metro Code*	3,806		91.64%
Metro	347		8.36%
Non-Metro			
Race			
White	3,223		77.61%
Black	675		16.25%
American Indian/Alaska Native	12		0.29%
Asian/Pacific Islander	162		3.90%
Other	81		1.95%
Non Hispanic	2,882		69.95%
Hispanic	1,331		32.05%
Summary Stage of Cancer	2,238		53.89%
In situ/local	1,640		39.49%
Regional	275		6.62%
Metastatic			
Distance from Trials (miles)	4,153	45.55 miles	

The 2,238 Early Stage patient population's dispersion across Texas is shown in Figure 2.1. The results of the ArcGIS Network Analysis showing the distance for

patients to the nearest Early Stage trials are shown in Figure 2.2. There were 23 open and accruing Early Stage breast cancer clinical trials located at 67 different sites in Texas. The 2,238 patients classified as Early Stage would most likely have been eligible for this type of trial. The majority of the 67 Early Stage breast cancer trial locations were in the larger urban areas of Texas with 28 in Houston and 21 in the Dallas/Fort Worth metro area. San Antonio was home to six trials and the Austin metro area to 10 trials. The other trials were spread across Texas with two each in Laredo and Lubbock and the remaining four in smaller communities. To reach the nearest trials in Lubbock, Texas, patients living in the El Paso using major roadways would be required to drive out of Texas to and into New Mexico to reach Texas trial locations.

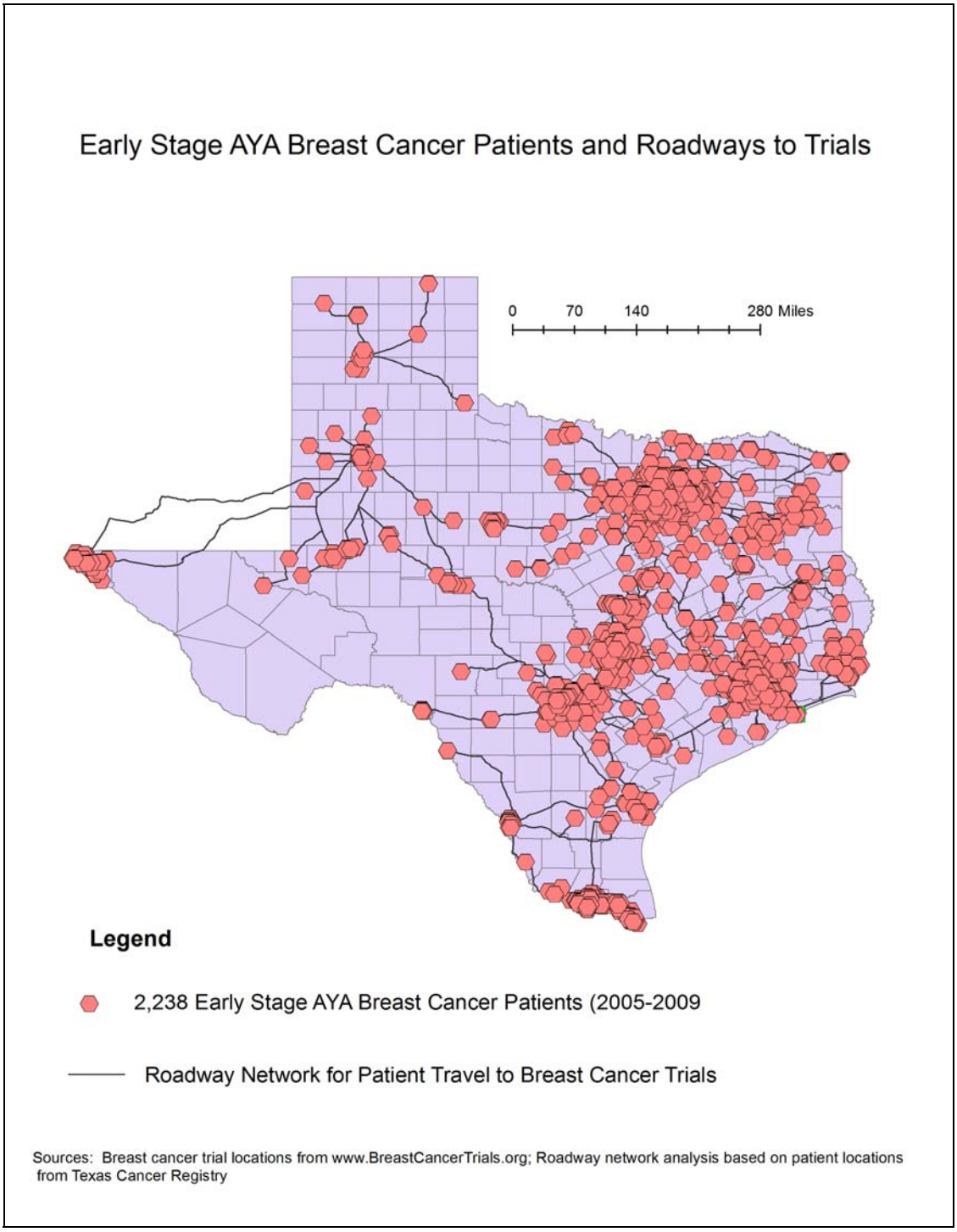

Figure 2.1 Early Stage AYA Patients and Roadways to Trials

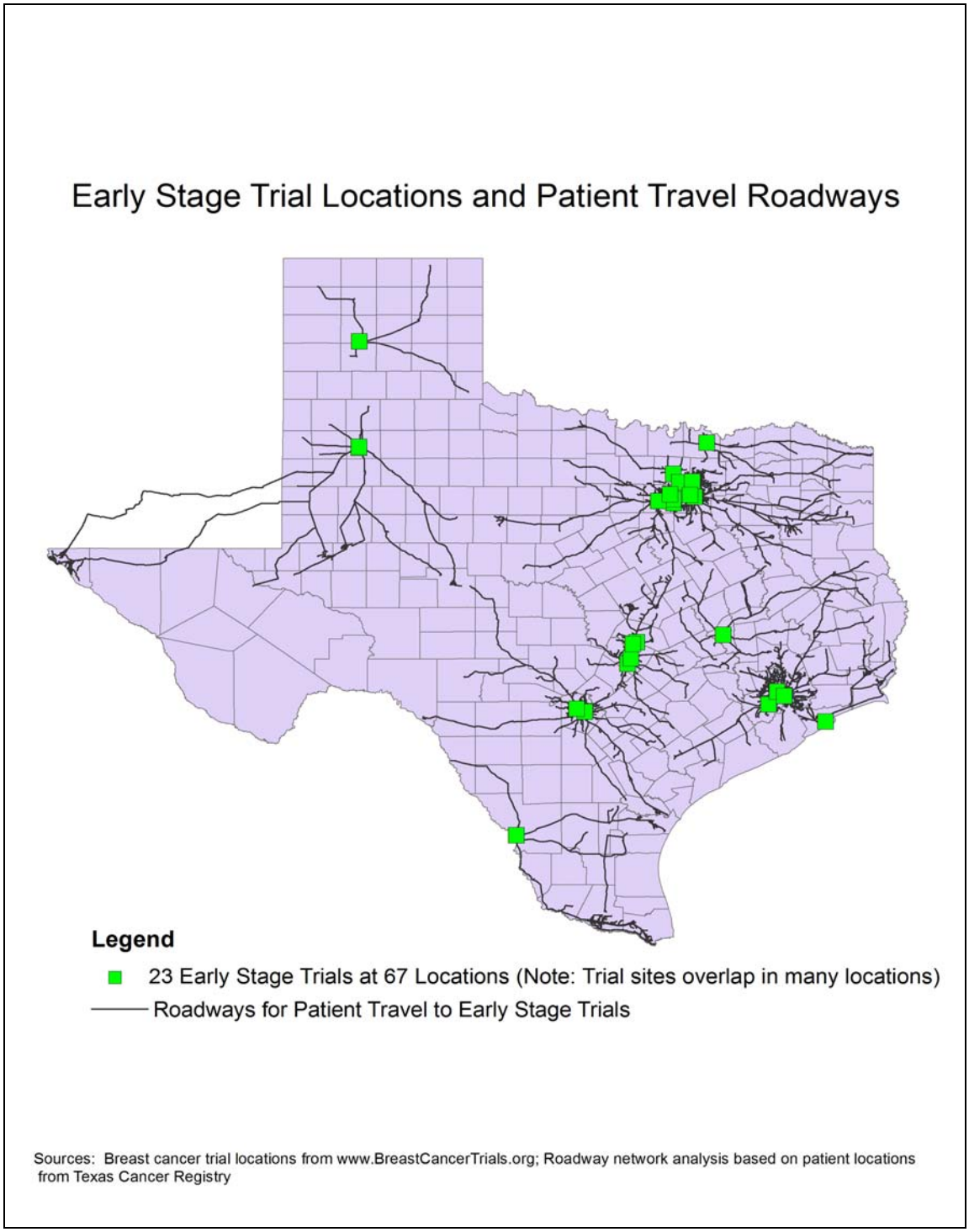

Figure 2.2 Network Analysis for Early Stage Trials

Figure 2.3 shows the dispersion of the 1,915 patients classified as Late Stage across the state of Texas. Figure 2.4 shows the roadway network analysis for the Late Stage patients' travel to the nearest of the 93 locations for the 52 Late Stage trials. Similar to the early stage trials, the Late Stage breast cancer trials were primarily in the Houston and Dallas areas with 34 trials in various cancer centers in the Houston and Galveston region and 37 trials in the Dallas/Fort Worth Metroplex. San Antonio had six late stage trials across five locations in that city; one location in Tyler, Texas had four late stage trials. The remainder of the trials were located in smaller cities including Austin, Temple, and Abilene among others.

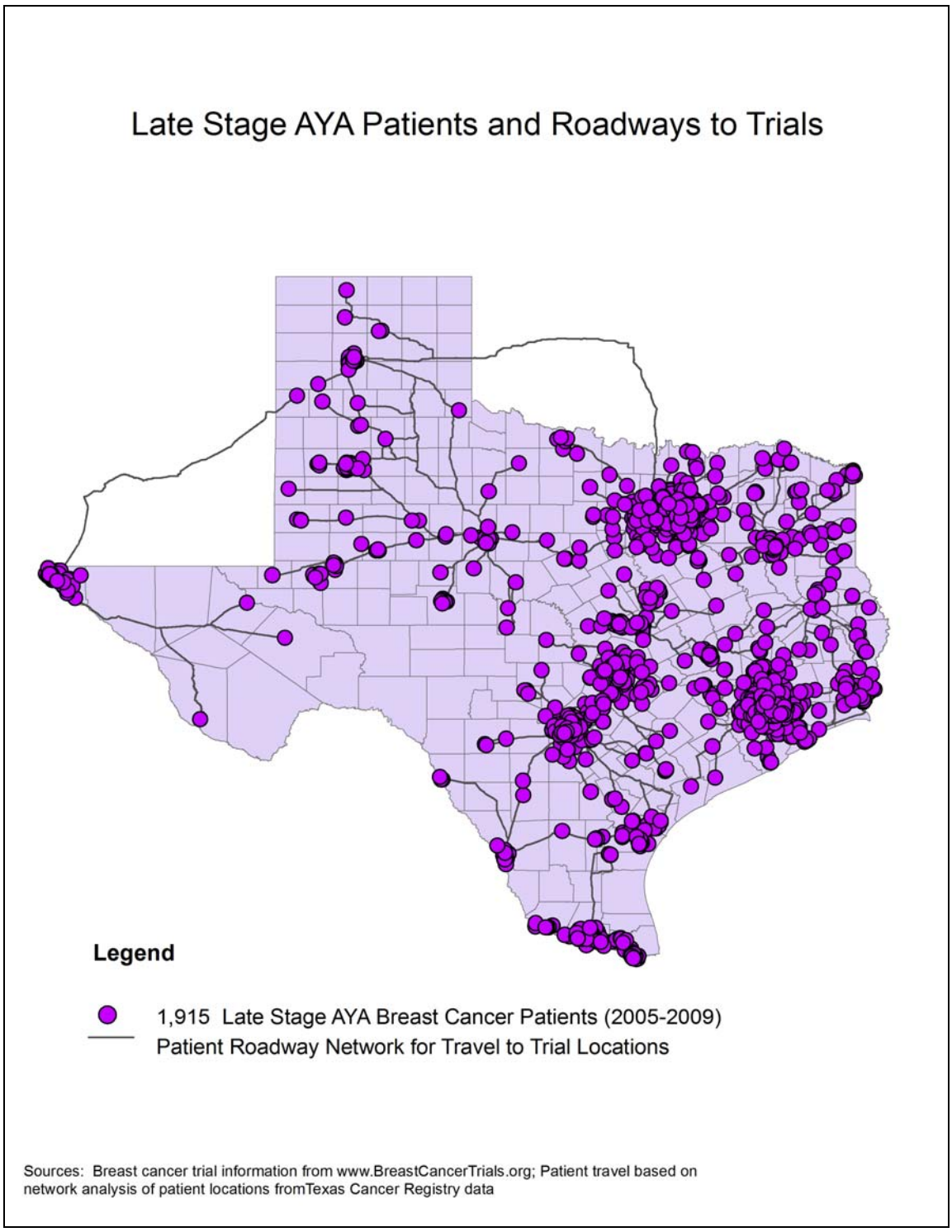

Figure 2.3 Late Stage Patients and Roadways to Trials

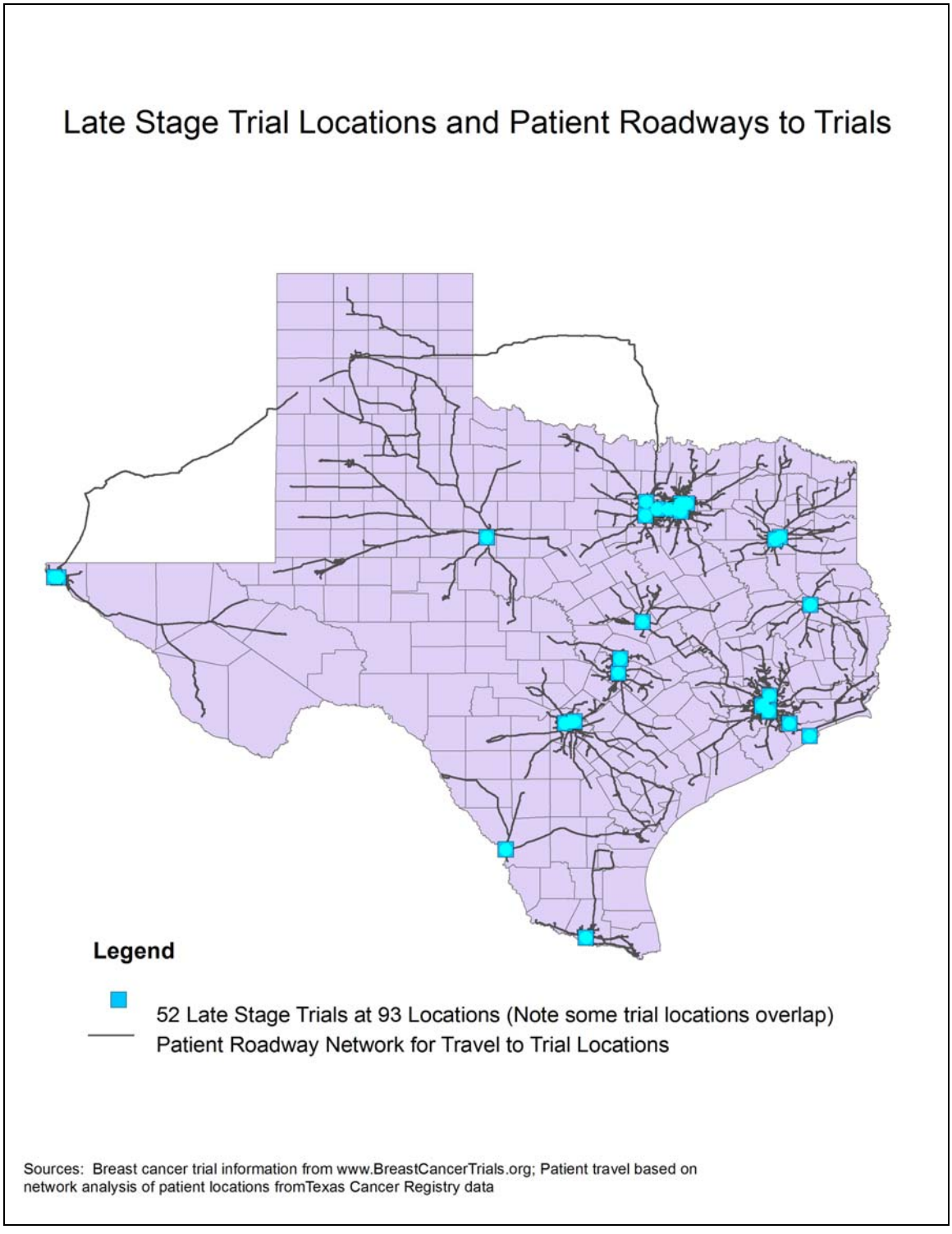

Figure 2.4 Network Analysis for Late Stage Trials

Table 2.3 provides bivariate analyses of multiple demographic variables as compared to distance from clinical trials. The variables including age group at time of diagnosis, vital statistics, metro-versus non-metro residency, race, Hispanic/Non Hispanic ethnicity, and type of insurance provider at time of diagnosis. Of these, the variable age group was non significant with *p*-value of 0.792, which suggests the need use age at diagnosis as a continuous variable in the regression analysis to obtain greater age differentiation. As might be expected, the percentage of breast cancer diagnoses among AYAs was greatest among the older AYAs with 32.4% (N=993) in the 31-35 age group and 54.4% (N=1,669) in the 36-39 year age group.

Type of insurance at diagnosis was explored based on prior research suggesting insurance status as a risk factor in breast and other cancer diagnoses. [29] Among the Texas AYA breast cancer patients, 55.5% (N=2,306) had some type of coverage, including private and public insurance, at diagnosis. The TCR data indicated that 7.4% (N=309) reported no insurance and/or provided some level of self-pay. Approximately 37% of the participants from the TCR database were reported as “insurance status unknown.” Whites dominated the racial groups with 77% of the sample populations. The TCR codes for Spanish/Hispanic origin were categorized into two groups: Non-Hispanic Non-Spanish with 67.95% (N=2,822) and Spanish, Mexican, South/Central American, and Other Hispanic, including those with Spanish surnames at 32.05% (N=1,331) of the sample.

Table 2.3 Associations Between Travel Distance to Breast Cancer Trials and Risk Factors

Demographic Variables	Distance Via Roadway to Nearest Breast Clinical Trial					
	<45 Miles (N=3068)	**45-100 Miles (N=500)**	**101-200 Miles (N=416)**	**>200 Miles (N=169)**	**N=4153**	***p*-value**
Age Group (yrs.)						0.792
15-19	.17%	0.00%	0.02%	0.02%	9	
20-25	1.66%	0.19%	0.29%	0.12%	94	
26-30	7.90%	1.32%	1.16%	0.43%	449	
31-35	23.96%	4.02%	3.06%	1.54%	1,353	
36-39	40.19%	6.05%	5.49%	1.95 %	2,248	
% total	73.87%	12.04	10.02%	4.07%	4,153	
Vital Statistics						0.597
Dead (all causes)	11.70%	13.80%	13.54%	12.43%	497	
Alive	88.30%	86.20%	86.46%	87.57%	3,656	
Metro[1]						<0.000
Metro	99.12%	62.20%	71.15%	93.49%	3,806	
Non-Metro	0.88%	37.80%	28.85%	6.51%	347	
Insurance						<0.002
Insured	55.60%	53.80%	56.73%	56.22%	2,306	
Uninsured/selfpay	7.20%	6.00%	7.69%	15.38%	309	
Unknown Ins.	37.19%	40.20%	35.58%	28.40%	1,538	
Race						<0.000
White	74.151%	82.00%	89.18%	98.82%	3,223	
African American	18.45%	14.80.%	8.16%	0.59%	675	
American Indian	0.33%	.20%	0.24%	0.00%	12	
Asian/Pacific Isl.	4.66%	2.20%	1.68%	0.59%	162	
Other/Unknown	2.41%	0.80%	0.72%	0.00%	81	
Hispanic Ethnicity[2]						<0.000
Non-Hispanic	71.61	79.80%	51.20%	7.69%	2,282	
Hispanic	28.39%	20.20%	48.80%	92.31%	1,331	

1. Metro areas are based on the Rural Urban Continuum Beale Code 2003
2. Hispanic ethnicity includes those with Hispanic surnames.

Table 2.4 shows the associations between cancer diagnostic factors and the distance of the patient's place of residence at time of diagnosis to breast cancer trials. As distances from trials increased beyond 45 miles, so did the proportion of patients

diagnosed with regional or metastatic cancer, with 60.4% (N=258) of those living between 45-100 miles from a cancer trial and 57.9% (N=98) more than 200 miles from a trial. The exception from this trend was for those women living 101-200 miles from a trial; among this group only 37.9% were diagnosed at later stages. Tumor grade of the AYA breast cancer patients was somewhat evenly dispersed over the distances from trials. Sequence of tumors for the AYA cancer patients was non-significant, with a *p*-value of .684, ruling out its consideration as a variable in the logistic analysis.

Table 2.4 Associations Between Cancer Diagnostic Factors and Distance From Clinical Trials

Cancer Diagnosis Factor	Distance Via Roadway to Nearest Clinical Trail					
Cancer Diagnosis Factors	**<45 Miles (N=3068)**	**45-100 Miles (N=198**	**101-200 Miles (N=460)**	**>200 Miles (N=375)**	***N*=**	***p*-value**
Summary Stage	3,068	500	416	169		<0.000
In Situ/Local	55.80%	39.6%	62%	42%		
Regional/Metastatic	44.23%	60.4%	37.98%	57.99%		
Tumor Grade[1]						0.028
Well Differentiated	6.03%	5.80%	4.33%	5.92%	242	
Moderately Differentiated	25.88%	28.80%	24.04%	26.04%	1,082	
Poorly Differentiated	50.46%	50.60%	52.64%	53.25%	2,110	
B-Cell/T-Cell & other Cell Types	2.12%	3.60%	5.05%	2.37%	108	
Undifferentiated	15.51%	11.20%	13.94%	12.43%	611	
Sequence						0.684
One Primary	90.68%	89.20%	93.03%	88.76%	3,765	
First of 2 or more	4.11%	5.60%	2.40%	6.51%	175	
2nd of 2or more	4.95%	5.00%	4.33%	4.33%	203	
Unspecified/Other	0.26%	0.00	0.00	0.00	10	

[1] Tumor Grade is the degree of abnormality of cancer cells based on ICD-03

A logistic regression analysis model was built to compare AYA women diagnosed at in situ or localized breast cancer as compared with AYA women diagnosed at regional and metastatic summary stage (Table 2.5). Among the demographic variables, not having insurance, being of Hispanic/Latina ethnicity, and being African American were significantly associated with being diagnosed at a later summary stage (i.e., regional or metastatic).

Table 2.5. Texas AYA Breast Cancer Characteristics Associated With Being Diagnosed at a Later Versus Earlier Summary Stage

Characteristic	Odds Ratio	*p*-value	95% CI
Insurance at Diagnosis			
Insured	Reference		
Not Insured/Self Pay	1.70	0.000	1.31 - 2.20
Insurance Status Unknown	1.35	0.073	0.98 - 1.30
Hispanic Ethnicity	1.36	0.000	1.16 - 1.58
Race			
White	Reference		
African American/Black	1.31	0.004	1.09 -1.58
American Indian/Alaskan Native	.776	0.680	0.23 - 2.59
Asian/Pacific Islander	.915	0.610	0.65 - 1.29
Vital Statistic (0=Alive; 1=Dead)	.185	0.000	0.15 - 0.23
Beale Metro vs. Non Metro*	.780	0.076	0.59 - .03
Distance From Breast Cancer Trials			
Less than 45 Miles	Reference		
>45-100 Miles	2.02	0.000	1.65 - 2.48
101-200 Miles	0.73	0.006	0.58 - .915
More than 200 Miles	1.49	0.021	1.06 - 2.09
Grade of Cancer			
1=Well Differentiated	Reference		
2=Moderately Differentiated	2.10	0.000	1.53 - 2.87
3=Poorly Differentiated	2.11	0.000	1.56 - 2.85
4= Undifferentiated	0.96	0.884	0.57 - 1.61
5= Grades 5-8 Cell Types	5.27	0.184	0.45-60.95
6=Undetermined/Unknown	1.34	0.091	0.95 - 1.86

Table 2.5 Continued

Notes: Beale Metro versus Non-Metro Codes are determined on the basis of population. Metro areas are defined as areas with a population of 250,000 to 1 million or more; Non-Metro areas are less than 250,000 and include small cities, suburban and rural areas.

Overall, uninsured patients, including those who self-pay, were 70% more likely to be diagnosed at a later stage (*p*-value <0.000, 95% CI 1.31, 2.20). Being of Hispanic/Latino ethnicity was associated with a 36% increased risk of being diagnosed at a regional/metastatic stage (*p*-value <0.000, 95% CI 1.16,1.59). Similar to prior research on risk factors among breast cancer patients by Ghafour et al., African American AYA breast cancer patients in Texas were 31% more likely to be diagnosed at later stages of cancer (*p*-value 0.004, 95% CI 1.08. 1.58) [38]. None of the other race categories were statistically significant in the model.

Distance from breast cancer clinical trials was significantly associated with diagnosis at later stages by 102% (*p*-value<0.000; CI 1.65, 2.48) for those living at distances between 45 and 100 miles from a trial. This was not a consistent trend, since those patients living between 101 and 200 miles from a trial were 23% less likely to be diagnosed at a later stage (*p*-value 0.006, 95%CI .585, .916). This protective factor may be due to socio-economic factors or other confounding issues not captured in the analysis. However, those patients living furthest from a clinical trial, over 200 miles, were 49% more likely to be diagnosed at later summary stage (*p*-value 0.020, 95% CI 1.06,2,09).

Grade of tumor at diagnosis was significant for those breast cancers with higher grades, those that were moderately or poorly differentiated. Higher grades indicate a tendency for tumors to grow and spread faster and have a poorer prognosis. AYAs diagnosed with moderately differentiated cancer cells were 110% more likely to be diagnosed at a later stage as compared to those with well-differentiated tumor cell structure (*p*-value <0.000, 95% CI 1.54, 2.88). Similarly, those AYA breast cancer patients diagnosed with poorly differentiated cells were 111% more likely to be diagnosed at later stages (*p*-value <0.000, 95% CI 1.56,2.89). None of the other grades analyzed in the model showed statistical significance.

Discussion

Our study findings are consistent with prior studies assessing the multifactorial nature of delayed diagnosis of breast cancer among AYA women, which may be driven by patient, provider, system, and environmental factors [39]. Encouraging increased AYA enrollment in breast cancer clinical trials and improving access to tertiary cancer treatment centers that offer specialized cancer care may improve outcomes among AYA breast cancer patients. However, a clear obstacle in Texas, and perhaps elsewhere, is the lack of clinical trials and the distances patients must travel to participate in trials. Mechanisms, such as the online matching system offered by BreastCancerTrials.org, currently exist to provide breast cancer patients and providers information on existing trials. Future research should identify more effective ways to promote utilization of these services among patients and especially among referring physicians.

This study indicated higher risk factors for Black or African American AYA women. Previous research indicated that White women had higher rates than Black women after age 40, and that the reverse was true among younger cancer patients. This is known as the black-white crossover and, in our results, the Black AYAs in Texas had higher rates of incidence than White AYAs [38].

Other factors that may influence the rates of AYA cancer incidence include higher diagnoses of familial and genetic cancers such as triple negative breast cancers and BRCA1/2. However, for the time period in which the data was collected (2005-2009) the Texas cancer registry did not capture patients' hormone receptor status, including triple negative breast cancer status. In 2011, the TCR began collecting hormone receptor status for cancer patients, including triple-negative status. However, they do not collect, and have no plans to add, BRCA1/2 status. The SEER databases began collecting this type of information in 1990.

This population-based study is among the first to assess risk factors for in situ and local diagnoses as compared to regional and metastatic summary stage diagnoses for AYA breast cancer patients in relation to distance to breast cancer clinical trials. The findings were consistent with previous studies among older women that found higher risk for later stage diagnosis among Black/African American and Latina/Hispanic breast cancer patients, as well as recent studies of AYA breast cancer patient considering biological factors [27].

Future AYA breast cancer studies should be designed to include information on breast cancer sub-types, especially those found more frequently among young women of

Black/African American and Hispanic descent. Future studies should consider factors not covered by this study including physical activity, body weight, and co-morbidities. Other risk factors that might be included in future AYA studies include multi-parity, oral contraceptive use, smoking, lifestyle, and environmental contextual factors [39].

The findings in this study are subject to several limitations. One limitation is the lack of income and education levels of the individual patients. Both poverty and education have been shown to be factors in breast cancer stage at diagnosis. [40,41]. There may be other factors that affect AYA women's decisions to participate in clinical trials that were not considered in this analysis. The matching of women to the open and accruing early and late stage trials is a possible limitation, as each trial would have specific inclusion and exclusion criteria. However, this is more a limitation to the Late Stage trials as most of the Early Stage trials inclusion criteria are simpler and primarily require a histologically confirmed diagnosis of breast cancer. The trials considered in this study were those open and accruing in 2012-2013. It is possible that some portion of the trials that were considered would have been open during the later part of the study period (i.e., 2007-2009), as Phase III trials are often open for 5-7 years. The actual numbers and types of trials to which the women might have been considered for could have been different during the 2005 to 2009 time period. However, the diagnosis for early or late stage among the patients is consistent with their eligibility for participation in trials. During the time period that the patients in this study were diagnosed (2005-2009) there were fewer breast cancer trials and potentially fewer trial locations open in

Texas. Thus, this makes the analysis of risk factors associated with trial distance conservative.

In summary, our study identifies several factors that increase risk for AYA women to be diagnosed with breast cancer at later stages including travel distance to trials, insurance levels, and being of African American or Hispanic descent. The study suggests opportunities for additional research considering distance and other factors that may influence the stage at which AYA women are diagnosed with breast cancer. These findings support the need for improving access to clinical trials for AYA breast cancer patients, for additional research on the unique physical and biological characteristics of young breast cancer patients, and the need for continued education of both patients and treating physicians, which ultimately will translate into improved AYA patient survival.

III. QUALITATIVE EVALUATION OF ACCESS AYA CANCER SURVIVORSHIP EDUCATIONAL PROGRAMMING

Introduction

In the United States, improvements in overall cancer survival rates experienced by AYA cancer survivors ages 15-39, have not kept pace with survival rates for adults and pediatric patients [12]. AYA cancer survivors face long term risks from their cancer care, including excess risks of mortality, incidence of secondary primary neoplasms, cardiovascular disease, neuroendocrine and neurocognitive dysfunction, and psychosocial effects [11]. Intellectual and psychosocial concerns such as depression and anxiety also affect this group, as they frequently suffer developmental, cultural, and educational setbacks as a result of their cancer treatment [43]. Researchers speculate that the lack of improvement in AYA survival may be due to a combination of factors including lack of access to care [12].

Albritton and Bleyer's research suggests that there are gaps in both provider and survivor education to address the unique needs of AYA cancer survivors [19]. Since 2006, with the publication of the NCI's and LIVESTRONG Foundation's first joint Progress Review Group in AYA Oncology, AYAs have received increased attention as a population that experiences disparities in care, including poorer survival rates overall than both older and younger cancer patients [11].

Yet, today, few resources exist to train community medical professionals on the unique survivorship needs of AYA cancer survivors. This lack of information

underscores the need for integrated programs that: 1) train providers and educate survivors; 2) establish networks and shared models of care with transition paths from treatment to community care; and 3) build health promotion tools to support improved quality of life among AYA cancer survivors.

The After Cancer Care Ends, Survivorship Starts for Adolescent and Young Adults (ACCESS AYA) patient and family educational programming was designed to build health literacy around AYA survivorship issues, and to stimulate improved communications between survivors and healthcare providers with the goal of improving overall quality of life and wellbeing among survivors, their families, and caregivers. The project was funded by the Cancer Prevention and Research Institute of Texas and operated by the Seton Healthcare Family, a hospital system in Central Texas. This evaluation effort was funded through the grant to Seton Healthcare Family to the Texas A&M School of Public Health. The ACCESS AYA evaluation was conducted under protocol IRB2013-0498D approved by the Texas A&M University Institutional Review Board (IRB).

The primary aim of this paper is to share results from a mixed methods, but primarily qualitative, evaluation of the ACCESS AYA project based on semi-structured interviews from four sets of stakeholders: AYA survivors, healthcare providers including both nurses and physicians, hospital administrators, and leaders of cancer survivor advocacy groups. The paper addresses the central research question of "How did the ACCESS AYA program increase health literacy, communications, and understanding among AYA survivors and providers?" As sub-questions to this inquiry, we also focus

on the common barriers that AYA survivors experience and stakeholders' perceptions of opportunities for sustaining and expanding AYA survivorship education programs.

The qualitative themes and analyses of this study reflect and build upon the findings from the periodic and final quantitative evaluations and reports that were submitted to CPRIT and the Seton Healthcare Family executives. The quantitative assessments were important, as they reported on numbers of survivors and healthcare professionals served, and the types and numbers of print and digital health materials delivered throughout the project period [44]. This qualitative evaluation provides for deeper insights into what the participants valued, and provides richness in understanding what elements of the educational programs were most important across the spectrum of stakeholders. Additionally, the stakeholders' responses to question about what barriers continue to affect them can help identify areas for additional communication and educational programming. Finally, the themes and areas of discussion for sustainability and future development can be used to inform future system and policy changes.

ACCESS AYA Theoretical Framework

The ACCESS AYA program's educational efforts were focused on improving the AYA survivors' wellbeing, and supporting changes in their behavior, as well as changes in healthcare professionals' knowledge and clinical practice behaviors. We anticipated that the effects of the educational programming would extend into the broader clinical, social, cultural, and political environments of the survivors and providers. Based on McLeroy et al.'s social ecological framework for behavioral health,

the research team identified five levels of societal influence in order to construct a theoretical model (Figure 3.1) for use in our analyses of the interview narratives [45].

Our social ecological model places the AYA survivors at the center, where physical characteristics, attitudes about survivorship, knowledge, and values exist in relationship to individual health and wellbeing. The AYA survivors' educational node in the framework encompasses interpersonal relationships with clinicians, parents, partners, friends, and peers, including social media relationships that influence the survivors' care and health behaviors both at home and in clinical settings.

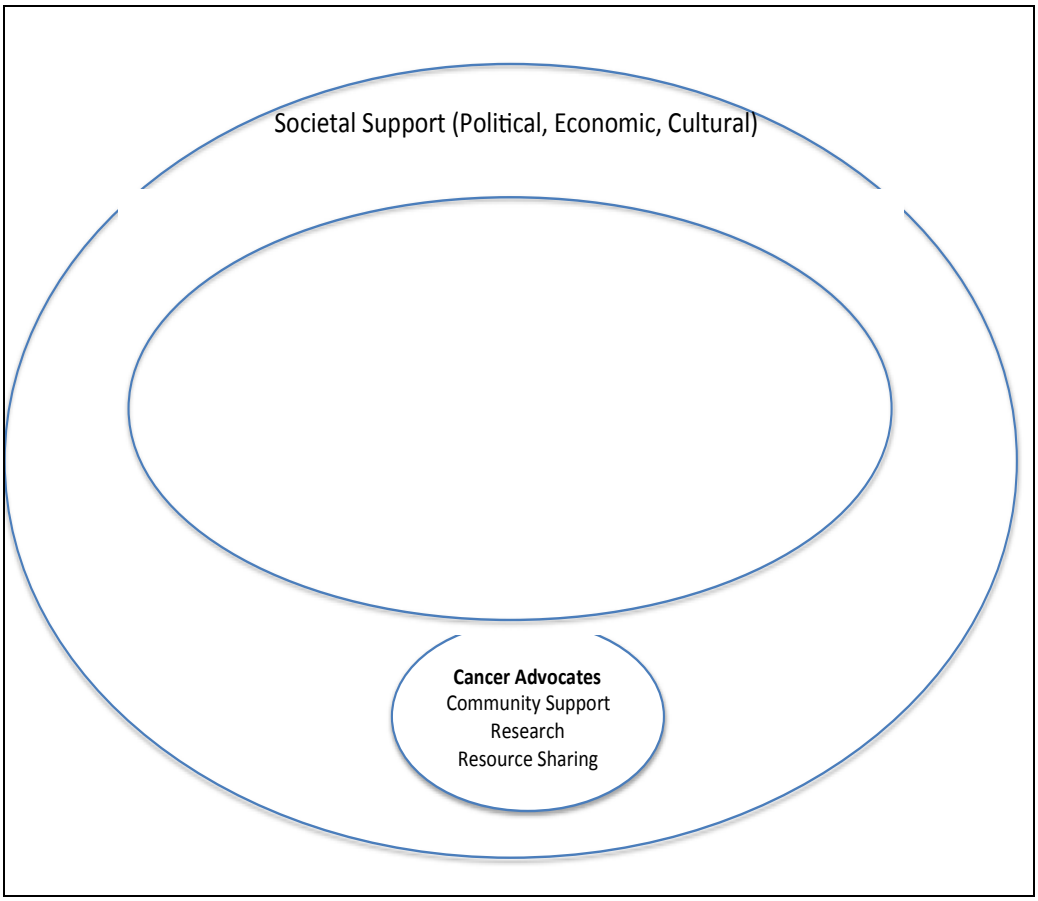

Figure 3.1 ACCESS AYA Theoretical Framework

On the right side node are the influences of the healthcare professionals' education—the knowledge base of physical and psychosocial late effects that influence care and treatment, awareness of transitional needs, and use of survivorship navigation services to support and sustain survivor wellbeing. The surrounding layer of the Seton Healthcare Family organization and community-based healthcare represents the organizational norms, culture, and resources of the community healthcare environment.

In the closer of two outer rings, the cancer advocacy groups represent a powerful and contributing sphere of influence in AYA cancer survivorship including physical, financial and social support, research efforts, resource sharing, and dissemination. The final outer ring indicates the levels of societal support for cancer survivor wellbeing including policies for insurance, financial and social support, and cultural attitudes and values that affect how AYA survivors are perceived and supported, or left isolated in the workplace, at school, and in the community.

Each of these levels, or spheres, in the theoretical framework is laden with value judgments of the research team, of the interviewers, and the individuals being interviewed. As such, this narrative evaluation of the ACCESS AYA program is naturally influenced by the social context and values embedded in each group as they relay their perceptions of the program effects, barriers, and potential for sustainability.

The criteria and approach for this qualitative evaluation are based in the constructivist models suggested by Guba and Lincoln with criteria including [45-47]:

- Credibility (i.e., faithful descriptions or interpretations of human experiences)
- Fittingness (i.e., how a study findings fit outside the study and if viewers will

find the evaluation results meaningful in their own experience)

- Auditability (i.e., if the study is detailed in such as way that it can be replicated)

The importance of auditability, especially for a qualitative evaluation is emphasized by Sandelowski who suggested that audibility can be enhanced through description of the project and clear explanations and justification of 1) study rational; 2) articulation of the researchers' views on the subject; 3) purposes/goals of the study; 4) description of participant engagement; 5) mutual influences among the researchers and participant/stakeholders; and 6) explicit details of data collection, analyses and transformation [48]. Using these criteria as guidelines and as a statement of the evaluators' philosophical approach to the evaluation, the remainder of this research report describes the methods, data analysis, findings, and results and a discussion of future directions.

Methods

The ACCESS-AYA program was designed as a strategic combination of provider and survivor education directed at community healthcare providers, AYA survivors, their families, and cancer patient advocates. The program's professional medical education was targeted at community and hospital-based family practice and internal medicine physicians and nurses, as suggested by Freyer, these are the professionals most likely to provide follow-up medical care to AYA cancer survivors who have transitioned from oncology care into community care [49]. There were three elements to the professional education: 1) formal, for-credit, accredited continuing medical education program (CME); 2) a half-day live educational CME session that

included case studies and presentations on AYA late effects; and 3) a series of medical briefs titled *"AYA Prompt Evidence Assessment and Review of the Literature,"* known as "AYA-PEARLS." Examples of the AYA-PEARLS and a list of the program's professional and patient education videos and print materials are provided in Appendix B.

Feelings of isolation and lack of peer support has been identified by Zebrack as an important issue and concern among AYA cancer survivors, both during their time in-treatment and post-treatment [50]. To address this need, the ACCESS AYA program produced two annual, half-day interactive, educational sessions for survivors, friends and family, and community cancer advocates. During the project operating period, an estimated 4,000 Central Texas AYA survivors, 15,000 physicians, and 18,500 nurses across Texas received information about the ACCESS AYA program via mail, email, or print materials. As reported in the project's final report to CPRIT, direct interpersonal contact was made with approximately 325 AYA cancer survivors, 785 health care professionals, including nurses, physicians or residents, and over 175 cancer advocates and care givers [44].

Use of mHealth social and digital media was an important element in the survivor public education efforts. In collaboration with the Communities of Texas Cancer Activity Resource Education Support (CTxCARES, a Center For Disease Control (CDC) Cancer Prevention and Control Research Network funded project at Texas A&M School of Public Health, the ACCESS AYA grant supported marketing and dissemination of the AYA Healthy Survivorship iPhone app. Over 850 users

downloaded the Healthy Survivorship app from the Apple App store during the project period.

The app provides an interactive AYA survivor health and well-being assessment and links to the Children's Oncology Group's *Health Links*, several of which are offered both in English and Spanish. Both the iPhone app and its companion website (www.healthysurvivorship.org) offer AYA survivors links to the LIVESTRONG and Journey Forward cancer survivorship care plans.

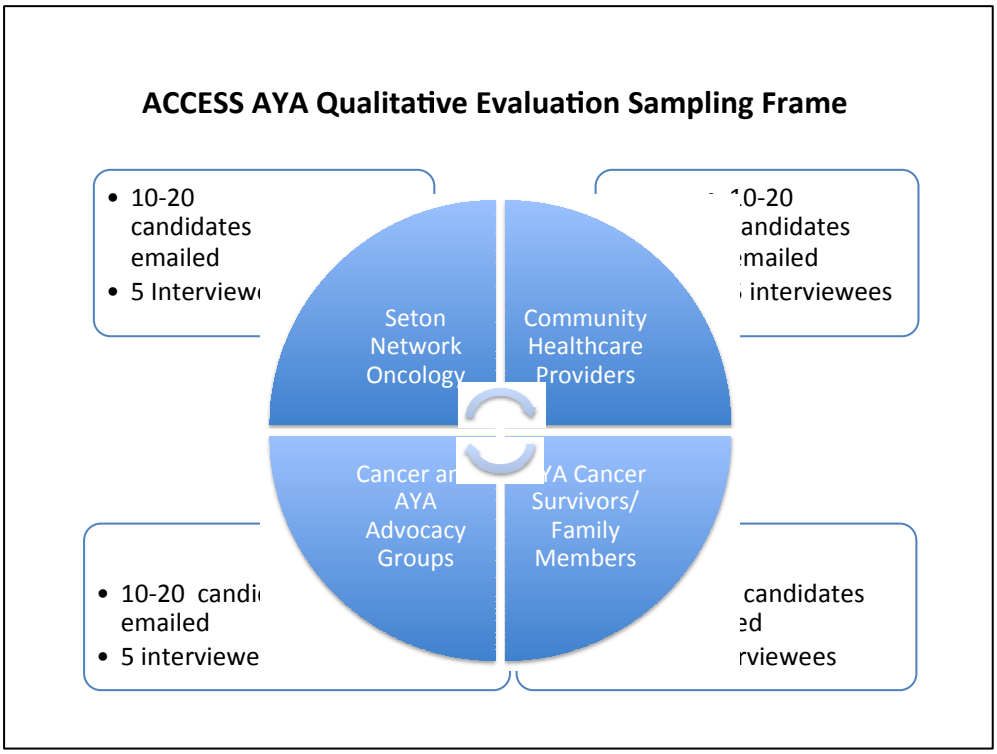

Figure 3.2 ACCESS AYA Evaluation Sampling Frame

The evaluation sampling frame, shown in Figure 3.2 was designed to include approximately twenty participants, five from each of the following groups: 1) healthcare professionals (i.e., nurses and doctors); 2) hospital administrators and executives; 3) AYA survivors; and 4) community cancer advocates. The initial contact with the participants was via an email that included a survey to ascertain their willingness to participate, an online consent process, and information on how to contact informants who agreed to participate in the evaluation process. This survey also assessed respondents' awareness of the ACCESS AYA programs and their perceptions about program effectiveness.

In addition to the email request, a request for interested AYA survivors to participate in the research study with a link to the survey was posted on a Facebook page operated and maintained by Central Texas AYA survivors. Of the 22 informants who participated in the survey, 21 were willing to be interviewed, and 18 interviews were conducted. Table 3.1 provides information on the degree to which survey participants were aware of the ACCESS AYA programs and their perceived level of effectiveness of the program

The team included two investigators conducting the interviews, with two different investigators, of which I was one, analyzing the raw data and providing the coding and analyses of the materials. The coding was done under the guidance of an experienced qualitative researcher, and all members of the team have experience in health behavior research in cancer survivorship. A general interview guide was developed and tailored with questions specifically relevant for each type of participant.

The semi-structured interview questions were designed with reference to Stufflebeam's Context Input Process Product (CIPP) model of evaluation practice [51, 52]. The CIPP model considers evaluation as an essential component of improvement efforts and adapts well to qualitative evaluation of programs like ACCESS AYA where there is a need to include context, input, process, and impact statements with deep engagement of a variety of stakeholders. Examples of the consent documents and the full interview protocols for each of the stakeholder groups are provided in Appendix A.

The interview guide questions for healthcare professionals and AYA cancer survivors are provided in Figures 3.3 and 3.4, respectively. From among the 21 stakeholders who agreed to participate in interviews, 18 interviews were conducted (scheduling conflicts accounted for the loss of three subjects). The researchers and research assistants individually or jointly conducted 20- to 30-minute telephone interviews with study participants. The telephone interviews were recorded with the participant's agreement, and each participant confirmed they had understood and agreed to the consent process. Once consent agreement was confirmed, the interviewers no longer used the participant's names so that the recorded and transcribed interviews would remain anonymous to the research team coding the interviews.

The researchers conducting the interviews were experienced health behaviour professionals who sought to apply an open and receptive aspect to accommodate positive, neutral, and negative attitudes articulated by the participants. The tape-recorded interviews were transcribed by an external contractor, and returned as text documents.

The interviews were coded by the type of participant (i.e., physicans, nurse, hospital executive, advocate, or AYA survivor). In cases where a participant had more than one role (e.g., both survivor and advocate) the interviewers asked the participant to respond to the questions specific to one role, to the greatest extent possible.

Healthcare Professional Questions

1) In what ways have Seton's professional and patient education programs on Adolescent and Young Adult Cancer helped you understand the needs of these survivors?

2) In what ways have you shared information on the AYA cancer survivor professional or patient education programs with your colleagues or staff?

3) In what ways, if any, have information or educational materials about AYA cancer survivors changed the way in which you do your job?

4) What barriers or challenges are you aware of regarding how AYA cancer survivors are cared for or treated in Central Texas?

5) Has the information or education regarding AYA cancer survivors changed how you think about or treat other cancer survivors? If so, can you provide some examples?

6) What opportunities or challenges do you believe exist in sustaining or expanding programs for educating professionals about AYA cancer survivors?

7) What opportunities or challenges do you believe exist in sustaining or expanding programs for educating AYA cancer survivors and their families/caregivers?

8) Do you have any additional thoughts or information you would like to share as part of this evaluation of the ACCESS AYA grant?

Figure 3.3 Healthcare Professional Interview Guide

Cancer Survivor/Family Member/Caregiver Questions

1. In what ways have Seton's education programs on Adolescent and Young Adult cancer survivorship helped you as a survivor (or as a survivor's caregiver/family member)?
2. Have you shared any of the information or education materials, including the videos or the AYA iPhone app, with other AYA survivors? What about caregivers or family members? Is there an anecdote or story you can share?
3. In what ways, if any, has information or educational materials about AYA cancer survivorship helped you? For example, learning about healthy diets or physical activity for AYA survivors?
4. What barriers or challenges are you aware of regarding how AYA cancer survivors are cared for or treated in Central Texas?
5. Has the information or education regarding AYA cancer survivors changed how you think about or treat other cancer survivors? If so, can you provide some examples?
6. What opportunities or challenges do you believe exist in sustaining or expanding programs for AYAs?
7. Do you have any additional thoughts or information you would like to share as part of this evaluation of the ACCESS AYA grant?

Figure 3.4 AYA Survivor Interview Guide

Once transcribed, the interview narratives were read and checked for accuracy by the first author and a research assistant prior to coding. The electronic files were loaded into Atlas.ti (Atlas.ti Qualitative Data Analysis v.7, Germany, 2014) for coding and analysis.

The descriptive coding and framework followed fundamental approaches of identifying themes, developing codebooks, and constructing models guided by the theoretical frameworks provided by Miles et al. and Saldaña and assessed statements about the merit, worth, satisfaction, and/or significance of the educational programming

for the evaluation [52, 53]. These themes were present in the interview guide questions, thus supporting efforts to code statements in interviews to specific themes. In the First Cycle coding, both Descriptive and In Vivo codes were applied. The coding process started with both researchers independently reading the transcripts and then discussing early findings. First Cycle coding themes were developed independently from the interview guide, and additional themes emerged during the Second Cycle coding process. Memos were inserted into the Atlas ti database. Data analysis for the evaluation was informed by an analytical approach suggested by Creswell in efforts to grasp the themes and essential meaning of the stakeholder's comments [55].

During the first and second stages of analysis, both research team members independently coded and met with a senior researcher to discuss findings. Any differences or disagreements in coding or thematic analysis were resolved through discussions among the research team members. The inter-rater reliability of the First Cycle coding was 89.3%, and 78.4% for Second Cycle coding based on kappa analyses using Stata 12.1 statistical analysis software (Stata Corporation, Version 12.1,2012, College Station, TX). Quotations from the stakeholders were further categorized based on coding domains associated with the evaluation's theoretical framework.

Results

The ACCESS AYA evaluation results are structured using the characteristics provided in the theoretical framework, beginning with the analyses of the interviews with the AYA survivors who participated in the program. Table 3.1 provides the results of the initial email survey that was used to preliminarily assess the participants'

perceptions of the program and also to recruit participants for the telephone surveys.

Table 3.1 Survey of Awareness and Effectiveness of ACCESS AYA Program (N=22)

Question	Mean	Standard Error	95%Confidence Interval
Level of awareness	3.2	0.098	3.02-3.43
ACCESS AYA Program effectiveness	4	0.132	3.72-4.27

Note: The response scale was 1-5, with 5 as the high score.

Table 3.2 provides examples of the First Cycle descriptive codes and their relationship to the theoretical model. Focal areas for the First Cycle code reflect perceived participant areas of concern and need from the interview transcripts.

Table 3.2 List of First Cycle Codes and Focal Areas

Framework Region and First Cycle Descriptive Codes	**Focal Area**
AYA Survivor Wellbeing	
Barriers to care/lack of access to care	Physical concerns
Awareness of late effects	
Use of care plans	
	Psychosocial concerns
Educational needs	
Personal reflection on survivorship	
Need for community/peer sharing	
	Financial/Insurance concerns
Needs of daily living	
Costs of past care	

Table 3.2 Continued

Framework Region and First Cycle Descriptive Codes	Focal Area
AYA Survivor Education	
Need for survivor education	Information
AYAs use of apps/digital technology	
Use of survivorship plans	
Information sharing practices	Training/education
AYA self advocacy	
Lack of ability to communicate with physicans	
Use of Case managers/navigators	Human Resources
Healthcare Professional Education	
Age Appropriate Care	Education/Training
Awareness of late effects	
Knowledge of AYA needs	
Knowledge of Seton AYA program	
AYA sparseness/fragmentation	
CME uptake and professional education programs	Time constraints
Referrals and transitions in care	Insurance coverage concerns
Coordination with navigators	
Use of survivorship plans with patients	
Cancer Advocates	Information gathering/sharing
Advocates role in information sharing	
Attitudes about AYA research	
Knowledge of Seton and other community programs	
Family and caregiver needs	Delivery of resources
Use of survivorship care plans for non medical needs	
Seton Healthcare Family/Community Physicians	Financial and Human Resources
Impact of AYA Educational Programs	
Knowledge of Seton AYA program	Sustainability
Societal Support (Political/Economic/Cultural)	Resources
AYA political advocacy	Influence/Power
AYA Fragmentation	Practice Change
Use of survivorship care plans	

The refined codes from the Second Cycle coding are shown in Table 3.3. These codes reflect much of the First Cycle code and include additional themes and constructs that emerged through code review and discussion as well as additional mining of the transcripts.

Table 3.3 Evaluation Theoretical Framework and Themes

Theoretical Framework Characteristics	Themes
Survivor Wellbeing	Self-Efficacy Social Interaction with other survivors Use of social media (i.e., Facebook)
AYA Survivor Education	ACCESS AYA Meetings/Programs Information on diet/nutrition Awareness of AYA psychosocial needs Self-advocacy training Information on late effects of treatment Use of AYA Healthy Survivorship App Increased level of peer support Use of Survivorship Care plans Awareness of AYA cognitive issues
Healthcare Professional Education	Awareness of AYA psychosocial needs Awareness of AYA late effects Palliation/end of life care Survivorship Care Plans Navigation services for patients Use of PEARLS for professional education Practice change as a result of ACCESS AYA Referrals and transitions in care
Cancer Advocates Role/Education	Resource sharing Importance of AYA Survivor Research Awareness of AYA unique needs
Seton and Community Healthcare Resources	AYA Survivorship Nurse Navigator AYA Group Meetings
Societal Support	Political awareness Advocacy for AYA resources/care

Survivor Wellbeing

The statements of AYA survivors relating to their own wellbeing gave evidence of ongoing struggles and challenges physically, emotionally, and socially. Education programs like ACCESS AYA address a number of the issues that affect AYA survivors. However, for many of these young adults, the challenges and barriers of survivorship are considerable.

A young brain cancer survivor shared her frustrations about the transition from being in treatment to the "new normal" of survivorship and her concerns about the ongoing financial costs of cancer care and survivorship.

> *"What would be really helpful is to figure out financial help because that's kind of one of the big things. It just costs so much for all the treatment…the biggest thing is trying to get back to normal routines because you're used to just being home and dealing with your sickness."* (AYA Survivor and Program Participant)

For AYA survivors, the concept of wellbeing is transient and is as much mental and emotional as physical. They struggle with the affects of their treatment across all the areas of the social ecological framework, physically, intellectually, socially, and financially. Several of the survivor stakeholders expressed concerns about the effects of their treatment on their mental capacity, and worried about how that might affect their future employment and educational opportunities. Wellbeing among survivors was also expressed in changed awareness and increased empathy for those they encounter.

> "*A lot of people might not even realize how sick people might be and not even look it. I think my experience has made me more aware and less judgmental*."
> (AYA Survivor, ACCESS AYA Participant)

When asked to address the benefits of the ACCESS AYA program, several survivors commented on the value of being more informed and connected to the community of AYA survivors. According to Schroevers et al. positive social support is strongly protective against the distress and depression that may affect AYA cancer survivors and many AYAs suffer from post-traumatic stress conditions [56].

> "*I appreciated the connection point, to meet some more people… doctors are brilliant and all, there are things that they simply don't understand because they've never been through it …there's a difference between science and experience."* (AYA Survivor/ACCESS AYA Program Participant)

AYA Survivor Education

The ACCESS AYA educational programming for survivors covered medical and clinical issues, survivor advocacy, self-efficacy, and opportunities for social engagement with other survivors, in real time and in virtual online space. Both patient and professional education programs stressed the importance of the development and use of Survivorship Care Plans.

> *"My memory is really, really bad, so it [the care plan] helps me to have a lot of information to hand over to my doctors. I have probably eight to twelve different medical people trying to keep me well and going. So, it's hard to keep up with all that. It helped me along the way when I can't remember stuff."* (AYA Cancer Survivor, ACCESS AYA Participant)

The ACCESS AYA Summits were half-day meetings designed to provide opportunities for interactions with peers, healthcare professionals, and community cancer advocates. The agendas included a variety of interactive elements including physical activity, cooking demonstrations, and physicans presentations on screening and

surveillance for second cancers and late effects such as cardiotoxicity.

> "*… some of it has been some good practical stuff on how to deal with finances, emotions, the insurance, second opinions, keeping records. My favorite part, honestly, is that it connects you to other people, both experts in the medical field, and other people who have been through it…*" (AYA Cancer Survivor/ACCESS AYA Program Participant)

A consistent theme throughout the ACCESS AYA education effort was the importance of self-advocacy and advocacy training. The educational seminars included survivor-led discussions on self-advocacy in dealing with the medical community and in life situations, as well as engagement in social advocacy for AYA survivorship concerns.

> *"I think that the benefit of a young person understanding and knowing that they are actually part of a larger community, they're not alone, that they're part of this community, they're part of something bigger and they can make a difference, I think is incredibly powerful and can be helpful to their own sort mental and emotional healing."* (AYA Cancer Survivor/Cancer Advocate)

The shared passion and desire to participate in social advocacy among the AYA survivor community is perhaps an unintended consequence of the ACCESS AYA educational program. Several of the AYA survivor participants stated that as a result of learning about national AYA advocacy organizations in the ACCESS AYA programs, like Critical Mass and the OMG Stupid Cancer Annual Conference, they are now participating in advocacy at a national level.

Healthcare Professional Education

Education of healthcare professionals appeared to be one of the more challenging aspects of the ACCESS AYA program. The initial plan of offering free online and DVD CME materials to physicians and nurses was deemed successful only for the nursing

professionals. Despite multiple attempts to deliver the CME to physicians, uptake was minimal. The innovation of creating the PEARLS, both as one-page briefs and short YouTube videos that included cases and evidence-based facts on AYA survivorship, offered improved dissemination of the professional education materials. Over 350 PEARL packets were delivered to Central Texas physician offices and clinics.

The PEARLS were delivered both as links from the Seton Survivor Center website and delivered directly to clinics and offices with brief presentations to the clinical staff. A qualitative assessment of the PEARLS dissemination effort is reported on elsewhere. A community physician comments on the difficulty of continuing education and the PEARLS as a delivery mechanism:

> *"So, the education probably has to come case-by-case. That is the way most of us learn anyway. A lot of people are getting a lot of education off emails, webcams and this kind of short vignette."*
> (Community Physician)

There were differing perceptions in the value and opportunity for providing physician education, as is evidenced by these comments from a second community-based physician:

> *"I think it's a challenge, frankly, to educate any professional once they've finished their training. I just think that a lot of people are so busy and so overwhelmed with just workload that taking time for professional education that isn't mandated by their specialty board, it's just not going to happen."* (Community Physician)

A cancer survivor advocate, who also served on the ACCESS AYA advisory group, had a differing opinion regarding healthcare professional education.

> *"I think educating professionals is a real problem in the young adult community. Because the young adults patient population is fragmented between adult and pediatric and community and academic, I think anything that we can do to break down those walls is what we have to do to move the field forward and to improve the care and treatment of these young adult patients."* (Cancer Advocate and ACCESS AYA Advisory Board Member)

Despite these concerns, there was dispersion of the professional training through the system as evidenced by resident training programs for AYA cancer survivorship provided by a Seton staff physician and via comments from both nurses and physicians about sharing the ACCESS AYA materials with staff and colleagues.

Concerns for the complexity of care of AYA patients and comments about the need for better transitions of patients from cancer care to community care were themes in the health care professional interviews. Both physicians and nurses expressed concerns about lack of time for education as well as the relatively few numbers of AYA survivors among their practice populations.

An ACCESS AYA goal for physicians' education, in addition to delivering information and education, was practice change. A community-based palliative care physician reflects on changes in her practice behavior as a result of the ACCESS AYA programming:

> *"I've tried to be more deliberate about preparing patients for survivorship while they're in treatment. I think systematically what we used to do is treat the patients, and then be a little befuddled as to why they weren't feeling great afterward, either physically or emotionally or both. I've started to be more deliberate about trying to prepare patients for when they finish treatment… I have gotten more tuned into the need for behavioral health support for patients who are not yet in*

> *survivorship... the bigger questions of meaning and co-morbid mental health problems are harder, a lot harder."*
> (Community Palliative Care Physician)

According to the views of both the health care professionals and healthcare administrators, the ACCESS AYA program was successful in creating the content and materials for professional education, but struggled in dissemination and adoption. The delivery of the video and print PEARLS were perhaps the most successful elements of the program in that they delivered evidence-based information in a timely and succinct manner and required little investment of time from the healthcare providers.

Community Cancer Advocate Education

Cancer advocacy groups and advocate leaders frequently take on the role of bridging between the medical community and the patients and their families. Modeled partially on the success of breast cancer advocacy, AYA advocacy groups work to ensure that the unique medical, psychosocial, supportive, and educational needs of teenagers/adolescents and young adults living with cancer are met. The roles of advocacy groups include bringing individuals interested in change together, and providing coordinated education and support services as well as policy analysis and response. Much of the focus of the national AYA advocacy groups is to bring researchers together with survivors to support increased recognition of the unique needs of this population including developing specialist facilities for treatment and survivorship, addressing concerns for delayed diagnosis and seeking to improve access and quality of care. Central Texas is home to both the national headquarters of the

LIVESTRONG Foundation, with its strong focus on AYA survivorship, and the newly formed Critical Mass AYA advocacy group.

> *"I think that it is not unique to Central Texas. I think that a challenge that is faced everywhere is this fragmentation of the young adult patient population, and the difficulty in breaking down silos of their care and treatment and service. I find that so often the frustration is people don't get me, they don't understand what it's like to be a young person with cancer. Why am I getting materials for old people? It's different to be in my position. This gives rise to the isolation and the fact that you don't have anyone, if you're socially isolated, to process your experience with."* (AYA Survivor and Cancer Advocate)

A consistent theme among the cancer advocates was their role in the community in sharing and distributing educational resources and programming. Several of the cancer advocates participated in the two AYA annual summits held during the project and used the venue to both distribute their own information and gather other resources for sharing with their constituencies.

Sustaining ACCESS AYA Educational Programs

Programs like ACCESS AYA face challenges in efforts to sustain and expand their reach due to competition for funding and ongoing challenges in hospital and healthcare operations. When asked about their thoughts regarding sustainability, most respondents mentioned the competition for funding. However, there are valuable insights regarding what it will mean to sustain survivorship education efforts in emerging areas such as caregiver support and palliative care both for pain management and end of life care.

> "*To make an analogy…we prep people for a hurricane. We take care of people during the hurricane, and we may provide some emergency services after the hurricane, but …we don't help people rebuild when that hurricane is all through… I look at caregivers as a patient population that's emerging and that we are ill-equipped to care for."* (Community Palliative Care Physician)

ACCESS AYA appears to have succeeded in increasing awareness of AYA survivors as a unique population and building a sense of community among AYAs, their caregivers, and advocates. The survivors' self-avowed increased social and political awareness and desires for activism is also an indicator of increased self-efficacy. These elements tie to the societal support realm in the evaluation's theoretical framework related to building skills and support for political, economic, and cultural aspects of AYA survivorship. Both the cancer advocates' and the AYA survivors' interviews indicated that the participants found value and benefit in the increased sense of community and the potential to take action based on information and education provided by the ACCESS AYA program. There were also indications among the healthcare professionals that increased advocacy and self-management both for patients and their families was a positive benefit of the ACCESS AYA programming.

Among the most powerful elements in programs like ACCESS AYA and the Seton Cancer Survivor Center are the creation and support for group meetings of AYA survivors. The online Facebook and in-person support community were primarily a creation of the Seton Cancer Survivor Center, but they also reflect the increased emphasis on survivor education and communication from the ACCESS AYA grant efforts. The engagement of the AYAs survivors in group meetings demonstrates the

development of a sustainable community engaged in sharing resources, wisdom, and information.

> *"I think a lot of people really identified with that because they were able to hang out with people that had, I guess, maybe the same limitations… or similar backgrounds to them and they felt more comfortable…*
> *They really seemed to enjoy the fact that it wasn't all based on the illness or the complications… it was based on having fun, being normal and moving on…"*
> (AYA Cancer Survivor/ACCESS AYA Participant)

Discussion

ACCESSS AYA was designed to address both a knowledge gap and a delivery gap among AYA cancer survivors and providers. The knowledge gap is the lack of information and awareness among AYA survivors and providers about the characteristics that make this population unique among cancer survivors as a group that experiences disparities in survival increased mortality, greater incidence of second cancers, and late effects of treatment and psychosocial concerns that affect quality of life. The stakeholder groups in the evaluation shared perceptions that were unique to their experience, some reflecting on the ACCESS AYA materials, and others on AYA survivorship concerns in general. The delivery gap is an opportunity for increased information and resource sharing among healthcare professionals, both oncologists and community providers as well as among the survivor and advocate stakeholder communities. This finding is supported by Zebrak in his analysis of the service needs of AYA survivors [43]. Across all of the stakeholders there was general agreement on the importance of programs and educational efforts to ensure the wellbeing of the survivors.

Similarly there was consensus that the building of a knowledge base and community repository of resources to support AYAs in their survivorship efforts. AYA survivors' needs regarding information sharing, especially among peers, were assessed in research by Freyer [48]. Among the survivors and cancer advocates there was acknowledgement and support for increased social support and peer engagement, which was identified as one of the key research gaps in a recent National Cancer Policy Forum Workshop held jointly by the LIVESTRONG Foundation and the IOM [57].

The results of the evaluation indicate that the program was perceived in a positive light, by the members of the representative stakeholder groups interviewed—AYA survivors, clinical healthcare professionals, administrative healthcare professionals, and cancer advocates. However, some of the physicians claimed to have not been fully informed of the program, and others indicated that difficulty in finding time for educational activities given their patient load and clinic demands. Among cancer advocates, there were concerns about the need for additional and ongoing dissemination of the educational materials. Among survivors, most indicated benefits from both the educational program and the navigation and care plan provision services provided by the Seton Survivor Center.

The survivor benefits were in the domains of increased awareness of late effects, use of the app and social media, and increased peer support and engagement. The AYA survivors also indicated increased self-efficacy both for their engagement with physicians and in healthcare settings and in policy advocacy for the regional and national AYA survivor community.

Among physicians, nurses, and health care administrators there was clear evidence of increased knowledge of AYA health and psychosocial concerns and greater awareness of the unique needs of the AYA population. There was evidence of practice change in the way nurses and physicians treated and perceived survivors' post-treatment needs, both physical and psychosocial. The high level of effectiveness and value of the nurse navigator and staff of the Seton Survivor Center were remarked upon by both survivors and providers. While the nurse navigator was not directly funded by the CPRIT grant, her engagement in the project as an advisor and collaboration was an important element in the success of the education programming.

With reference to the principles of triangulation in evaluations suggested by Jonson, qualitative evaluation findings are consistent with the findings of the objective qualitative evaluation of the ACCESS AYA program [44]. As was offered in the participant survey, the research team provided those participants who requested it the full report to review and have sought feedback and critique of the evaluation from project stakeholders.

Qualitative analyses and evaluations allow us to share the voices of the stakeholders and participants from an interpretive perspective. In considering the limitations in this evaluation, the research team attempted to recognize the subjectivity of their lenses in viewing the ACCESS AYA project. The selection of the interview participants may be perceived as a limitation, as they were self-selected. The participant sampling frame was well reasoned, and the inclusion of groups of AYA survivors, health care professionals, and advocates was highly relevant to the evaluation research. The

views expressed by the AYA survivors may not reflect the perspectives of AYA cancer survivors who prefer to forget about their cancer experience, or those who are less affected by late effects of treatment.

An assumption was made that data collection via phone interview was appropriate for the research objectives and the settings. Also, the limited time for some of the phone interviews was driven by the time constraints of the healthcare professionals. Limitations may exist in the narrow use of interviews as the primary source of data. However, the research team was familiar with the print and video materials of ACCESS AYA, and team members participated in field observations, providing additional richness and robustness to the evaluation analysis. Finally, the results and data must be appropriately analyzed and the findings adequately corroborated by using multiple sources of information. Qualitative studies such as this evaluation have the potential to complement the quantitative evaluations by bringing to the forefront the multiple realities of the various stakeholders. The values and benefits of the program evaluated reflect the realities of the lives and work of the participants. What worked in ACCESS AYA, and what challenges and opportunities remain, are articulated through the voices of those most affected.

In responding to the evaluation's primary and secondary research questions regarding the value and benefits of both AYA survivor and professional education, we suggest that overall, ACCESS AYA was moderately successful in reaching its intended population, but that additional work is needed to continue the educational efforts.

The evaluation and the ACCESS AYA program were built on an action agenda for change, through education and information, in the way that AYA survivors perceive themselves and are perceived by their peers, providers, advocates, and communities. The agenda for change includes ongoing developments in the skills and knowledge base of community healthcare professionals, doctors, nurses, and administrators who treat and care for AYA cancer survivors.

This evaluation offers a substantive contribution to the understanding of the AYA survivor community and to the healthcare professionals and advocates that aid them in their efforts to a new “normal” life and wellbeing in their survivorship. This evaluation highlights the need to continue to build the survivor and professional resources to address the unique impact of cancer on the quality of life and wellbeing of AYA cancer survivors. To adequately provide quality care for AYA survivors, health care organizations and providers must address both the health and the psychosocial needs of this population. To do so will require ongoing research in the understanding AYA survivors as a highly heterogeneous population that requires management of cancer and treatment late effects including fertility, body image, and cognitive and most particularly psychosocial effects and care needs. As part of this process, policy and programmatic improvements are needed to facilitate transition to AYA survivors into community and off treatment care through the provision of care plans and age appropriate information and support service resources.

The development of survivorship research methods and measurable outcomes to support evidence-based educational materials and guidelines depends on the availability

of funding opportunities at a time of increasingly limited resources and economic pressures in both academic and healthcare settings. The ability to develop quality research studies related to the AYA population is also dependent on the recruitment of sufficient numbers of survivors into these studies. It is hoped that through ongoing efforts to engage survivors, providers and advocates in programs like ACCESS AYA can also extend into community-based participatory research efforts.

An additional cost effective opportunity for engaging AYA survivors in evaluation and survivorship quality of life research is through the use of mobile based applications and technologies, as is demonstrated in the use and adoption of the AYA Healthy Survivorship app. Mobile technologies are emerging as effective tools for survivorship engagement and care as well as tools for provider and survivor education.

IV. APPS SEEKING THEORIES: MOBILE APPLICATIONS AND HEALTH BEHAVIOR CHANGE INTERVENTIONS

Introduction

"We tend to overestimate the effect of a technology in the short run and underestimate the effect in the long run." - Roy Amara, leader at the Institute for the Future

With the advent of smartphones and texting, the use of mobile phones has shifted from a voice device to an Internet accessible hand held compute. In this shift, the large market of mobile software applications has emerged. As of May 2014, the United States had 345.2 million mobile subscribers [59]. This is more than one mobile subscription per person, based on the U.S. World Bank population estimates of 313.9 million [60]. According the Pew Internet and American Life Surveys, 91% of U.S. adults own a cell phone and 60% use their phone to access the Internet [61].

Mobile technology, cell phones, smartphones, and tablets provide any time anywhere access to health information, health promotion, and behavioral interventions. Use of mobile technology for health seeking information is high, with 31% of smartphone owners using their mobile phones for health information [61]. Mobile health (mHealth) is defined as: “using wireless mobile communication technology to aid health services delivery” [60]. One of the promises of mHealth is that it can empower individuals to be active in their own care through tools that facilitate assessments, monitoring, communication, and self-management. Personal mobile applications (apps)

are a critical component of mHealth, providing educational resources, decision-making tools, psychosocial communication, and social support.

For the growing population of cancer survivors, many of whom experience differing needs in terms of medical care, psychosocial support, and practical needs of daily living, mHealth apps have the potential to provide access to information and health behavior interventions that are low cost, easy to access and personalized to their specific needs. Increasingly, socially disadvantaged populations, including racial/ethnic minorities, those with lower incomes, and the elderly use smartphones as their primary or only connection to the Internet [60,62]. Mobile interventions oriented to cancer care and survivorship, education, and social engagement have the potential to inexpensively support cancer survivors with tools to better understand and manage their cancer care, both during and after treatment. While sparse, studies such as those by Bender et al. that address the use of mobile app interventions in cancer are beginning to explore the efficacy and potential of apps [63]. For the most part existing cancer smartphone and app research articles are disease or symptom specific. Examples include a review of pain management apps in 2011, by Rosser, and an assessment of colon cancer apps by O'Neill and Brady in 2012 [64,65].

An emerging question concerning mHealth apps for health promotion and disease prevention is: "to what extent are apps based in behavior and health communication theories and frameworks?" With specific relation to disease specific apps, previous reviews have coded cancer apps to examine which apps were "scientifically/clinically based" or "evidence-based" or on the basis of the app's purpose

and content such as awareness, cancer treatment information, fundraising, or early detection [61, 64, 66].

A systematic review of mHealth research studies by Free et al. to quantify the effectiveness of mHealth interventions on health behavior change and disease management was largely inconclusive [67]. Free and colleagues found only two mHealth text message interventions that demonstrated effectiveness: one for antiretroviral medication adherence in low-income settings, and a second for increase in smoking cessation in high-income settings. They suggest the need for additional research to understand the impact of mobile health behavior change and disease management, including exploring interventions that utilize multiple behavior change techniques.

Riley and colleagues provided an overview of mobile non-cancer specific health apps that raised questions about the capability of current health behavior theories to measure mHealth effectiveness [68]. According to Riley et al., while mobile apps are evolving as a delivery system for health behavior interventions, few mHealth apps are grounded in health behavior theories. Additionally, Riley et al. suggest that current theories may not be “up to the task,” especially with regard to “within person changes” and the potential impact of dynamic feedback loops present in app operations [68].

To date, none of the research on mHealth cancer apps has systematically assessed the extent to which cancer survivorship apps, as health behavioral interventions, are theory-based. A sophisticated taxonomy of health behavior theories and behavior change frameworks developed by Abraham and Michie was later refined as a system to code Internet interventions associated with health behavior by Webb and colleagues [23, 69].

Our review further adapts that taxonomy to mHealth interventions for cancer survivorship and seeks to investigate if, and how, behavior change theories are being used to inform mHealth apps for cancer survivors. By doing so, we begin to answer important theoretical and applied questions: What theories should app designers and developers draw upon in developing mHealth cancer survivorship interventions? What behavior techniques may be effective when delivered by mHealth apps?

Methods

In November 2013, we conducted a computerized search for mHealth cancer survivorship apps on the Apple App Store, for iPhone® and iPad® apps and on Google Play™ for Android™ apps. We explored other mobile app markets including those for Nokia and Blackberry smartphones, but found no cancer apps, so we limited our search to the two major app markets. We used the following definitions and search criteria:

1) Native apps: Native apps were considered as software applications that must be installed on a device such as a smartphone, iPad, or tablet and could be available either for the iOS or Android platform or both. Apps could have elements or portions of the application that are linked to websites or cloud-based servers, including assessments, videos, pdfs, or other linked materials but the user interface must be initiated on the smartphone or tablet.
2) Cancer survivor: Any person who has been diagnosed with cancer from the time of diagnosis through the balance of life.

3) Mobile app searches were conducted on Google Plus and the Apple App Store using the search terms: cancer + survivor; cancer + survivorship; cancer + care; cancer + treatment; and cancer + management.
4) Web-based searches for mobile apps were also made on Google, Bing, and Yahoo, as these are among the top search engines used in English. Search terms included: “cancer + mobile web”; “cancer survivorship” + mobile web; and “cancer survivorship app.”

The inclusion criteria for the cancer survivorship apps include the following:

1. Information on cancer survivorship: To be included apps had to make specific mention of cancer care, treatment, survivorship, or cancer survivors in the description found on the app store, in the website listing, or in the “table of contents” of the app or its navigation terms/icons.
2. Not just a badge or skin: We excluded a large number of applications that were images to be used as mobile phone screen skins and did not have any interaction or content beyond an image.
3. Not a fundraising application: Apps had to provide some functionality for cancer survivorship education, information, or health behavior change.
4. Not just a glossary of terms or mobile version of a periodical or website. The application was required to offer some level of interaction for health behavior change beyond just a dictionary or the ability to read a publication in a mobile format.

5. Applicable to one or more cancer types or cancer care: Apps were considered if they included functionality and services for all cancers, if they provided information for one or more types of cancers, or if they specifically addressed cancer survivorship late effects as a condition.
6. Designed for patients/survivors: Apps were included if they were designed for caregivers and healthcare providers in addition to cancer survivors. Apps designed solely for use by providers were excluded.
7. Apps had to be available for public download and use, and not used solely for research studies.
8. Apps had to be relevant to cancer survivors beyond information specific to a unique or individual cancer center. Branding of a cancer center in an app was considered allowable, but the app had to be useful to cancer survivors other than those served by the institution or cancer center.
9. Only free apps were considered for inclusion, as there were no low cost (i.e., $.99 to $1.99) available for cancer survivorship. (Note: The paid apps in the cancer survivorship category cost from $5.99 to $19.99.)

The taxonomy for behavior change techniques used in this research study was derived from Mitchie et al.'s taxonomy of 26 health behavior change techniques with a few important changes based on the characteristics of mHealth apps [23]. The mHealth app taxonomy was limited to 15 health behavior change techniques (HBCT) with each described by one or more health behavior or communication theories. An additional area of HBCTs included in the mHealth taxonomy, but not found in Webb and Michie's

taxonomy is Tailored Health Communications (THC) [70]. As indicated by Rimmer and Kreuter, THCs are important elements of health communications and persuasion and may promote action through increased motivation to process information as suggested by Petty and Cacioppo's 1986 Elaboration Likelihood Model (ELM) [71].

The theoretical models and frameworks initially used by Webb and Mitchie that were included the in mHealth survivorship app taxonomy are as follows [70]: Social Cognitive Theory (SCogT) (Bandura), Information-Motivation-Behavioral Skills Model (IMB) (Fisher and Fisher), Control Theory (CT) (Carver and Scheier), and Operant Conditioning (OC) (Skinner). Also used are theories related to the impact of social support (SS) on health behaviors (Cohen) and social comparison (SC) (Festinger) [70-75].

A coding manual was developed specifically for use in coding the mHealth apps for cancer survivorship (Appendix B) based on Abraham and Michie's work, *A Taxonomy of Behavior Change Techniques Use in Interventions: The Coding Manual* [23]. A coding guide (Table 4.1) drawn from the mHealth cancer survivorship taxonomy of HBCTs and theories developed, analyzed and tested by the coders (DVD, KF, JP). The team tested and trained with the coding guide using three apps that existed both on iOS and Android mobile platforms. Master lists of identified iOS and Android apps were developed collectively by the coders for use in downloading the apps to their smartphones and tablets.

Two coders each were assigned to each type of app platform (i.e., iOS and Android platform) and each coder independently loaded the apps that met the eligibility

criteria onto one or more mobile devices (i.e., smartphone or tablet). The coding rubric for the HBCT change techniques used a score of 1 to indicate that the HBCT was present, and a score of 0 to indicate that the HBCT was absent. Based on two raters for each app, total possible scores for each platform are 72 for iOS apps, and 64 for the Android apps. Several apps were not working and could not be loaded and a few crashed consistently, thus preventing coding. The only major difference in coding approach was related to coding of games, and that issue was easily resolved by consensus.

Table 4.1. mHealth Cancer Survivorship Taxonomy for Coding

Behavior Change Techniques	Theory Basis	Definition
1. Personalized	THC/SCogT, ELM	Rimer & Kreuter, 2006 define personalization and tailoring as a process for creating individualized communications by gathering and assessing personal data, (i.e., logging in with personal information
2. Tailoring (macro/meso/micro)	THC, ELM	Macro occurs at the group level; meso is determined by individual needs of user, but not highly specific; micro is very specific to the user
3. Health Behavior Linkage	IMB	General information about linkage of individual behavior and health (e.g., benefits of good nutrition and physical activity)
4. Action/Behavior Consequences	TRA, TRB SCogT, IMB	Information about potential benefits and costs of action or inaction in relation to health and wellbeing (e.g., stop smoking)

Table 4.1. Continued

Behavior Change Techniques	Theory Basis	Definition
5. Intention formation	TRA TBP SCogT, IMB	Encouraging the person to take an action or decide on a goal to improve treatment response or survivorship.
6. Provide instruction	SCogT	Show or tell the user how to perform a behavior (e.g., asking your doctor questions).
7. Provide Materials for Education	SCogT	Provide information or educational materials about cancer care and survivorship
8. Goal Setting	CT	Prompting specific goal setting (e.g., walk 5 miles daily)
9. Self Efficacy	SCogT	Aids user in recognizing skills or education developed
10. Feedback on Performance	CT	Scores, tests, game results
11/12. Persuasion (general/targeted)	OC	Messages to strengthen self-efficacy/control beliefs
13. Social Influence: information on peer behavior (passive)	SCogT	Facilitate users access to information on how others have changed behavior or addressed challenges (non expert)
14. Opportunity for social comparison (active)	SS/SC	Facilitates active user engagement in social media for sharing and comparison
15. Mobilize Social Norms (exposure to important other	SS/SC	Provides user exposure to expert opinions and information

Note: OC= Operant Conditioning CT= Control Theory; Elaboration Likelihood Model; THC=Tailored Health Communication Model; IMB=information motivation behavioral skills model; TRA= Theory of Reasoned Action; TBP= Theory of Planned Behavior; SCogT= Social Cognitive Theory; SS= Social Support; SC=Social Comparison.

Results

The search of the mHealth cancer survivorship apps yielded a total of 97 potentially relevant apps that appeared to meet the selection criteria. A flow diagram

showing the numbers, source, and refinement of the apps identified for coding is shown in Figure 4.1.

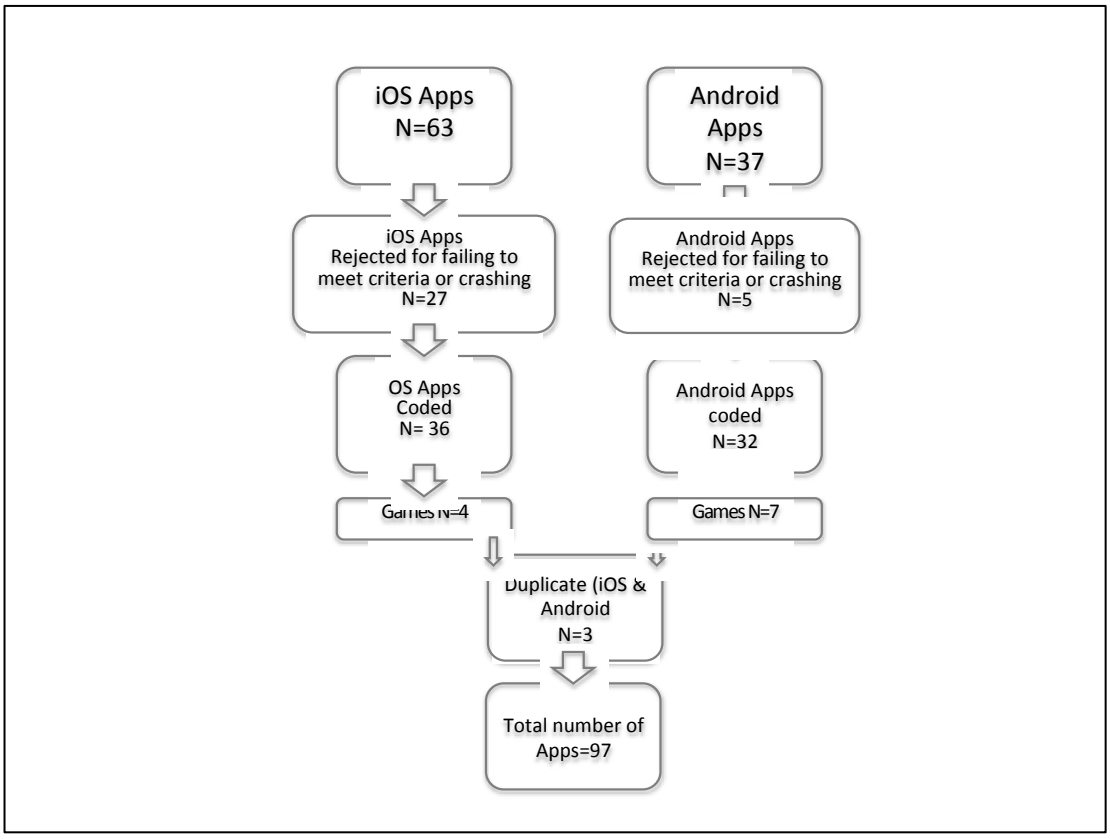

Figure 4.1 Android and iOS Selection Flow Diagram

There were three apps that were available on both the Apple App Store and Google Play, and both teams coded these apps. Seven of the Android cancer apps were configured as games, as were four iOS games. A total of 68 apps were coded and 65 of these were unique. The inter-rater reliability for the iOS apps was 86.1% (p<0.000) and for the Android apps it was, 77.4% (p<0.000) was absent. Table 4.2 shows the results of the teams' scoring of the HBCT for both Android and iOS platforms.

Table 4.2. Rating Totals for Health Behavior Change Techniques

Technique/Characteristic	iOS HBCT Scores (N=36)	Android HBCT Scores (N= 32)
Personalization	48	24
Tailoring		
- macro-tailoring	45	15
- meso-tailoring	8	6
- micro- tailoring	11	4
Health Behavior Linkage	32	32
Action/Behavior Consequences	21	2
Prompt for Intention Formation	48	10
Provide Instruction	54	10
Materials for Education	28	12
Prompt for Specific Goals	10	14
Review of Goal Activity	2	2
Self-Monitoring of Goals	24	13
Feedback/Evaluation of Goals	18	16
General Persuasion	25	2
Tailored Persuasion	10	0
Social Influence (passive)	17	0
Social Influence (active)	18	8
Social Norms -Opportunity for Comparison to Important Others	8	1

Note: Each item was scored as 1=present; 0=not present. Total possible scores for each platform are 72 for iOS apps and 64 for Android apps.

The iOS cancer survivorship apps received higher scores across nearly all of the HBCT areas. Additionally, the iOS apps appeared to have greater functionality and appeared to include more of the HBCTs overall, per app, than the Android apps. The percentage of HBCT's for each category of both the iOS and the Android platforms is shown in Table 4.3 and discussed in the following section.

Table 4.3 Category and Platform Percentages for Health Behavior Characteristics

Technique/Characteristic	iOS Platform (N=36)	Android Platform (N= 32)
Personalization	67%	38%
Tailoring		
- macro-tailoring	63%	23%
- meso-tailoring	11%	9%
- micro- tailoring	15%	6%
Health Behavior Linkage	44%	50%
Action/Behavior Consequences	29%	3%
Prompt for Intention Formation	67%	16%
Provide Instruction	75%	16%
Materials for Education	39%	19%
Prompt for Specific Goals	14%	22%
Review of Goal Activity	3%	3%
Self-Monitoring of Goals	33%	20%
Feedback/Evaluation of Goals	25%	25%
General Persuasion	35%	3%
Tailored Persuasion	14%	0
Social Influence (passive)	24%	0
Social Influence (active)	25%	13%
Social Norms -Opportunity for Comparison to Important Others	11%	2%

Note: Each item was scored as 1=present; 0=not present. Total possible scores for each platform are 72 for iOS apps and 64 for Android apps.

Personalization in the apps includes requiring that the user login with a user name and password. For most of the apps, personalization enabled access to selected parts of the app, and also allowed data to be entered and maintained on the app's server rather than being stored onto the phone, thus providing adequate security for sensitive health information. Several apps requested specific information about the user's type of cancer and then provided meso-or micro-level tailoring regarding concerns such as types

of treatment and late effects. An example of personalization (Figure 4.2), with both macro and meso or mid-level tailoring is found in the *My PearlPoint* app developed by The Minnie Pearl Foundation. The app allows the user to identify what side effects they may be experiencing (e.g., fatigue, dry mouth, nausea). Once the user selects a side effect, the app provides education, health behavior linkages, and may also suggest specific goals or actions to reduce the identified side effect.

Scoring on health behavior linkages was indicative of the app providing basic information about cancer care and survivorship, including diagnosis and treatment, and/or availability of resources for clinical or non-clinical purposes. Based on the high scores for this HBCT, on both iOS and Android apps, it appears that most of the apps, 94% (64/68), provide a basic level of health behavior information.

The HBCT for "Prompt for Intention Formation" was coded as positive if the application included suggestions for general behavior or for formulating desired outcomes of a behavior for healthy survivorship (e.g., maintain a healthy weight, exercise daily, stop smoking, consider mediation). This HBCT concerns the user's intent to do something and is different from taking the step to set a goal or initiate an action. An example of prompting for intent formation can be found in the *AYA Healthy Survivorship* app, an iOS app, shown in Figure 4.3.

Figure 4.2 My PearlPoint App Personalization

Figure 4.3 *AYA Healthy Survivorship App*: Intention Formation

An example instruction is found in detailed instructions on how to measure a survivor's arm to set a baseline and do ongoing measurements to track lymphedema on the iOS app, *Lymphedema Tracker*, shown in Figure 4.4. Following the trend, a greater percentage of the iOS apps (75% or 54/72) provided instruction on HBCT as compared to the Android apps (16% or 10/64).

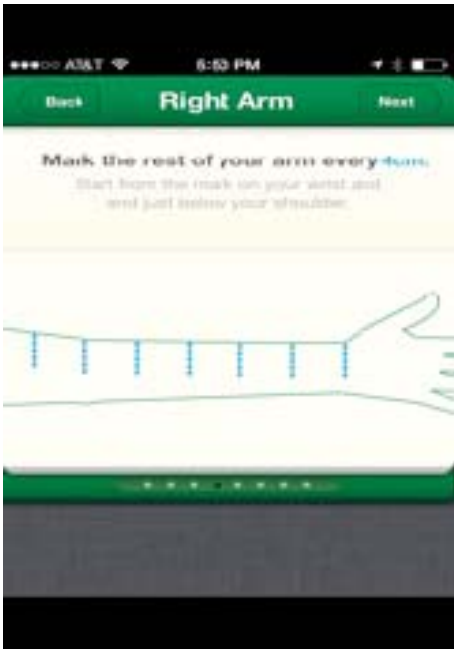

Figure 4.4 Lymphedema Tracker: Instructions for Use

A significantly greater percentage of the iOS apps demonstrated this HBCT, 67% (48/72), as compared to 16%, (10/64) of the Android platform apps. To be coded as positive for the HBCT item for instruction, the material on the app had to be directly related to showing or telling the user ways to facilitate a specific health behavior change. An example of education specific to managing fatigue, a common concern for survivors and in post treatment, is found in the iOS app, *My Cancer Manager* from the Cancer Support Community (Figure 4.5). The app educates the patient on the activity of tracking his/her fatigue and also instructs them to consider sharing information with a provider if the score stays persistently high. Overall the app scores for this HBCT were low with 39% (28/72) for the iOS apps and 19% (12/64) for the Android apps.

Figure 4.5 Cancer Support Community App: Education

The presence of activities or information across both iOS and Android platform apps for goal-setting activities (e.g., prompts for specific goals, review of goals, self monitoring of goals, and feedback or evaluation of goals) was low overall. An example in the area of self-monitoring of goals were suggestions found in several apps for the survivor to record brief notes or keep a diary or journal to record behaviors and actions related to health behaviors. Examples found among the apps included journals or tracking tools for pain and distress monitoring, as well as suggestions for practicing meditation.

Among the iOS apps, these categories ranged from a low of 3% (2/72) for reviews of goal activity to a high of 33% (24/72) for self-monitoring of goals. Similarly, but lower still, the Android apps ranged from a low of 3% (2/64) to a high of 25% (16/64]). These low scores included activities in the mHealth cancer survivor game applications for engaging in a first-person-shooter cancer destroying activity with goals for hitting targets. The user generally received feedback on scores for numbers of strikes or targets acquired. Other apps prompted goal setting via use of guided imagery suggesting that the user focus energy and concentration on specific body parts or processes affected by cancer.

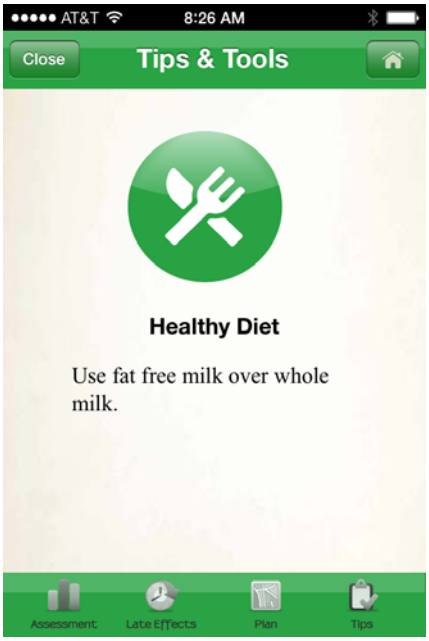

Figure 4.6 AYA Survivorship Tip of the Day

Figure 4.7 Re-Mission: NanoBot's Revenge

The delivery of personalized or tailored messages designed to strengthen efficacy/control beliefs related to the initiation or execution of health behavior change has been heralded as an area of promise for mHealth apps. The use of mHealth persuasion in cancer survivorship apps includes activities or signaling for new beliefs and or new information. Scores in this area were low for both general and targeted persuasion. An example (Figure 4.6) of general persuasion can be found in the *AYA Healthy Survivorship* iOS app that allows the user to elect to receive a "health tip of the day." The highest scores were found among the iOS apps, with a low for targeted persuasion of 14% (10/72) and a high of 35% (25/72). Persuasion barely registered as an HBCT area on the Android apps with a low of zero for tailored persuasion and 3% (2/64) for general persuasion.

Social influence is an area of HBCT techniques that would appear to be a strong opportunity area for mHealth apps in cancer survivorship, given the easy access to mobile communities including Twitter, Facebook, YouTube, and numerous other cancer related blog and social networking sites. The presence of passive social influence, where the app provides stories, anecdotes, interviews, or case histories about what other cancer survivors have done or experienced in relation to THBC was again, unexpectedly low. For the iOS apps, only 24% (17/72) offered access to such stories and Android apps had no scores for this HBCT. Active social influence, wherein a survivor might be invited to participate in a group or peer discussion and relay activities about their own also was relatively low with a score of 25% (18/72) for iOS and 0 for the Android apps.

The apps were examined for examples of "*mobilization of social norms*" in which the user would be exposed to the social norms of important others in relation to a healthy survivorship activity or health behavior change. Important others could be valued and trusted experts such as a healthcare professional, or a celebrity cancer survivor advocate. One of the apps that uses this HBCT most effectively is the *Cancer.net* app, which was developed by the American Society of Clinical Oncologists (ASCO) and is offered on both the iOS and Android platforms. *Cancer.net* provides the user with links for brief videos of well-respected cancer researchers and clinicians on a range of topics, including HBCTs. While this is an area of HBCT that offers easy access on mHealth apps, few of the apps reviewed in the study incorporated this potentially important element. Scores for these apps were 11% (8/72) for iOS apps, and 2% (1/64) for the Android apps.

The evidence base for considering highly interactive mobile games and interactive game-like elements for guided imagery in apps is very limited.
The potential applications of health behavior change theories in the design of game and game-like interventions are significant, ranging from elements of personalization and tailoring for scoring to goal setting, tracking and feedback, and potentially powerful elements of social interaction among game participants.

Our team was initially optimistic about the inclusion and rating of the four iOS and Android mHealth games and interactive apps for cancer survivorship through the selection criteria. App names such as *Cancer Fighter, Whip Cancer,* and *Play to Cure* promised much, but delivered little, as HBCT interventions. Few of the interactive or

game apps provided even basic education or information for HBCT. Rather, the user was launched into series of images and audio effects with opportunities to score by shooting down images on the mobile screen, but offered little or no explanation why or how they might be of benefit to the cancer survivor. An exception was found in *Re-Mission2: Nanobot's Revenge* a project of HopeLabs (Figure 4.7) which initiates the "shooter game" by explaining that the user is the Nanobot and the goal is to "fire targeted treatment at growing cancer and prevent it from escaping into the blood stream."

Discussion

A primary aim of this study was to analyze the linkage of HBCT interventions in cancer survivorship mHealth apps to theories and models that are used to predict health behavior change and communications. The mHealth apps in this study varied greatly in how they ranked in the use of theoretical elements of health behavior change. This study's findings and results are consistent with prior research that asserts that mHealth interventions could benefit from increased use of behaviour and communications theories in their design [64, 65, 67, 76]. In reviewing the HBCT scores for the apps, three theories/models appeared to be more influential: social cognitive theory (SCogT), tailored health communication model (THC), and control theory (CT). However, with no explicit discussion regarding the design or development of the apps reviewed in this study, it is not clear if these theories were intentionally applied or that the design deliberately reflected a theoretical approach. The coders disclosed that their perception of weakest area for health behavior linkages, meaning that they considered HBCT as

present, but just barely, was among the game apps which made up 16% (11/68) of all coded apps.

The mHealth cancer survivorship apps that appeared to be firmly based in HBCT theory were similar in that they offered multiple types of HBCTs, required personalization and some degree of tailoring, were highly interactive, included some type of questions or assessments, suggested goals and actions, and provided social engagement and the mobilization of social norms. Most of these examples were either developed by cancer advocacy groups, clinical associations, or academic researchers, which suggest that the information provided was more likely to be based in evidence and clinical research and health behavior theory. Examples include: 1) *LIVESTRONG Cancer Guide and Tracker* app, available only for iPad; 2) *Cancer.net*, developed by the American College of Surgical Oncologists, which is available on iOS and Android platforms and also offers a web-based version and one that is translated into Spanish; 3) *AYA Healthy Survivorship*, an iOS app developed for Adolescent and Young Adult (AYA) survivors developed by Texas A&M School of Public Health with late effects guidelines provided by the Children's Oncology Group, and 4) *My Cancer Manager*□ developed by the Cancer Support Community and available only as an iOS app.

An area of HBCT that demonstrated weak results in the coding of the mHealth apps considered in this study, but one that bears additional research consideration is the theoretical realm of social influence and social media. Cancer survivors are strongly influenced by their social ties and connections with others and social networks can have important effects on survivor health and wellbeing [78,79].

Clearly, the taxonomy provided in this research for mHealth cancer apps is not exhaustive, and additional theories and models across different behavioral change techniques should be defined. As the more highly rated apps in our study offered multiple HBCT techniques, it may be beneficial to design a study that takes into the account the interaction across multiple HBCT aspects. It may also be helpful to explore the differences in use, HBCT efficacy, and persistence on the device for single purpose apps for specific survivorship concerns in comparison to apps that offer multiple types of HBCT elements. mHealth is developing rapidly with tools and technologies that offer significant opportunities for improved clinician and patient engagement, for self-management and monitoring and deeper interactions with highly interactive social networks using text, photographs, and video to communicate. Additionally, research exploration into the theories and models relevant to interactive apps, mobile games, and the use of sensors in mHealth is timely and needed.

An article by Tomlinson et al. further articulates concerns about both the lack of evidence and theory in mHealth, and how theory when it is referenced, is actually applied. Tomlinson's article addresses use of mHealth primarily in lesser developed and under resourced counties, but raises concerns about level of evidence and generalizability of mHealth applications [80]. A World Bank report by Kay and associates that tracked over 500 mHealth pilot studies, reported that very little is known about likely uptake, best strategies for engagement, efficacy, or effectiveness of these initiatives [81]. Kay and colleagues' review of mHealth interventions suggest that the apps they reviewed lacked both theoretical foundations and evidence sufficient to

support an evidence-based scale up. The most recent systematic review on mHealth for health behavior change by Free et al. was not able to identify the theoretical basis for the research studies reviewed [67]. Both reviews confirm that there is mixed evidence for the effectiveness of health intervention delivery to health-care consumers using mobile technologies. Moreover, both reviews' conclusions highlighted the need for additional high-quality controlled trials of this mHealth application.

These findings, regarding the potential for use of theory, supports a call for mHealth intervention designers to reflect more deeply and extensively on the application of theoretical models and frameworks in the design and development of mobile HBCT applications.

The strength of this study is based in its reliance on the prior work of Abraham and Michie in defining the taxonomy and coding of behavior change techniques used in interventions and their basis in theory [32]. This research on mHealth cancer survivorship apps had certain limitations. The initial search and selection of cancer survivorship apps was restricted to the commercial descriptions of apps in the Apple App Store and Google Plus. As a result, we may have overlooked or missed apps. The search results were dependent on the terms included in the search strategy and the search functionality of the search engines used as well as the search engines found on the online stores. We attempted to overcome the search limitation by choosing common terms and combinations of terms, including those we found in literature reviews of cancer care and cancer survivorship. We considered only apps that were in English and also excluded paid apps. Our rationale for selecting free apps was that we wanted to ensure that under-

resourced survivors would likely consider the apps selected. Moreover, we only considered apps that were focused on cancer, and included the word cancer in the title or the description. It is possible that we missed apps that include cancer care and survivorship in addition to other chronic diseases.

The study provides a framework for future research and contributes to the emerging science of mHealth interventions for behavior change. The findings suggest a strong rationale for investing the time and diligence into more rigorous theory-based mHealth interventions that may incorporate, as did the apps reviewed, multiple levels and types of health behavior change strategies and techniques. Similarly, our results reinforce the need for carefully constructed studies to measure the effect and impact of mHealth interventions

This research study provides insights into the use of theoretical frameworks and models associated with mHealth. Our findings contribute to behavioral health literature and to health policy initiatives by demonstrating the mHealth intervention design needs stronger theoretical and evidence-based underpinning. The field of research on mHealth interventions for behavior change is a rapidly shifting landscape with new technologies and systems for sensors, big data analytics, and opportunities for more patient-centric health care. If mHealth interventions for cancer survivors and others with chronic health conditions are to be successful, they will need to demonstrate that they are guided by theory and designed to deliver value and effectiveness. The informed use of theory in app development and application and translation of health behavior research on of what kinds of apps and HBCT actually provide lasting change and benefits to users appears to

be lagging behind release of new mHealth technologies. The integration of apps with mobile hardware, including sensors and electronic medical records, is rapidly emerging as evidenced by the ongoing announcements of new mhealth hardware and software. While the promise of inter-operability of apps, sensors and clinic data will soon be a reality, what is missing is the understanding of how this will translate into benefits to users with chronic medical conditions like cancer survivors. What is also missing is how, where and when will the clinicians access and use this data to educate, inform and offer improved opportunities for health and wellness to their patients.

V. SUMMARY AND CONCLUSIONS

AYA cancer survivors and their community healthcare providers continue to face significant disparities in access to care, in transitions from treatment to community care, and in how to prevent and monitor for late effects of treatment. Across my three studies we found continued evidence of the gaps and challenges that were identified by early researchers, including heterogeneity of the AYA population, a lack of best practices in institutional delivery of care models, limited access to clinical trials, and a need for more astute fostering of transitions into survivorship care. As in both prior and more recent studies, I found that differences among ethnic, racial, and socio-economic groups appear to influence outcomes.

The population-based study of Texas' AYA breast cancer patients is the first to assess demographic and diagnostic risk factors associated with late versus earlier stages of cancer diagnosis. My findings are consistent with prior studies that found higher risk of later stage diagnoses among Black/African American and Latina/Hispanic women [27,38] African American/Black AYAs in Texas were 31% (*p*-value<0.000, 95% CI 1.09, 1.58) more likely to be diagnosed at a later stage than White AYAs. Being an AYA woman of Hispanic/Latina ethnicity was associated with a 36% increased risk of being diagnosed at a later stage of breast cancer (*p*-value<0.00, 95% CI 1.16,1.59).

Distance from breast clinical trials was significantly associated with a 102% (*p*-value<0.000, 95% CI 1.09,1.58) greater likelihood of a later stage breast cancer diagnosis for those living at distances between 45 and 100 miles. While the trend did not

hold for all travel distances, the likelihood of a later stage diagnoses as compared to an earlier stage for those AYAs living more than 200 miles was 49% (*p*-value 0.020, 95% CI 1.06,2.09). While our study was not able to report on risk factors for breast cancer sub-types including triple negative breast cancers among Texas AYAs, these data are now being collected by the TCR and should be on a research agenda for the near future.

My findings add to the growing body of literature identifying the need for more effective mechanisms to recruit AYAs into clinical and supportive care cancer research trials. AYAs have traditionally had low participation rates in cancer clinical trials. For breast cancer patients, the use of patient-friendly online matching system offered by BreastCancerTrials.org may be an effective method of increased recruitment for AYAs. However, additional opportunities may exist in emerging patient-centered recruiting efforts including online databases and data linkages for trial recruitment.

Our results that uninsured AYA women, including those who self-pay, were 70% more likely to be diagnosed at a later stage of breast cancer (*p*-value <0.000, 95% CI 1.31, 2.20) are consistent with a recent study by Keegan et al. that suggests that lack of insurance is a significant barrier overall for AYAs diagnosed with cancer [20]. It appears likely that the lack of health insurance among AYA breast cancer patients may be a factor in delayed diagnosis and, for more advanced cancers, the lack of progress in extending survival and reducing mortality. It is unclear if the Patient Protection and Affordable Care Act will provide sufficient increased coverage among Texas AYAs, especially those who are Black or Latina and who may live at significant distances from care, including clinical trials. These are the AYA women who are perhaps most

vulnerable to higher risk breast cancer sub-types and delays in diagnosis. This is an area for future research to determine policy and system approaches to address this type of disparity, including mechanisms to support more efficient referral mechanisms to tertiary cancer centers that are more likely to offer supportive navigation, multidisciplinary care, and a range of breast cancer trials.

Many of the areas of practice and research gaps that were explored in the AYA breast cancer study were present in the qualitative evaluation research for the ACCESS AYA project. The stakeholders in the qualitative study identified as valuable the access to educational information related to late effects and improved models of transitioning from treatment into community-based care. The survivors' interviews, especially, gave evidence of the perceived value and utility of survivorship care plans and the services of a nurse navigator in providing guidance on screening, access to health care, and insurance. The ACCESS AYA program evaluation findings were consistent with prior studies done by Zebrack et al. in identifying activities and factors that may enhance resilience and quality of life among AYA cancer survivors including the influence of peer social networks [50].

In efforts to improve survivorship care models, stakeholders in the ACCESS AYA evaluation identified gaps in training programs focused on the care of AYA patients including integrating information about fertility, palliative care, and more proactive approaches to helping patients understand the stressors and issues they may face as they transition out of cancer care into the "new normal" of survivorship. Research gaps that emerged from the evaluation study from across all of the stakeholder

groups include addressing lack of best practices, policies and systems approaches to gaps in psychosocial care, and socioeconomic consequences that appear to deeply affect younger people including impacts on career, education, family finances, and employment opportunities.

As I continued to identify the barriers and challenges associated with improving quality of life and the need for AYAs to engage in self-advocacy and self-management of cancer survivorship as a chronic disease, I initially hoped that mobile apps for cancer survivors would provide low cost, easily accessible information and opportunities for health behavior change interventions. While I found significant numbers of mHealth apps focused on cancer survivorship, for the most part the theory and evidence base for these mHealth applications to build upon the existing knowledge base of interventions was missing. My conclusions about the potential for mHealth apps in cancer are similar to those stated by Bender et al. [63], that research and work needs to be done to develop theory and evidence-based cancer interventions using mobile technology.

While I remain optimistic about the potential for mHealth, especially among younger populations like the AYA survivors, the reality is not yet meeting the promise. As the field of mHealth in cancer survivorship and other chronic diseases continues to mature and to take advantage of emerging technologies in mobile sensors and monitoring, we may see greater benefits. The possibilities for increased communication and information sharing through mHealth applications with regard to survivor/provider communications and transitions in care hold great potential.

The AYA survivors in the evaluation study evidenced a strong desire for advocacy and engagement. I believe that this type of advocacy can be a motivation and a resource for engaging more AYA survivors in research with mHealth apps as technology facilitators. Cancer is a life-changing experience, and in making meaning of their experiences younger cancer survivors often seek a way to give back and express their gratitude [82]. Use of mobile resources, including apps and sensors could be leveraged to capture important and useful research data for survivor care patterns and assessments including location-based information. Engaging young, or even older cancer survivors in well-structured community-based participatory research, as a form of "crowd-sourcing" may offer a low cost way to capture information on important behavioral and psychosocial data on survivorship topics such as pain, cognitive function, and lifestyle interventions.

The AYA population covers a broad age range and a number of different types of cancer. The experiences of the AYA survivors vary greatly depending on the type of cancer, the age at which they are diagnosed, and treatment they experience. Significant future opportunities exist in identifying and reducing the multifactorial disparities and risk factors experienced by AYA cancer survivors through the development of theory and evidence-based interventions. The limitations of the findings with regard to Texas AYA breast cancer patients include a lack of behavioral data on the individual patients and more precise information on their educational and socio-economic status. For example, my findings suggested that the women who lacked insurance at time of diagnosis had a higher risk of being diagnosed at a later stage. It was

notable that no payer information was available for over 37% of the AYA breast cancer patients. Risk factors such as the information on having insurance at time of diagnosis can mask what happens over time during a survivor's transition through cancer care and into survivorship. Many of the costs of cancer are not covered by insurance and insurance status may change during or after cancer care due to job loss, divorce, or other factors [83]. Some patients may start and then defer or delay treatment due to costs. Thus without detailed information on the costs of care and treatment it is difficult to ascertain the degree to which having insurance at diagnosis is a protective factor.

The focus on the Texas AYA population is a limit to the generalizability of the AYA breast cancer risk assessments. Texas has a broad and diverse population spread across great distances. The relative percentage of the breast cancer population with access to nearby breast cancer trials may be very different for other regions of the country. Also, Texans may be more likely to travel larger distances for care, as longer travel distances are an aspect of the state's geography.

In the evaluation of the ACCESS AYA program, the study team was limited by the time and costs to a fairly small sample size of stakeholders. It is possible that engagement in a larger group would have provided added insights. However, the depth and engagement with our stakeholder subjects provided information and insights similar to prior qualitative and quantitative studies on educating health care professionals and young adults with regard to cancer survivorship issues and concerns [49].

In my assessment of mHealth apps, we relied on the theoretical framework developed by Webb and Mitchie [69]. The analysis of the mHealth apps by coding them

for health behavior change techniques could be perceived as limiting. It is possible that deeper insights into the applicability and potential for behavior change techniques may be different if evidence and information is gathered on the actual use of the mHealth apps.

These studies add to the evidence that, despite recent improvements and greater attention paid to this unique population, AYA cancer survivors continue to face challenges in cancer survivorship. My analysis of Texas AYA breast cancer patients contributes to the understanding of variability in demographic and clinical risk factors and suggests opportunities for studies of AYA breast cancer patients that would include information on hormone receptor status as well as lifestyle factors. The evaluation of the ACCESS AYA project suggests that additional survivor and professional education on late effects, both psychosocial and physical, are needed as more survivors, AYAs, as well as older adults will transition into community care. Evidence and research on the potential for mHealth applications in cancer survivorship health and behavioral interventions, patient/provider engagement, and in clinical and community-based participatory research is in its infancy. As use of mHealth apps expands with greater use of sensors and monitoring, significant attention is needed to ensure that the designers and builders apply the knowledge and power of theoretical health behavior and communication frameworks.

My findings suggest that there remain significant gaps and disparities among AYA cancer survivors that offer direction for future investments in research including the following:

1) Geographic and socioeconomic risk factors that may affect how and where AYAs seek treatment and the quality of treatment they receive; 2) Increased efforts to identify genetic and familial risks that may predispose AYAs to cancer, such as young women with higher risks of triple negative breast cancers, and the development of evidence and risk-based strategies; 3) Psychosocial and developmental issues that result from treatments that may result in difficulties in education and underemployment of AYA survivors; and 4) Greater collaboration across disciplines of care including oncologists, community-based providers and navigators, and nurses including collaborative education and knowledge sharing for transitions.

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APPENDIX A

Table A.1 Early Stage Trial Listing

Trial Number	Trial Name	Trial Location	City/State
NCT00555152	Lapatinib in Treating Women With Ductal Carcinoma In Situ of the Breast	Dan L. Duncan Cancer Center at Baylor College of Medicine M. D. Anderson Cancer Center at University of Texas	Houston, TX Houston, TX
NCT00669747	A Phase II Randomized Study Of Intraductal Carboplatin In Women With Ductal Carcinoma In Situ	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT00677430	Multimodality Anthropometric Analysis for Quantitative Assessment of Outcomes in Breast Reconstructive Surgery	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT00999804	TBCRC 023: A Randomized Multicenter Phase II Neoadjuvant Trial of Lapatinib Plus Trastuzumab, With or Without Endocrine Therapy for 12 Weeks vs. 24 Weeks in Patients With HER2 Overexpressing Breast Cancer	Dan L. Duncan Cancer Center at Baylor College of Medicine	Houston, TX

Table A.1 Continued

Trial Number	Trial Name	Locations	City/State
NCT01008150	A Phase II Randomized Clinical Trial Evaluating Neoadjuvant Therapy Regimens With Weekly Paclitaxel and Neratinib or Trastuzumab Followed by Doxorubicin and Cyclophosphamide With Postoperative Trastuzumab in Women With HER2+ Disease	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01036087	Phase II Study of Panitumumab, Nab-paclitaxel, and Carboplatin for Patients With Primary Inflammatory Breast Cancer (IBC) Without HER2 Overexpression	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01042379	I-SPY 2 Trial (Investigation of Serial Studies to Predict Your Therapeutic Response With Imaging And molecular Analysis	M. D. Anderson Cancer Center at University of Texas Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center - Dallas	Houston, TX Dallas, TX
NCT01162200	Partial Breast Irradiation (PBI) for Early Stage	Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center - Dallas	Dallas, TX

Table A.1 Continued

Trial Number	Trial Name	Location	City/State
NCT01245712	Assessing the Cosmesis and Toxicity of Partial Breast Irradiation Using Proton Beam Irradiation (NCT01245712)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01266642	Randomized Trial of Hypo fractionated Whole Breast Irradiation Versus Conventionally Fractionated Whole Breast Irradiation for Ductal Carcinoma in Situ and Early Invasive Breast Cancer	University of Texas M.D. Anderson Cancer Center Harrington Cancer Center Doctor's Hospital of Laredo Southwest Oncology Group St. Joseph Regional Cancer Center Dan L. Duncan Cancer Center at Baylor College of Medicine All Saints Episcopal Hospital - Fort Worth Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center - Dallas University Hospital - San Antonio Texas Tech University Health Sciences Center University of Texas Health Science Center at San Antonio Covenant Medical Center University of Texas Medical Branch Cancer Therapy and Research Center Baylor Medical Center at Irving Methodist Hospital	Houston Amarillo Laredo San Antonio Bryan Houston Fort Worth Dallas San Antonio Lubbock San Antonio Lubbock Galveston San Antonio Irving Houston

Table A.2 Late Stage Trial Listing

Trial Number	Trial Name	Locations	City/State
NCT00003135	Whole Body Hyperthermia Combined With Chemotherapy in Treating Patients With Metastatic Breast, Ovarian, Endometrial, or Cervical Cancer (NCT00003135)	University of Texas Health Science Center at Houston	Houston ,TX
NCT00570908	A Phase 2 Trial of Capecitabine Concomitantly With Whole Brain Radiotherapy(WBRT) Followed by Capecitabine and Sunitinib for Central Nervous Suste, (CNS) Metastases in Breast Cancer (NCT00570908)	Dan L. Duncan Cancer Center at Baylor College of Medicine	Houston, TX
NCT00929214	Aggressive Local Therapy for Limited Bone-Only Metastasis to Improve Progression-Free Survival in Breast Cancer Patients (NCT00929214)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT00968968	A Randomized, Open-label Study of Lapatinib Plus Trastuzumab Versus Trastuzumab as Continued HER2 Suppression Therapy	GSK Investigational Site M. D. Anderson Cancer Center at University of Texas	Houston, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01048099	Use of the PRO Onc Assay to Assess HER2 Amplification and Activation in Patients With Metastatic Breast Cancer Whose Tumors Are HER2-Negative by Standard FISH Testing (NCT01048099)	Center for Cancer and Blood Disorders - Fort Worth	Ft. Worth, TX
NCT01061840	Phase I Trial of Bi-shRNAfurin and GMCSF Augmented Autologous Tumor Cell Vaccine for Advanced Cancer (NCT01061840)	Mary Crowley Medical Research Center at Sammons Cancer Center	Dallas, TX
NCT01149083	Veliparib With or Without Carboplatin in Treating Patients With Stage III or IV Breast Cancer (NCT01149083)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01156870	Dose Escalation, Safety and Pharmacokinetic, First in Man Study, of SAR566658 Administered as a Single Agent by Intravenous Infusion Every 3 Weeks in Adult Patients With DS6-positive and Refractory Solid Tumors (NCT01156870) (NCT01156870)	Investigational Site Number 840001 Audie Murphy VA	San Antonio, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01177397	A Phase 1/2, Multi-Center, Open-Label, Dose Finding Study to Assess the Safety, Tolerability, Pharmacokinetics and Preliminary Efficacy of the mTOR Kinase Inhibitor CC-223 Administered Orally to Subjects With Advanced Solid Tumors,... (NCT01177397)	Mary Crowley Medical Research Center at Sammons Cancer Center	Dallas, TX
NCT01197170	Hormone Receptor Positive Disease Across Solid Tumor Types: A Phase I Study of Single-Agent Hormone Blockade and Combination Approaches With Targeted Agents to Provide Synergy and Overcome Resistance (NCT01197170)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01221870	A Phase II Study of Tesetaxel as First-line Therapy for Subjects With Metastatic Breast Cancer (NCT01221870)	Texas Oncology, PA at Charles A. Sammons Cancer Center	Dallas, TX
NCT01231802	A Comparative, Multicenter, Open-Label, Randomized, Phase 2 Study of the Safety and Antitumor Activity of Oral Eniluracil + 5 Fluorouracil + Leucovorin Versus Capecitabine Monotherapy in Subjects With Metastatic Breast Cancer (NCT01231802)	Methodist Hospital	Houston, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01242800	Early Surgery or Standard Palliative Therapy in Treating Patients With Stage IV Breast Cancer (NCT01242800)	Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center Methodist Hospital University of Texas Health Center at Tyler University of Texas M.D. Anderson Cancer Center Scott and White Cancer I Baylor Medical Center at University of Texas Medical Branch UTMB Cancer Center at Victory Lakes Doctor's Hospital of Laredo	Dallas, TX Houston, TX Tyler, TX Houston, TX Temple, TX Galveston, TX Clear Lake, TX Laredo, TX
NCT01262027	A Phase II Study of TKI258 (Dovitinib Lactate) as Salvage Therapy in Patients With Stage IV HER2-negative Inflammatory Breast Cancer (IBC) and Local or Distant Relapse	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01325207	Phase I/II Dose Escalation Trial to Assess Safety of Intrathecal Trastuzumab for the Treatment of Leptomeningeal Metastases in HER2 Positive Breast Cancer	Texas Oncology - Midtown Austin	Austin, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01325441	A Phase Ib/II Clinical Study of BBI608 Administered With Paclitaxel in Adult Patients With Advanced Malignancies (NCT01325441)	Tyler Cancer Center Texas Oncology- Fort Worth Texas Oncology- Baylor Charles A. Sammons Cancer Center	Tyler, TX Ft. Worth TX Dallas, TX
NCT01332630	A Phase II Open-Label Study of TPI 287 in Patients With Breast Cancer Metastatic to the Brain (NCT01332630)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01351103	A Phase I, Open-label, Dose Escalation Study of Oral LGK974 in Patients With Melanoma and Lobular Breast Cancer (NCT01351103)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01411410	A Phase 1 Study of BAY80-6946 (Phosphatidylinositol 3´-Kinase Inhibitor) in Combination With Paclitaxel in Subjects With Advanced Solid Malignancy (NCT01411410)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01421524	A Phase 1a/1b, Multi Center, Open-Label, Dose-Finding Study to Assess the Safety, Tolerability, Pharmacokinetics and Preliminary Efficacy of the Pleiotropic Pathway Modifier CC-122 Administered Orally to Subjects ... (NCT01421524)	South Texas Accelerated Research Therapeutics	San Antonio, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01434303	Entinostat and Lapatinib Ditosylate in Patients With Locally Recurrent or Distant Relapsed Metastatic Breast Cancer Previously Treated With Trastuzumab (NCT01434303)	University of Texas M.D. Anderson Cancer Center	Houston, TX
NCT01437566	A Phase II, Double-Blind, Placebo Controlled, Randomized Study of GDC-0941 or GDC-0980 With Fulvestrant Versus Fulvestrant in Advanced or Metastatic Breast Cancer in Patients Resistant to Aromatase Inhibitor Therapy (NCT01437566)	University of Texas M.D. Anderson Cancer Center	Houston, TX
NCT01446016	Phase II Study of The Efficacy And Safety of Chloroquine (C) in CombinAtion With Taxane	Methodist Hospital	Houston, TX
NCT01494662	A Phase II Trial of HKI-272 (Neratinib) for Patients With Human Epidermal Growth Factor Receptor 2 (HER2)-Positive Breast Cancer and Brain Metastases (NCT01494662)	Dan L. Duncan Cancer Center at Baylor College of Medicine	Houston, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City, State
NCT01506609	A Randomized, Phase 2 Study of the Efficacy and Tolerability of Veliparib in Combination With Temozolomide or Veliparib in Combination With Carboplatin and Paclitaxel Versus Placebo Plus Carboplatin and Paclitaxel in Subjects With BRCA1 or BRCA2 (NCT01506609)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01516307	A Double-blind, Randomized Trial of Active Immunotherapy With Globo H-KLH (OPT-822) in Subjects With Metastatic Breast Cancer (NCT01516307)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01528345	A Multicenter, Randomized, Double Blind, Placebo Controlled, Phase II Trial Evaluating the Safety and Efficacy of Dovitinib Combined With Fulvestrant, in Postmenopausal Patients With HER2- and HR+ Breast Cancer That Have... (NCT01528345)	Cancer Care Centers of South Texas	San Antonio, TX
NCT01529593	Phase I Study of Temsirolimus in Combination With Metformin in Patients With Advanced Cancers (NCT01529593)	M. D. Anderson Cancer Center at University of Texas	Houston, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01548144	A Two Steps Phase I Trial of Pazopanib or Pemetrexed in Combination With Crizotinib Followed by the Triplet, Crizotinib Plus Pazopanib Plus Pemetrexed in Patients With Advanced Malignancies (NCT01548144)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01556789	Phase 1 Study of ONT-10, a Liposomal MUC1 Cancer Vaccine, in Patients With Solid Tumors (NCT01556789)	Mary Crowley Medical Research Center at Sammons Cancer Center	Dallas, TX
NCT01572727	A Randomized, Double-blind, Placebo Controlled, Phase II Study of BKM120 Plus Paclitaxel in Patients With HER2 Negative Inoperable Locally Advanced or Metastatic Breast Cancer, With or Without PI3K Pathway Activation. (NCT01572727)	Texas Oncology, P.A. Central Austin Cancer Center Baylor Health Care System/Sammons Cancer Center Baylor Texas Oncology Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center - D	Austin, TX Dallas, TX Dallas, TX
NCT01576666	A Phase Ib, Multi-center, Open Label, Dose Escalation Study of Oral LDE225 in Combination With BKM 120 in Patients With Advanced Solid Tumors (NCT01576666)	Sammons Cancer Center - Texas Oncology SC-2 M. D. Anderson Cancer Center at University of Texas Texas Oncology, P.A. SC	Dallas, TX Houston, TX Austin, TX

Table A.2 Continued

Trial Name	Trial Number	Locations	City/State
NCT01610284	A Phase III Randomized, Double Blind Placebo Controlled Study of BKM120 With Fulvestrant, in Postmenopausal Women With Hormone Receptor-positive HER2-negative Locally Advanced or Metastatic Breast Cancer Which Progressed ... (NCT01610284)	Oncology Consultants Oncology Consultants, P.A. Texas Oncology, P.A. TX Onc - Med City Dallas CTRC Cancer Center	Houston, TX Dallas, TX San Antonio, TX
NCT01623349	Phase I Study of the Oral PI3kinase Inhibitor BKM120 and the Oral PARP Inhibitor Olaparib in Patients With Recurrent Triple Negative Breast Cancer or Recurrent High Grade Serous Ovarian Cancer (NCT01623349)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01624441	A Phase 1 Study With Dose Expansion of Dinaciclib (SCH 727965) in Combination With Epirubicin in Patients With Metastatic Triple Negative Breast Cancer (NCT01624441)	University of Texas M.D. Anderson Cancer Center	Houston, TX
NCT01625234	Phase 1, First-in-Human, Dose-Escalation Study to Evaluate the Safety, Tolerability, and Pharmacokinetics of X-396 in Patients With Advanced Solid Tumors (NCT01625234)	M. D. Anderson Cancer Center at University of Texas	Houston, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City, State
NCT01627067	Circulating FGF21 Levels and Efficacy of Exemestane, Everolimus and Metformin in Postmenopausal Women With Hormone Receptor Positive Metastatic Breast Cancer and BMI >/= 25 (NCT01627067)	M. D. Anderson Cancer Center at University of Texas	Houston, TX
NCT01633060	A Phase III Randomized, Double Blind, Placebo Controlled Study of BKM120 With Fulvestrant, in Postmenopausal Women With Hormone Receptor-positive HER2-negative AI Treated, Locally Advanced or Metastatic Breast Cancer Who Progressed on... (NCT01633060)	US Oncology, Incorporated - Central Office Methodist Hospital Texas Tech University Health Science Center Dept of Texas Tech Texas Oncology, P.A. Texas Oncology - Fort Worth (3 Texas Oncology, PA at Charles A. Sammons Cancer Center Simmons Comprehensive Cancer Center at University of Texas Southwestern Medical Center - Dallas	Houston, TX Houston, TX Lubbock, TX Fort Worth TX. Dallas, TX Dallas, TX
NCT01663727	A Phase III, Randomized, Double-Blind, Placebo-Controlled, Multicenter Study To Evaluate the Efficacy and Safety Of Bevacizumab, and Associated Biomarkers, In Combination With Paclitaxel Compared With Paclitaxel Plus Placebo... (NCT01663727)		

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01677455	An Open Label Multicenter Phase 2 Window of Opportunity Study Evaluating Ganetespib (STA-9090) Monotherapy in Women With Previously Untreated Metastatic HER2 Positive or Triple Negative Breast Cancer (NCT01677455)	MD Anderson Cancer Center	Houston, TX
NCT01698918	An Open-label, Phase II, Single-arm Study of Everolimus in Combination With Letrozole in the Treatment of Postmenopausal Women With Estrogen Receptor Positive Metastatic Breast Cancer (NCT01698918)	East Texas Hematology & Oncology Clinic, PA	Tyler, TX
NCT01783444	A Phase II Study of Everolimus in Combination With Exemestane Versus Everolimus Alone Versus Capecitabine in Advance Breast Cancer.	The Center for Cancer and Blood Disorders Dept. of The Ctr for C & BD	Ft. Worth. TX
NCT01802970	Pilot Safety and Blood Immune Cell Transcriptional Profiling Study of Weekly Nab Paclitaxel Plus Anakinra in Metastatic Breast Cancer Patients (NCT01802970)	Baylor University Medical Center - Dallas	Dallas, TX

Table A.2 Continued

Trial Name	Trial Number	Locations	City/State
NCT01808573	A Study of Neratinib Plus Capecitabine Versus Lapatinib Plus Capecitabine in Patients With HER2+ Metastatic Breast Cancer Who Have Received Two or More Prior HER2 Directed Regimens in the Metastatic Setting (NCT01808573)	Houston Cancer Institute	Houston, TX
NCT01818999	A Phase II Trial Of Ixabepilone and Stereotactic Body Radiation Therapy (SBRT) For Patients With Triple Negative Metastatic Breast Cancer (NCT01818999)	Simmons Comprehensive Cancer Center at University of Texas	Dallas, TX
NCT01881230	A Phase 2/3, Multi-center, Open-label, Randomized Study of Weekly Nab-paclitaxel in Combination With Gemcitabine or Carboplatin, Compared to the Combination of Gemcitabine and Carboplatin, as First-line Treatment in Female Subjects ... (NCT01881230)	Center for Cancer and Blood Disorders - Fort Worth Texas Oncology, PA at Charles A. Sammons Cancer Center Texas Oncology, PA at Presbyterian Hospital Dallas	Ft. Worth, TX Dallas, TX Dallas, TX

Table A.2 Continued

Trial Number	Trial Name	Locations	City/State
NCT01945775	A Phase 3, Open-Label, Randomized, Parallel, 2-Arm, Multi-Center Study of BMN 673 Versus Physician's Choice in Germline BRCA Mutation Subjects With Locally Advanced and/or Metastatic Breast Cancer, Who Have Received No More Than 2 Prior Chemotherapy Received (NCT01945775)	Texas Oncology P.A. Texas Oncology P.A. Texas Oncology P.A.	Dallas, TX Houston, TX Austin, TX

APPENDIX B

Appendix B.1 ACCESS AYA PEARL

ACCESS AYA PEARLS

CHILDHOOD, ADOLESCENT AND YOUNG ADULT (AYA) CARDIOTOXIC CHRONIC LATE EFFECTS

One in 640 young adults between the ages of 20 and 39 is a survivor of childhood cancer. [1]
Nearly 70,000 young adults between the ages of 15-39 are diagnosed each year in the US. [2]

THE EVIDENCE

- Compared with those who have never had cancer, more AYA survivors had heart disease (14% vs.7%) and high blood pressure (35% vs. 29%); these conditions may be long term effects of being treated for cancer as a child or young adult. [1]
- Anthracycline-based therapy has correlated with an increased risk of cardiac disease, and expert panels recommend that AYA and childhood cancer survivors who received anthracyclines be monitored for cardiac disease. [2, 3]
- Many other chemotherapy agents, as well as new oral "targeted" agents may have cardiotoxic side effects, but these are more likely to be acute, rather than long term effects. [4, 5, 6]
- Female gender has also been associated with increased risk for cardiac disease in several studies. The reason female gender has been correlated with this risk is unknown. [7]
- Mediastinal radiation, radiation to the lungs, left abdomen and treatment for Wilms Tumor and Ewing's Sarcoma may raise concerns for cardiac issues. [8]

WHAT SHOULD I DO WITH THIS INFORMATION?

1. Take steps to identify AYA and childhood cancer survivors among your patient panel.
2. A detailed cardiac assessment should be performed for survivors of childhood cancer and AYAs who are pregnant or planning a pregnancy or who wish to take part in competitive sports.
3. Recognize potential barriers to care including survivors' lack of knowledge about late effects and unawareness of risks, low health literacy, lack of insurance and financial resources.
4. Refer survivors and family members to resources including Seton Survivor Center, Seton Heart Institute's Cardio-Oncology Program, LiveSTRONG, Cancer Care and other regional/national resources.
5. Encourage your survivor patients to develop a personalized survivorship care plan that includes recommended screenings (both cancer specific and recommended health screenings as well as psychosocial resources and needs.

WANT MORE INFORMATION?

Children's Oncology Group, ed. Long Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers.

Arcadia CA: Children's Oncology Group 2006.

www.survivorshipguidelines.org

Seton Cancer Survivor Center Nurse Navigator

Tel: 512.324.3343

www.seton.net/survivorship

AYA Healthy Survivorship iPhone app and Cancer Survivorship Plans

www.healthysurvivorship.org

REFERENCES

1. Tai E, Buchanan N, Townsend J, Fairley T, Moore A, Richardson LC. (2012) Health status of adolescent and young adult cancer survivors. Cancer.

2. Mulroney DA, Yeazel MW, Kawashima T, et al. (2009) Cardiac outcomes in a cohort of adult survivors of childhood and adolescent cancer: retrospective analysis of the Childhood Cancer Survivor Study cohort. BMJ 2009; 339: b 4606.

3. J. Leandro, J. Dyck, D. Poppe et al.1994) "Cardiac dysfunction late after cardiotoxic therapy for childhood cancer," American Journal of Cardiology 74:11. 1152–1156.

4. Hinkle AS, Proukou CB, Deshpande SS. Cardiovascular Complications: Cardiotoxicity Caused by Chemotherapy. In: Wallace H Green DM, Eds. Late effects of Childhood Cancer New York. Oxford University Press; 2004895-100.

5. Green DM, eds. (2000) Late Effects of Childhood Cancer. New York: Oxford University Press; 2004:85-100. V. B. Pai and M. C. Nahata, "Cardiotoxicity of chemotherapeutic agents. Incidence, treatment and prevention," Drug Safety .22:4. 263:302.

6. Garcia-Alvarez, X. Garcia-Albeniz, J. Esteve, M. Rovira, and X. Bosch,(2010) "Cardiotoxicity of tyrosine-kinase-targeting drugs," Cardiovascular and Hematological Agents in Medicinal Chemistry. 8:1.11:21.

7. Green, YA. Grigoriev, B. Nan et al., "Congestive heart failure after treatment for Wilms' tumor: a report from the National Wilms' Tumor Study Group," Journal of Clinical Oncology 2001. 19:7.1926:934.

8. Hull MC, Morris CG, Pepine CJ, Mendenhall NP.(2003) Valvular dysfunction and carotid, subclavian, and coronary artery disease in survivors of Hodgkin lymphoma treated with radiation therapy. JAMA 2003; 290 2831-7.

REFERRALS

The Seton Cancer Survivor Center sees patients ages 18-39 that have completed cancer treatment. Patients may call 512-324-9652 and choose to speak with the nurse navigator, or you may call the nurse navigator directly (512) 324-3343.

Referrals may be emailed to aya-survivorship@seton.org or faxed to (512) 406-6515.

More information is available at http://seton.net/survivorship.

ACCESS AYA PEARLS SPONSORED BY

Seton Healthcare Family

ACCESS AYA

CPRIT CANCER PREVENTION & RESEARCH INSTITUTE OF TEXAS

B.2 PEARL Tab for Physician Offices

Caring for Adolescent and Young Adult (AYA) Cancer Survivors -Ages 15-39

PROVIDER RESOURCES

AYA Prompt Evidence Assessment and Review of the Literature Services (AYA PEARLS) PDFs

Available at **www.seton.net/survivorship** - For Providers Tab

- Cardiotoxicity
- Late Effects
- Psychosocial
- Breast Health
- Endocrine

Video PEARLS: Short Videos on AYA Late Effects and Care Topics

Available at **www.seton.net/survivorship** - For Providers Tab

AYA Late Effects and Caselett - Dan Bowers, MD, UT Southwestern Medical Center
AYAs and the Childhood Cancer Survivor Study - Angelina Orlino, MD, UT Southwestern Medical Center
AYA Cardiotoxicity and Caselett - Thomas Andrews, MD, UT Southwestern Medical Center
AYAs and Psychosocial Late Effects - Barbara Jones, PhD, University of Texas at Austin
AYA Psychological Late Effects Including PTSD - Heidi Hamann, PhD, UT Southwestern Medical Center
AYA Survivorship Care for PCPs - Beth Miller, MD, University of Texas Physicans at Seton
AYA Navigation - Maria Marek, RN, Seton Healthcare Family

PATIENT REFERRALS, SECOND OPINIONS AND SURVIVORSHIP CARE

Seton Cancer Survivor Center

tel: 512.324.3343 **fax**: 512.406.6515 **email**: aya-survivorship@seton.org

PATIENT AND FAMILY RESOURCES

Survivorship Plans and Navigation Services - Seton Cancer Survivor Center

tel: 512.324.9652 **fax**: 512.406.6515 **email**: aya-survivorship@seton.org

Twitter: @AYAsurvivorship

Facebook: www.facebook.com/SetonCancerSurvivorCenter

Survivor and Care Giver Videos (English & Spanish): www.seton.net/survivorship - For Patients Tab

Young And Strong Fight Club (for AYA Survivors) Facebook: www.facebook.com/groups/youngandstrongfightclub

B.3 ACCESS AYA Recruiting Script and Consent

Email Script for Seton ACCESS AYA CPRIT Grant Evaluation Participants

Seton Healthcare Family Oncology Network staff members identified you as a potential interviewee for an evaluation of Seton's Adolescent and Young Adult Cancer Survivor grant project. The grant project was funded by the Cancer Prevention and Research Institute of Texas and you can find information about the project on Seton's Survivorship website pages for patients and providers.

http://www.seton.net/medical_services_and_programs/cancer_care/cancer_survivorship/

Texas A&M's School for Rural Public Health (SRPH) is conducting the evaluation. The goal of the evaluation is to learn more about how the grant activities and materials are being used.

The purpose of this email is to find out if you are willing to be interviewed as part of the evaluation and, if you are, to gain your consent and capture some basic background information. Attached to this email are an information sheet about the project and additional materials about confidentiality and consent.

If you are willing to participate, please follow this link to consent and to provide demographic information and information about how best to contact you. (www…link to be provided)

If you agree to be interviewed we will set up a specific time and date for an interview call that will last between 20-30 minutes. Either Dr. Marcia Ory or Ms. Debra Kellstedt from Texas A&M will conduct the interviews.

All the information you provide will be kept strictly confidential and will not be associated with your name. Your responses will be combined with responses of other interview participants. We will not share your personal information with any other organization or individuals. The data collected during the interviews will be stored and secured at SRPH on a portable hard drive or in text documents in a locked file. In the event of any publication or presentation resulting from this research, no personally identifiable information will be disclosed.

Thank you for your time and consideration. If you do not click on the link for consent and information, we will delete your name and information from our files and

will not retain any record that you were considered as a potential interviewee for this evaluation study.

Please feel free to contact either Christopher Hamilton or me, Deborah Vollmer Dahlke, if you have any questions about the project or your participation as an interview candidate. You may also contact Dr. Marcia Ory, the principal investigator on the project. We have provided all of our emails and phone numbers below for your convenience.

Thank you for your consideration.

Kind regards,

Deborah Vollmer Dahlke
deborahvd@gmail.com
512.699.4493

Christopher M. Hamilton
cmhamilton@seton.org
512. 705.5600

Dr. Marcia Ory
mory@srph.tamhsc.edu
979 458 1373

B.4 Facebook Recruiting Script

ACCESS AYA Survivor Recruitment on Facebook Group Site

You are invited to participate in a research project to evaluate Seton's AYA survivorship education programs. You must be 18 years or older to participate. You will be asked to fill out a few demographic questions an online survey and to schedule a 20-30 minute phone interview to answer questions about AYA educational programs.

Survey Link
All the information you provide will be kept strictly confidential. Your responses will be combined with responses of other participants in the evaluation. We will not share your personal information with any other organization or individuals.

To learn more about participation in the evaluation, please contact Deborah Vollmer Dahlke at 512.699.4493 or at deborahvd@gmail.com

B.5 Interview Guide: AYA Survivors

Interview Guide for CPRIT ACCESS AYA Grant
Cancer Survivor/Family Members/ Caregivers

You previously gave consent for this brief interview regarding the impact and outcomes of Seton's ACCESS AYA grant from CPRIT. The purpose of the grant was to provide education for both professionals and the public regarding the unique needs of Adolescent and Young Adult (AYA) cancer survivors (ages 15-39).

I will be asking you a series of open-ended questions so you can share your thoughts about and experiences with the AYA survivorship education programs at Seton. There are no right or wrong answers. You do not need to answer any interview questions that you do not wish to answer. Your responses will be kept confidential, and reports will not identify any individual respondents.
Are you comfortable with our recording this conversation? (If respondent says "yes' start recording, if "no," then take notes but do not record).

1) In what ways have Seton's education programs on Adolescent and Young Adult cancer survivorship helped you as a survivor (or survivors caregiver/family member)?
2) Have you shared any of the information or education materials, including the videos or the AYA app, with other AYA survivors? What about caregivers or family members? Is there an anecdote or story you can share?
3) In what ways, if any, has information or educational materials about AYA cancer survivorship helped you? For example learning about healthy diets or physical activity for AYA survivors?
4) What barriers or challenges are you aware of regarding how AYA cancer survivors are cared for or treated in Central Texas?
5) Has the information or education regarding AYA cancer survivors changed how you think about or treat other cancer survivors? If so, can you provide some examples?
6) What opportunities or challenges do you believe exist in sustaining or expanding programs for AYAs?
7) Do you have any additional thoughts or information you would like to share as part of this evaluation of the ACCESS AYA grant?

Thank you for your time.

B.6 Interview Guide: Cancer Advocates
Interview Guide for CPRIT ACCESS AYA Grant
Cancer Advocates/Community Partners

You previously gave consent for this brief interview regarding the impact and outcomes of Seton's ACCESS AYA grant from CPRIT. The purpose of the grant was to provide education for both professionals and the public regarding the unique needs of Adolescent and Young Adult (AYA) cancer survivors (ages 15-39).

I will be asking you a series of open-ended questions so you can share your thoughts about and experiences with the AYA survivorship education programs at Seton. There are no right or wrong answers. You do not need to answer any interview questions that you do not wish to answer. Your responses will be kept confidential, and reports will not identify any individual respondents.
Are you comfortable with our recording this conversation? (If respondent says "yes' start recording, if "no" then take notes but do not record).

1) In what ways have Seton's professional and patient education programs on Adolescent and Young Adult Cancer helped you in your work as a cancer advocate?
2) Can you give examples of how you have shared educational materials or information on the AYA cancer survivorship with your staff or your constituents/stakeholders? Is there an anecdote or story you can share?
3) In what ways, if any, has information or educational materials about AYA cancer survivors changed they way in which you do your work as an advocate?
4) What barriers or challenges are you aware of regarding how AYA cancer survivors are cared for or treated in Central Texas?
5) Has the information or education regarding AYA cancer survivors changed how you think about or treat other cancer survivors? If so, can you provide some examples?
6) What opportunities or challenges do you believe exist in sustaining or expanding programs for educating healthcare professionals about AYAs?
7) What opportunities or challenges do you believe exist in sustaining or expanding programs for educating AYA cancer survivors and their families/caregivers?
8) Do you have any additional thoughts or information you would like to share as part of this evaluation of the ACCESS AYA grant?

Thank you for your time.

B.7 Interview Guide: Healthcare Professionals

Interview Guide for CPRIT ACCESS AYA Grant
Healthcare Professionals Interview Guide

You previously gave consent for this brief interview regarding the impact and outcomes of Seton's ACCESS AYA grant from CPRIT. The purpose of the grant was to provide education for both professionals and the public regarding the unique needs of Adolescent and Young Adult (AYA) cancer survivors (ages 15-39).
Consent previously provided ☐

I will be asking you a series of open-ended questions so you can share your thoughts about and experiences with the AYA survivorship programs at Seton.
There are no right or wrong answers. You do not need to answer any interview questions that you do not wish to answer. Your responses will be kept confidential, and reports will not identify any individual respondents.
Are you comfortable with our recording this conversation? (If respondent says "yes' start recording, if "no" then take notes but do not record).

Yes ☐

No☐

1) In what ways have Seton's professional and patient education programs on Adolescent and Young Adult Cancer helped you understand the needs of these survivors?
2) In what ways have you shared information on the AYA cancer survivor professional or patient education programs with your colleagues or staff?
3) In what ways, if any, have information or educational materials about AYA cancer survivors changed the way in which you do your job?
4) What barriers or challenges are you aware of regarding how AYA cancer survivors are cared for or treated in Central Texas?
5) Has the information or education regarding AYA cancer survivors changed how you think about or treat other cancer survivors? If so, can you provide some examples?
6) What opportunities or challenges do you believe exist in sustaining or expanding programs for educating professionals about AYA cancer survivors?
7) What opportunities or challenges do you believe exist in sustaining or expanding programs for educating AYA cancer survivors and their families/caregivers?
8) Do you have any additional thoughts or information you would like to share as part of this evaluation of the ACCESS AYA grant?

Thank you for your participation in this evaluation.

APPENDIX C

C.1 Coding Manual for Cancer Survivorship Apps

Coding Manual for mHealth Behavioral Change Techniques in Cancer Survivorship Applications
2014

(An adapted version of the coding manual from Abraham C and Michie S. A Taxonomy of Behavior Change Techniques use in Interventions: The Coding Manual) (2007)

General Instructions for Coding Mobile Health Applications

Please review the mHealth theory and behavior change taxonomy before coding the mobile health applications (mHealth apps). Discuss the techniques with co-coders to ensure that all coders interpret these materials, definitions, and techniques similarly. Conduct at least one practice coding session jointly with practice materials that are comparable (but different from) the final study materials and discuss these results with the team before beginning coding the study applications. The following suggestions assume that the selection of the mHealth apps has already been made and that there is agreement among the team that all of the selected apps meet the stated criteria for inclusion in the study.

Suggestions for optimal coding of health behavior mhealth apps:

- Read all selection and coding material before coding.
- Scan the different health behavior techniques presented in the coding table or Coding Scoring Sheet as these may differ by different types of apps.
- Print out the Behavior Change Theory Definition Matrix and one Coding Scoring Sheet for each mHealth application. Put the name and source of the mHealth Application on the Coding Scoring Sheet
- Start coding using the Coding Scoring Sheet. In case of any doubts between the techniques, please re-read the descriptions in the Theory Analysis and Definition Matrix

After you have finished coding a mHealth application, please review the completed coding scoring sheet to make sure that you have scored the correct techniques and that

you have crossed out any techniques that are not use in the mHealth app under consideration.

Request: If you have suggestions for improvements or extensions of this coding manual please make them prior to beginning to code. The coding manual is a work in progress, but for consistency in the study all coders need to begin and end with the same set of instructions.

General Techniques in mHealth Applications

Each scoring sheet has specific areas to score or annotate the presence of personalization, tailoring and participation.

1.Personalization: This is the provision of opportunities in the mHealth application to make elements of the application personal by the selection of tools or elements that are specific to the individual using the application. An example would be the ability to select a disease type from among several available in the application and then to follow a specific path or set of tools or systems. For example, being able to select "breast cancer" and then being provided sets of information specific to that type of cancer. Another example would be the ability to select to receive emails or texts of a specific nature. The choice of "yes" or "no" to a specific capability of the application would be considered personalization.

2. Tailoring: Coders are asked to annotate the score sheet for each mHealth application to indicate the app's capability to include an intervention element or component that is specific to the characteristics of the person using the app. Coders will be asked to score tailoring at three different levels in the initial assessment of the mHealth application (see Coding Scoring Sheet):
1) Macro-tailoring at the group level. In this instance the mHealth application can be adapted to adjust the intervention materials (including information) that the participant receives based on pre-tested characteristics. For example an app may ask the user if he/she wishes to receive texts and/or assessments on diet, on exercise or smoking cessation.
2) Meso-tailoring at the individual level. The amount or type of intervention depends on the individual needs of the participant. For example, the participant could select between texts delivered once a day versus once a week.
3) Micro-tailoring at the individual level. Specific techniques in the mHealth application are tailored to the unique individual. For example personalized goal setting and reporting tailored to the individual's own needs and desires for physical activity. Or GPS tracking and reporting of an individual's walking or running activities.

Note that all of these general techniques may be used in one mHealth application. It is possible to have personalization, macro-, meso- and micro-tailoring techniques. To score these general techniques the user or participant must be prompted to select an answer or provide input and make decisions in relation to the techniques.

Specific Techniques By Determinant

(Note: The examples given are specific to Cancer Survivorship, but can be adapted for other mHealth behavior techniques or topics.)

Scoring is accomplished by marking the technique with a 1 or 0 in each element or section of the sheet. A "1" indicates that the technique is present in the app, a "0" indicates that it is not present. Personalization and tailoring scoring are provided as additional elements for each major determinant.

Knowledge/Awareness

1. **Provide information about health behavior linkages**.
   This section provides basic information about cancer and cancer survivorship, diagnosis, treatment, and/or availability of resources for clinical or non-clinical purposes. If ***Personalized***, the user is prompted to select or provide personal answers about type of cancer or stage of survivorship for example. If ***Tailored,*** the user is required to select actions or elements specific to the intervention and the way information or activities are delivered to them as a result of these choices.

2. **Provide information on action/behavior and consequences.** Information is provided about the cost/risks/benefits of action or inaction with respect to certain cancer survivorship behaviors. This scoring would also consider risk-communication strategies such as persuasive communications for example post treatment health screening, smoking cessation or adherence to flu-shot recommendations.

Intention

3. Prompt Intention Formation. The mHealth application includes suggestions for general behavior setting or formulating desired outcomes of a behavior for healthy survivorship, e.g., maintain a healthy weight, exercise regularly, eat 5 fruits and or vegetables daily. It may be sometimes difficult to distinguish this from knowledge or awareness, but coders should look for language that indicates a specific action or activity. Also, note that this technique is different from the actual setting of a goal or behavioral objective to facilitate change or adherence.

Facilitation

4.Provide Instruction. This technique involves telling or showing the user or participant ways to facilitate behavior change. For example explaining "SMART" goal setting, or

how to use an app's function to record questions on a mobile phone to ask a provider during an appointment. The function of the instruction must be directly related to the improvement or behavior change, not for general use of the phone or the app. The facilitation may be in the form of written instructions, videos on YouTube that link from the app or images or cartoons that show a step-by-step instruction.

5. Provide materials for education/information. The app provides the cancer survivor with specific materials and information that are suggestions for behavior change. These differ from 1. Knowledge/Awareness in that the education is specific to a behavior change or an action. For example, information on late effects of cancer treatment with prompts of when to contact a healthcare professional. Another example would be educational information about health screenings specific to cancer survivors, for example breast mammograms for female survivors treated with whole body or mantle radiation starting at an early age.

Intention

6. Prompts for Specific Goal Setting. This involves planning and setting a specific goal for what a person would do within a specific time and includes the specific context within which a behavior will be performed. This would include selecting or writing down (micro-tailoring) of a specific goal for example setting a personal goal to "engage in physical activity for 150 minutes each week." Goal setting would include information on when, where, how to act in a specific behavior.

7. Review of general or specific goals. This would involve using the mHealth app in reconsideration of previously set goals or intentions and would require an indication of behavioral performance resulting from self-monitoring or tracking. An example would be review of tracking a goal setting for intake of a specific amount of calories per day or number of minutes of physical activity for a week. Another example might be noting a set of questions to be asked at a healthcare provider appointment regarding levels of pain or emotional distress during a past week or month.

Self-Efficacy

8. Prompt self-monitoring of behavioral goals. The mHealth app suggests that the person record brief notes or keep a journal or diary to record behaviors and actions related to health behaviors. Examples might be a journal of physical activity or pain or distress monitoring and actions taken to alleviate such as meditation or self-talk.

9. Persuasion (verbal or written) The mHealth app delivers messages (may be personalized or tailored) designed to strengthen efficacy/control beliefs related to the execution of target or suggested behaviors. Examples might be often-used successful strategies (e.g., "park at the far end of the parking lot", or "use the stairs instead of the elevator to increase physical activity") or general tips. New beliefs may be induced

and/or new information provided to the participant or user to create new control or behavior beliefs.

Social Influence

10. Provide information about peer behavior (Peer passive). The mHealth app provides information about what other cancer survivors do and think in relation to targeted behavior change. This can be provided in the form of written anecdotes YouTube videos and may be presented as interviews or case studies.

11. Provide opportunities for social comparison (Peer active) The mHealth app offers participation in Facebook, Twitter or other social media and networking in which discussion and social comparison may occur. The focus is on providing social reference for the behavior change or activity. Only score this technique when examples of group or peer discussion including personal stories of behavior are shared. For example, a participant cancer survivor shares that "setting my own goals for physical activity and sharing those with my Facebook friends really helped me make my goals." Or, "writing down my concerns about pain helped me communicate more effectively with my doctor."

12. Mobilize Social Norms (Important Others) The mHealth app provides exposure to the social norms of important others in relation to a healthy survivorship activity or health behavior change. Important others may be valued and trusted experts such as a recognized healthcare professional, a celebrity cancer survivor or a recognized cancer survivorship researcher or advocate (e.g., Nancy Brinker of Susan G. Komen for the Cure or Cathy Giusti, founder of the Multiple Myeloma Research Foundation

Table C.1 iOS and Android App Scoring Sheet

Application Name			Source	iOS Phone	iOs iPad	Android
Coder						
Determinant	**Number**	**Technique**	**Coding (1/0)**			
General Techniques						
1 Personalization	1					
2. Tailoring	2.1	Macro-tailoring				
(note may be all 3)	2.2	Meso-tailoring				
	2.3	Micro-tailoring				
3.Knowledge/Awareness	3.1	Health behavior linkage				
	3.1a	Personalized				
	3.1b	Tailored				
	3.2	Action/behavior consequences				
4.Intention	4	Prompt for Intention Formation				
5. Facilitation	5.1	Provide Instruction				
	5.2	Materials for Education				
6. Goal Setting	6.1	Prompt for Specific Goals				
	6.2	Review of Goal Activity				
7. Self Efficacy	7	Self Monitoring of Goals				
8. Feedback on Performance	8	Feedback or evaluation of goals				

Table C.1 Continued

9. Persuasion	9.1	General Persuasion				
	9.2	Tailored Persuasion				
10. Social Influence	10.1	Information on Peer Behavior (passive)				
	10.2	Opportunity for Social Comparison				
11. Mobilize Social Norms	11	Exposure to Important Others				

Table C. 2 iOS Apps and URLs

iOS App Name	**URL**
AYA Cancer Survivorship	https://itunes.apple.com/us/app/aya-healthy-survivorship/id513642187?mt=8
Pocket Cancer Care Guide	https://itunes.apple.com/us/app/pocket-cancer-care-guide/id453059212?ls=1&mt=8
Cancer 101	https://itunes.apple.com/us/app/cancer-101/id634255819?mt=8
My Cancer Coach	https://itunes.apple.com/us/app/cancer-coach/id468322618?mt=8
Cancer Defeated	https://itunes.apple.com/us/app/cancer-defeated/id734799886?mt=8
Cancer Quotes	https://itunes.apple.com/us/app/cancer-quotes/id633379119?mt=8
Cancer Risk Reduction	https://itunes.apple.com/us/app/cancer-risk-reduction/id525906303?mt=8
Cancer Treatment Support	https://itunes.apple.com/us/app/cancer-treatment-support/id529556518?mt=8
Cancer.net Mobile	https://itunes.apple.com/us/app/cancer.net-mobile/id433501257?mt=8
Cancer Discover Your Healing Power	https://itunes.apple.com/us/app/cancer-discovering-your-healing/id499076412?mt=8

Table C.2 Continued

iOS App Name	URL
Cancer Care	https://itunes.apple.com/us/app/cancercare/id322892401?mt=8
Cancer Defense	https://itunes.apple.com/us/app/cancerdefense/id489556956?mt=8
Cancer Late FX	https://itunes.apple.com/us/app/cancerlatefx/id725634267?mt=8
Cancer Zapper	https://itunes.apple.com/us/app/cancer-navigator/id738587966?mt=8
Cancer fighter	https://itunes.apple.com/us/app/cancer-zapper/id441135097?mt=8
Breacan Navigator	https://itunes.apple.com/us/app/cancerfighter/id508348299?mt=8
Breast Cancer Your Personal Assistant	https://itunes.apple.com/us/app/breacan-navigators/id715478052?mt=8
Breast Cancer Treatment Summary	https://itunes.apple.com/us/app/breast-cancer-your-personal/id636462141?mt=8
Colon Cancer (iPad)	https://itunes.apple.com/us/app/childhood-cancer-facts/id550933125?mt=8
Kidney Cancer	https://itunes.apple.com/us/app/colon-cancer-for-ipad/id815572678?mt=8
Lung Cancer Handbook	https://itunes.apple.com/us/app/kidney-cancer/id363469578?mt=8
Lymphedema App	https://itunes.apple.com/us/app/lung-cancer-handbook/id675750229?mt=8
Prostate Cancer Educated Patient	https://itunes.apple.com/us/app/lymphtracker/id555832934?mt=8
Prostate Pal	https://itunes.apple.com/us/app/prostate-cancer-treatment/id713615914?mt=8

Table C. 3 Android Apps and URLs

Android App Name	URL
Breast Cancer 411	https://play.google.com/store/apps/details?id=com.appmakr.app381412&hl=en
Lung Cancer 411	https://play.google.com/store/apps/details?id=com.appmakr.app381393&hl=en
Breast Cancer	https://play.google.com/store/apps/details?id=com.a16239921575042ebe1deeba8a.a17836414a&hl=en
Ask the Nutritionist	https://play.google.com/store/apps/details?id=org.danafarber.recipes&hl=en

Table C.3 Continued

Android App Name	URL
My Breast Cancer Team	https://play.google.com/store/apps/details?id=com.myhealthteams.MyBCTeam&hl=en
CML Tracker/Recorder	https://play.google.com/store/apps/details?id=air.com.cml.recorder&hl=en
Befitting You	https://play.google.com/store/apps/details?id=com.app_bfy.layout&hl=en
Cancer.net Mobile	https://play.google.com/store/apps/details?id=com.fueled.cancernet&hl=en
Cancer	https://play.google.com/store/apps/details?id=com.historia.cancer&hl=en
Sign Guidelines (132)	https://play.google.com/store/apps/details?id=com.rootcreative.sign&hl=en
Cancer Coach	https://play.google.com/store/apps/details?id=com.genomichealth.CancerCoach&hl=en
Esophageal Cancer Care	https://play.google.com/store/apps/details?id=com.a1783027583500afc06278009a.a35570151a&hl=en
ESMO Guidelines	https://play.google.com/store/apps/details?id=com.appyzz.android.esmo&hl=en
Re-Mission	https://play.google.com/store/apps/details?id=air.com.rm2.nbr&hl=en
Breast Cancer Updates	https://play.google.com/store/apps/details?id=com.phonegap.breastcancer&hl=en
Breast Cancer Awareness	https://play.google.com/store/apps/details?id=com.magna.srior.breastcancer&hl=en
Prostate Cancer Calculator	https://play.google.com/store/apps/details?id=com.borinfer.test&hl=en
Liver Cancer 411	https://play.google.com/store/apps/details?id=com.appmakr.app381467&hl=en
Prostate Pal	https://play.google.com/store/apps/details?id=com.quarkstudios.prostatepal&hl=en
Navigating Lung Cancer	https://play.google.com/store/apps/details?id=com.realintelligence.BJALungC&hl=en
Focus on Lymphoma	https://play.google.com/store/apps/details?id=com.acrosshealth&hl=en
Testicular Cancer	https://play.google.com/store/apps/details?id=com.a5997895965034aaf7cc5469a.a56473555a&hl=en

Table C.3 Continued

CANCER.GOV	http://m.cancer.gov/
Play to Cure: Genes In Space	https://play.google.com/store/apps/details?id=com.guerillatea.elementalpha&hl=en
Lymphedema Breast Cancer App	https://play.google.com/store/apps/details?id=com.kellylymphoedemabreastcancerapp.com.au.Lymphoedema_Breast_Cancer_App&hl=en
CANCER SMASHER!!	https://play.google.com/store/apps/details?id=org.example.cancersmasher&hl=en
Cancer Fighter	https://play.google.com/store/apps/details?id=com.NewHopeGames.cancerfighter&hl=en
Cancer Blockade	https://play.google.com/store/apps/details?id=com.bodyxq.cancerblockade2&hl=en
Lite Match3 for Breast Cancer	https://play.google.com/store/apps/details?id=AKnght.Studios.CureLite&hl=en
Hit Cancer for 6 as Yuvi	https://play.google.com/store/apps/details?id=com.pecs.playwithyuvi&hl=en
Stop Cancer	https://play.google.com/store/apps/details?id=com.triton.stop&hl=en
Re-Mission2: Nanobot's Revenge	https://play.google.com/store/apps/details?id=air.com.rm2.nbr