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Communication Channels For Cancer Survivorship: Addressing Information Dissemination, Clinical Trial Recruitment And Social Networking

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COMMUNICATION CHANNELS FOR CANCER SURVIVORSHIP: ADDRESSING
INFORMATION DISSEMINATION, CLINICAL TRIAL RECRUITMENT AND
SOCIAL NETWORKING

by

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Bachelor of Arts, Pacific Lutheran University, 2007
Master of Arts, University of North Dakota, 2013

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Submitted to the Graduate Faculty

of the

University of North Dakota

In partial fulfillment of the requirements

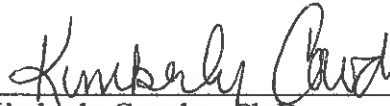
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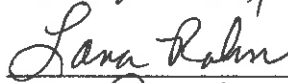
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This thesis, submitted by Carly Steen in partial fulfillment of the requirements for the Degree of Master of Arts from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done, and is hereby approved.



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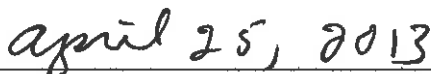
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Title Communication Channels for Cancer Survivorship: Addressing
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Networking

Department Communication

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Carly E. Steen
April 25, 2013

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Abstract

More people are surviving cancer than ever before due to early detection and advances in treatment (Kazanjian, Smillie, Howard, Ward and Doll, 2009). With a growing group of cancer survivors, a group expected to grow to 18 million by 2020, additional informational resources must be put in place (Cancer Survivorship Training, 2013). This study seeks to better understand 1) where cancer patients and survivors are finding cancer resources, 2) what computer-mediated communication channels they use and prefer and 3) who they trust the most to educate and recruit them for clinical trials. Twenty in-depth interviews were conducted and analyzed with cancer patients and survivors from the HUGS Cancer Survivorship Program, a pseudonym, at a mid-sized, mid-western hospital to comprehend these questions. The study revealed that cancer patients and survivors are selective in their media choices and these choices are based on a variety of factors. It also reinforced the current literature that physicians are the most valued resource in learning more about cancer clinical trials. Sensitive health content impacts an individual's use of social media tools, which ultimately determines one's willingness to be recruited via social media sites for clinical trials.

CHAPTER I

INTRODUCTION

Communication Channels for Cancer Resources: Addressing Information Dissemination, Clinical Trial Recruitment and Social Networking

People are surviving cancer more than ever before due to early detection and advances in treatment (Kazanjian, Smillie, Howard, Ward, & Doll, 2009). With a growing group of cancer survivors, a group expected to grow to 18 million by 2020, survivorship programs are being developed to inform and support these populations (Cancer Survivorship Training, 2013). By 2014, The American College of Surgeons Commission on Cancer is mandating that all health care facilities create a formal plan of delivery for cancer survivorship programs and implement said plan by 2015 (Cancer Survivorship Training, 2013). With a mandate in place and an increasing number of cancer survivors joining “survivorship” each year, cancer survivorship groups across the country are working to create, improve or simply maintain their programs in order to help the large number of individuals in need (Cancer Survivorship Training, 2013).

Statement of Problem

An influx of cancer survivors is occurring for three reasons. One, medical advances are more effective in eliminating cancer cells. Chemotherapy, radiation and advanced surgical procedures have resulted in less evidence of disease worldwide (Campbell et al., 2009). A second reason for more cancer survivors is the improvement in early detection methods. Health promotion campaigns and an emphasis on preventative

care have resulted in individuals getting more physicals, mammograms and check ups. As more people catch and eliminate cancer early on, the larger the survivorship population grows. The third way that there is an increase in cancer survivors is due to cancer clinical trials. Clinical trials are a way to increase knowledge of new cancer drugs, diagnostic procedures, symptom management and therapies. There are various stages of clinical trials and ways of administration, but one common denominator; clinical trials aid in the development of effective therapies and advancement in medicine (Miller et al., 2011). These three reasons can be credited with extended life spans and quality of life for 13 million Americans who are living as cancer survivors (Cancer Survivorship Training, 2013).

Those individuals leaving hospitals and cancer centers without any evidence of cancer in their bodies are faced with a particular set of physical, psychological and social issues (Kazanjian, Smillie, Howard, Ward, Doll, 2012). These issues are consequences of cancer and its treatments. This post-cancer treatment situation leaves cancer patients, now survivors, in a unique position. There are a variety of social support groups and health resources that are established to empower the new cancer survivor. These resources can be found at local cancer centers, online, at community organizations or through national organizations such as Livestrong. There are resources everywhere to empower the cancer survivor, and it appears that cancer survivors are reaching out and using the available resources including burgeoning Internet health information.

Computer-mediated health communication (CMHC) is a growing phenomenon. Over 81 percent of adults are using the Internet and of these adults, 80 percent use the Internet to locate health information (Pew Internet and American Life Project, 2012).

Websites like WebMD, Mayo Clinic, and M.D. Anderson are projected as being survivors' "go to" when they have health related questions. The existence and appearance of more cancer survivorship programs means that survivors are still not acquiring all of the resources they need. Additionally, cancer survivors are not taking the initiative to locate clinical trial participation information. If clinical trial recruitment declines, there is potential for cancer survivorship rates to decline as well. Clinical trial recruitment and cancer survivorship are intimately connected.

Although computed-mediated health communication is popular and survivors may be using it to communicate with other survivors, how are survivors utilizing social media sites? If they are using them, how are survivors using them to learn of clinical trials if at all? Although there is dialogue about utilizing social media as an effective recruitment strategy on medical blogs, there has been little empirical research on successful clinical trial recruitment via social networking sites. One notable recent study resulted in a highly successful clinical trial recruitment via a social networking site. Looking to successes like this may result in increased clinical trials recruitment nation-wide.

In August of 2011, the Mayo Clinic released findings on their website reporting their successful use of social media to recruit for clinical trial for a rare heart condition (Klein, 2011). The Mayo Clinic study issued a call for participants in a clinical trial for spontaneous coronary artery dissection (SCAD). Utilizing a website called inspire.com, an online health and wellness support, forum, the study recruited 18 participants for a 12 participant study (Klein, 2011). SCAD affects just a few thousand Americans each year, so Mayo's successful recruitment strategies were certainly surprising. The principal

investigator of the study boasted that the study's characteristics made the study "truly patient-initiated research" (Klein, 2012, para 3).

There were six characteristics that made the Mayo Clinic study such a recruitment success. Pharmaceutical blogger, Rahlyn Gossen, identified these areas where the conditions for successful clinical trial recruitment were "just right" (2011). She designated the following six factors as salient influences on the success of online clinical trial recruitment: 1) the research focuses on a rare disease, 2) the call is issued to a concentrated and organized patient population, 3) there exists patient-initiated research and ownership for success, 4) the site has favorable demographics for patient recruitment, 5) there is widespread positive brand awareness for the institution issuing the call, and 6) there is a lack of geographic restraints. Even with the perfect environment for clinical trial recruitment, Gossen still describes recruitment via social media as an "uphill battle" (Gossen 2011, para 12). While Mayo clinic experienced great successful recruiting for clinical trials, their accomplishment is not indicative of all diseases, health facilities or types of patients. This research study will expand upon Mayo Clinic's work to include perspectives from cancer survivors and their views of clinical trial recruitment and social networking sites.

This study focuses on one cancer survivorship program, the HUGS* program and its efforts to recruit survivors to cancer clinical trials. The purpose of this study is to better understand the role of social media in the recruitment of participants in cancer clinical trials. Specifically, this study seeks to understand cancer survivor usage of Facebook and other online tools with a sample of cancer survivors affiliated with a mid-

* The name of the cancer survivorship program has been changed.

sized Midwestern cancer center survivor program in the United States. The study's objective is to understand patient preferred communication channels, where they seek cancer resources, what computer-mediated tools they prefer and whom they trust when recruited for clinical trials.

Significance of Study

This study is important because 80% of clinical trials fail due to lack of enrollment and recruitment is the number one challenge for research professional (Norris, 2012). With 138,698 clinical trials offered in 2012, there are significant losses associated with an 80% clinical trial failure rate (Number of Registered Studies Over Time, 2013). Additionally, potentially life saving drugs and procedures are at risk with these low enrollments thus potentially reducing the mortality and morbidity rates of cancer patients. The next section describes the HUGS program, and reports data on patient adoption of clinical trials before providing a section on term definitions to establish a clear understanding of terminology.

The HUGS Cancer Survivorship Program

The HUGS Cancer Survivorship program started in 2008 by a medical oncologist at the cancer center who conducted a series of focus groups to reveal the need of such a program. The HUGS program was modeled after the Livestrong survivorship program that works to improve the lives of those who are diagnosed with cancer. The founding oncologist sought insight from literature produced from the Institute of Medicine and National Research Council, entitled, *From Cancer Patient to Cancer Survivor: Lost in Transition* (2006). Now, the HUGS program automatically enters all patients into their database when individuals are diagnosed. Staff sends out newsletters and communicates

online via social media tools such as Facebook and Twitter. Additionally, the program offers workshops and a summer picnic to help educate survivors and provide opportunities to interact. Currently, the HUGS Cancer Survivorship Program's main goals are to connect, educate and empower cancer survivors. A particular concern for the program is the issue of bolstering cancer clinical trial recruitment at the cancer center.

The HUGS program is currently communicating with survivors regularly via newsletters. The program occasionally sends out emails to all who have email addresses in their database and the program has a webpage hosted on the cancer center website. The program hosts educational events with guest speakers who work in a variety of health care professions such as physicians, psychologists or nutritionist.

Clinical Trial Recruitment

The cancer center in this study is part of an integrated health care system that serves nearly 2,000 new cancer patients each year, serving over 70 counties within three states, making it the largest cancer center in the upper Midwest. The cancer center is staffed by twelve medical oncologists, one pediatric oncologist and 113 oncology nurses (HUGS Cancer Survivorship Program Coordinator, Personal Communication, November 4, 2011). The center currently recruits patients for clinical trials via physician contact, signs in waiting rooms and examination rooms and via the center's website. The website also refers interested individuals to the national clinical trial registry (www.clinicaltrials.gov). The website boasts that the facilities offer over 150 open clinical trials opportunities and have 350 ongoing clinical trials (Clinical Trials at Sanford Health, n.d.). The health care facility with its multiple sites has over 1000 physicians representing 70 medical specialty areas over 112 communities within a four-state radius.

This radius encompasses all aspects of the health care facility that participate in clinical trial research. The cancer center leads National Cancer Institute (NCI) as well as other nationally sponsored cooperative group study programs involving both adult and pediatric oncology. The clinical trials conducted within the cancer center are recognized and regulated through NCI. There are also industry-sponsored and physician-investigator drug and device trials conducted throughout the health care facilities' multiple sites. Types of clinical trials include studies to improve standard of care, prevention studies, diagnostic and screening studies and quality of life studies (Clinical Trials at Sanford Health, n.d.). Those who meet the eligibility requirements are able to participate in a study. Eligibility requirements may include age, gender, health and risk factors.

The HUGS program is like many cancer survivorship programs across the nation. Low clinical trial recruitment is not unique to the HUGS program. It is also a problem nation-wide as is evidenced in the literature and the nation-wide statistics that report the same recruitment issues (Norris, 2013).

Weak clinical trial recruitment is a salient issue. Clinical trials are a way for health care providers to gather information pertinent to the medical field about different medical treatments to improve symptoms or the nature of the disease itself (Miller et al., 2011). Without individuals to participate in cancer clinical trials, the number of survivors may decline or the number or there may not be an increase of survivors. The way an individual is recruited for a clinical trial is the ultimate factor in whether or not they will participate. Bolstering the communication channels used for clinical trial recruitment will result in more recruited participants and more clinical trial completions. The way

potential participants prefer to receive communication about important health issues will dictate how they would like to hear about clinical trials.

Clinical trial participation is on the decline; therefore, there has been an influx in research regarding trial recruitment and retention factors (Mills et al., 2006; Sharp et al., 2006). Research has found that distrust, lack of awareness, lack of access and fear were all reasons why people were not participating in clinical trials. At times, patients feared that clinical trials served no purpose to better their cancer treatment and that the standard treatment was sufficient in addressing their treatment needs, therefore, they did not participate (National Cancer Institute, 2001). Patients also cited physician-related factors such as conflict of interest, uncertainty, lack of awareness and resources, lack of available trials and difficulty with logistics (Avis, Smith, Link, Hortobagyi and Rivera, 2006; Fallowfield et al., 1998; Jenkins and Fallowfield, 2000). Yet others cite lack of physician discussion, which results in lower clinical trial participation (Kaas, Hart, & Rutgers, 2005). There are many factors that influence a patient's participation, however the majority of reasons are physician-specific, thus, a focus on patient-provider communication is necessary in order to work to bolster clinical trial recruitment. One way to address this issue is to bolster patient trust.

There can be risks involved with the clinical trials, which makes trusting the individual providing the details of the trial is of utmost importance. Kaas, Hart and Rutgers (2005) suggest that patients trust clinical trial information about recruitment the most when it comes from the their personal physician or nurse. Physicians only take the opportunity 65% of the time to recruit potential trial participants, even further decreasing the chances of cancer patients becoming involved with clinical trials. Hunter et al.'s

(1987) findings suggest that patients may be willing to participate on their own, but some prefer that their physician make the decision before them.

Kaas, Hart, and Rutgers (2005) found that the most clinical trial recruitment success was evident when the doctors and nurses were directly involved with the study and recruited for the study. The successful trial found that the communication skills of the physicians and nurses were the ultimate determinant. Physician commitment to clinical trial accrual was identified as a vital component to clinical trial recruitment. There is a push for clinical trials being incorporated into the standard of care (Maslin-Prothero, 2006). They suggest that only a limited number of physicians and nurses who are involved in research mention clinical trials to patients, but also, clinical trials should be integrated into each appointment and offered to all patients who are eligible.

A physician's role in clinical trial enrollment is indisputable, as previous studies have indicated that a physician's trust is the most determining factor (Kaas, Hart, & Rutgers, 2005; Mills et al., 2006; Yang et al., 2010). Yet, other studies suggest that there are a variety of unpractical factors that influence clinical trial enrollment, more than comprehension of clinical trials information or the clinical trial process. Yang et al. (2010) describes these factors to be general clinical trial beliefs, message cues and effective evaluation of doctor-patient interactions. These factors may have more influence on some individuals than the patient's actual knowledge and understanding of the clinical trials. Today, patients can learn about clinical trials in a variety of ways. The most common way to learn of clinical trials is through one's physician; however, there are online portals designed for patients and providers to log on and learn about available

clinical trials such as the National Cancer Institute, American Cancer Society, University Cancer Center and local clinics and health systems (National Health Institute, 2013).

In addition to communication issues, sometimes the timing of clinical trials can prohibit participation. Often times, people have an interest in a study, but are too preoccupied with their cancer treatment (Reed, Simmonds, & Corner, 2009). Juggling a clinical research trial and cancer treatment was too overwhelming for patients. Some cited that once they were done with treatment, they felt they were able to manage participation in a clinical trial. Using the Internet to learn about clinical trials also offers some practical challenges. The Internet's unregulated nature poses significant threats for the patients and their privacy. Researchers must take extra care to not jeopardize a patient's identity, privacy or health status when using the Internet (Reed, Simmonds, & Corner, 2009).

Chou, Hunt, Beckjord, Moser and Hesse (2009) documented the accrual of participants for a clinical trial on the social networking site, Facebook. The study found, however, that particular generations, especially the younger generations were more apt to join a clinical trial because it was something they saw on Facebook than individuals of older generations. Chou et al. (2009) found that Facebook may have been an appropriate way to appeal to "secondary audiences", a patient's friends and/or family. However, Facebook wasn't appropriate to connect with the "primary audience," cancer patients or survivors themselves.

A recent article in *The Chemotherapy Advisor* focused on oncologists and their social media use, yet did not consider whether or not a patient wanted to use social media (Hughes, 2013). It is clear that social media and medicine is a popular field, yet very few

have focused on the preferences of the patient, especially as it related to clinical trials recruitment. (Dizon, 2012; Thompson, Younges, & Miller, 2012).

The Internet is changing the way the world communicates and interacts. For those experiencing a health event, the Internet is a possible resource option. There are more resources available online each and every day. The number of cancer survivors is also increasing every year, with an estimated 18 million survivors living in America today (Cancer Survivorship Training, 2013). In order to continue to support survivorship, measures such as cancer clinical trial research must be encouraged. Recruiting for clinical trials is a complicated issue and 80% of clinical trials fail to meet their enrollment goals (Norris, 2012). Without adequate recruitment methods and clear communication channels with cancer survivors, clinical trial recruitment and eventually survivorship will suffer. This research study centers on the convergence of these two phenomena.

General Research Questions

The overarching research question this study examines is how do cancer survivors who participate with the HUGS program prefer to receive communication. More specifically, this study seeks to understand cancer survivor preferences for learning about cancer clinical trials and the role of social media in the recruitment process. Subordinately, this project will focus on investigating cancer patients' opinions and attitudes regarding why they do or do not participate in clinical trials, who they trust and how they come to trust individuals who recruit them for clinical trials and, finally, their uses and perceptions of social networking sites. Within the exploration of communication channels, the research will investigate what barriers stand in the patients' way, what bolsters their communication and their observations about communication itself.

Before a review of the literature or a discussion of the method, a working knowledge of the relevant terms and concepts is necessary. Next, terms and concepts relevant to the issue of survivorship, this study and cancer patients will be discussed. In many of the interviews, cancer or cancer survivorship jargon was used. A definition of terms will allow for a more comprehensive understanding of survivorship, clinical trials and cancer treatment.

Definition of Terms

Some terms used throughout this study may be unclear to the reader. Definitions of terms are provided below to facilitate the reader's understanding. Some terms can be understood in a variety of ways and this list clarifies how the study will use these terms throughout the project. A thorough list is provided below.

Cancer Clinical Trial: According to the National Cancer Institute, a clinical trial is A type of research study that tests how well new medical approaches work in people. These studies test new methods of screening, prevention, diagnosis, or treatment of a disease (National Cancer Institute, 2012). There are clinical trials that also test new approaches to reduce or eliminate symptoms related to cancer treatment.

Cancer Journey: A term used to describe an individual's experience with cancer from day of diagnosis to no evidence of disease and full remission. The Oncology Nursing Society (ONS) coined the term and dedicated a website to the concept of a cancer journey (The Cancer Journey, 2013).

Cancer Patients: Traditionally it is an individual who has been diagnosed with cancer and is receiving cancer treatment such as radiation or chemotherapy. It also applies to an

individual who has recently completed surgery to remove the cancer, yet they still must undergo treatment to fully eliminate all of the cancerous cells or tissue.

CaringBridge: CaringBridge is an online health site where individuals can create their own page or for a loved one when they are experiencing a health crisis. This could range from a cancer diagnosis to the birth of a child to a broken leg. This study mentions CaringBridge and asks interview participants about CaringBridge as most have heard or did have a CaringBridge site when they were first diagnosed with cancer. CaringBridge's mission is as follows: "Our mission is to amplify the love, hope, and compassion in the world, making each health journey easier. Our three goals to fulfill the mission are: 1) Serve more people in more ways. 2) Ensure families can connect, share and receive support during any type of health event. 3) Create a grateful, engaged community of volunteers, supporters and donors" (CaringBridge, 2012).

Communication Channels: These are the mediums through which, for the purposes of this study, cancer patients and survivors are communicating. Communication channels include email, phone, face-to-face communication, social networking sites, online chat, online messages (asynchronous), and text messaging.

Computer-Mediated Communication (CMC): CMC is the communicative transaction of two or more networked computers. The communication includes asynchronous discussion forums such as email, blogs, message boards or email-type messaging systems. Also included is synchronous communication or real-time discussions such as those found on social media sites, email sites, or a variety of other social media platforms (Bender, O'Grady & Jadad, 2008). CMC could take place within a social networking site, through email, through an online support group portal. This term refers to asynchronous

and synchronous messages that are supported through computer technology and the Internet.

Computed-Mediated Health Communication (CMHC): This is computer-mediated communication that takes place online, via the Internet, but relates to health communication. This could include health support groups, WebMD, CaringBridge sites, clinical trial websites or any other website or asynchronous or synchronous communication online that pertains to health.

Diagnosis: Diagnosis refers to the professional statement of health given to an individual when they are first notified of their illness. Diagnosis could refer to terminal or temporary illness and is the long-term view of the illness based upon the patient's health history, age, gender and other demographics.

Diagnosed: When an individual refers to the day they were diagnosed, it refers to the appointment when they were first told of their diagnosis. Typically, respondents remembered this moment very well. Diagnosed is a marked moment in a patient's life and their lives are often referred to broken up into "Before I was diagnosed" and "After I was diagnosed".

Internet: The Internet is the web application that allows individuals to access a variety of websites. It is also defined as "an electronic communications network that connects computer networks and organizational computer facilities around the world" (Merriam-Webster, 2013). Mostly, throughout this study, the Internet will be mentioned when talking about support groups or health information found on the Internet, or on the computer-based networking of websites and information.

Facebook: Facebook is an online social networking tool popular among a variety of age

groups. It has been in existence since 2004 and has a membership of over 618 million daily active users (Facebook, 2012). Facebook's mission is, "Facebook's mission is to give people the power to share and make the world more open and connected" (Facebook, 2013).

N.E.D: These are the initials for "No Evidence of Disease". During interviews, patients and survivors would often use N.E.D. as a way to pinpoint their location on the cancer continuum. Throughout interviews, this term was used more often than the more traditional term, "remission".

Online: This refers to something that is hosted through the Internet or another web-based application. To say, for example, the support group was online suggests that the support group was available on the Internet and could only be participated in through the use of a computer and access to the Internet.

Online Cancer Communities: Computer-mediated health communication that takes place for people specifically dealing with cancer (Ginossar, 2008). These are groups that typically support one another going through cancer; the online community is designated to involve those who have been diagnosed with cancer.

Remission: Physicians often refer to this stage when an individual is showing no evidence of the cancer disease for an extended period of time. It varies by physician, but sometimes a physician won't categorize someone as "in remission" unless it has been 3 to 5 years of check ups without any indicated that disease has come back. A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and

symptoms of cancer have disappeared, although cancer still may be in the body (National Cancer Institute, 2012).

Social Media: Social media sites are websites created for social interaction. On these sites, individuals can comment on other people's online posts, chat with people synchronously or asynchronously and share popular national or international trends or headlines. Popular sites include Facebook and Twitter. Social media sites are used interchangeably with social networking sites in this study.

Social Network: This study refers to social networks or social networking as it relates to online use. A social network online is a community of individuals who coalesce around communal interests. This study also refers to social networking sites, which include Facebook or Twitter. Social networking sites are used interchangeably with social media sites in this study.

Survivor: People who have been diagnosed with cancer are now living longer because of medicinal advances in the 20th and 21st century. A survivor is an individual who has undergone cancer treatment and no longer show evidence of the disease in their body. The contemporary definition of survivor is an individual diagnosed with cancer and their friends and family from the day of diagnosis throughout their entire cancer journey (Leigh, Williams & Stoval, 1998; Shapiro et al., 2009). Due to this drastic shift in survivorship discourse, the term and its objectives remain ambiguous and difficult to understand by cancer patients and oncologists alike. This study will refer to those all people who currently have or did have cancer as a "survivor".

Survivorship: Survivorship is a time of transition where priorities and foci shift. Concerns are different for each survivor as their location on the survivorship continuum

is unique to their own journey. It is during this stage of survivorship that there is miscommunication about the values, goals and procedures of survivorship care affecting all survivors as well as all oncology staff. The HUGS Cancer Survivorship Program offers a variety of resources to survivors to assist in their treatment and post-treatment concerns. The most notable resource given to survivors is the Embrace newsletter, a resource that survivors receive automatically, as their diagnosis and subscription to the newsletter are simultaneous.

The part of the cancer continuum beyond “no evidence of disease.” When an individual is deemed a survivor in the more traditional sense (no evidence of disease, remission, after all treatments have been completed), there are many concepts related to survivorship. There are specific topics related to survivorship that cancer patients who are post-treatment can only experience. There are many resources available to those experiencing survivorship and they may include survivorship exercise programs, diets, and suggestions on how to go back to work, dealing with new or different levels or hormones.

Delimitations

This research study is limited in a few ways. First, this research study only worked with one cancer survivorship organization. The study can only report and discuss the implications relevant to this organization at this health care facility. Additionally, this study was limited to only one disease. The study focuses on those who had cancer, not any other illness who may be deemed chronic or terminal.

This study was also limited in its participants. This study was not offered to a younger demographic. Those who participated were required to have been diagnosed

with cancer, but no age parameters were identified. The recruitment tool utilized for study participation required potential participants to self-select themselves for their involvement in the study, therefore the range of volunteers was limited.

Finally, this study was limited in the methodology it utilized. In-depth interviews were the only methods being used to investigate the preferred communication channels of cancer patients and survivors. A triangulated study may have offered different insights into the phenomenon of cancer survivorship.

In this chapter the problem, significance of the problem, rationale for the study and a series of operationalized definition were detailed. Chapter two explores the relevant literature in computer-mediated health communication to illuminate the gaps in our current knowledge before stating research questions. The literature review will uncover gaps in the current literature and end with this study's prominent research questions. Chapter Three defines and defends the use of in-depth interviews for data collection and outlines the data analysis-coding schema. The results of the data analysis are reported in Chapter Four. Finally, discussion of the results and interpretation of the results are presented in Chapter Five.

CHAPTER II

REVIEW OF LITERATURE

This study centers on a cancer survivorship program, the HUGS program, at a mid-sized, mid-western health care facility. The program struggles to effectively recruit participants for clinical trial. Currently, the program uses the social media platform, Facebook, to dissemination information and recruit participants for clinical trials offered at the cancer center, yet adoption of their social media platform has been slow. This literature review examines the HUGS program's areas of concern: computer-mediated communication, computer-mediated communication and illness, computer-mediated communication and health communication, and the use of social media for cancer clinical trial recruitment.

Computer-Mediated Communication and Health Communication

Society will continue to see increased online use (Tredinnick, 2006; Waters, Burnett, Lamm, & Lucas, 2009). There are, however, particular nuances evident when communication occurs online about health or via computers. Computer-mediated health communication will continue to work with a variety of online sites in order to support patient care.

To define computer-mediated communication means to talk about what falls under the CMC umbrella. CMC is the communicative transaction of two or more networked computers. The communication includes asynchronous discussion forums such as email, blogs, message boards or email-type messaging systems. Also included is

synchronous communication or real-time discussions such as those found on social media sites, email sites, or a variety of other social media platforms (Bender, O'Grady and Jadad, 2008). The type of computer-mediated communication an individual uses depends on their anticipated gratifications. A discussion of virtual communities and how they can transform a person's physical body follows.

There are other, more general advantages and disadvantages to computer-mediated communication. Advantages of CMC include being able to communicate with people despite geographical barriers or proximity, the ability to speak to someone synchronously or asynchronously and to engage with individuals with whom one has never had experiences (Caplan, & Turner, 2005). Individuals participating in CMC can choose whom they want to associate with and can leave an online situation whenever they choose. Individuals can also participate from wherever they want, as location is not an issue, simply access to a computer and an online source is the requirement. CMC does not have material limits; there can be unlimited members and groups (Caplan and Turner, 2005; Miller, 2011; Wright & Bell, 2003). CMC can also be a great stress reliever. For example, Albrecht, Burleson and Goldsmith (1994) discovered that individuals who enjoy the advantages of CMC and are satisfied with their experiences will adapt quicker and easier to a stressful situation, thus CMC can assist those who may be experiencing worry during health.

Since older individuals are up against so many challenges, CMC is playing a larger role in their lives. Older adults are encountering challenges such as fixed incomes, relocation, restricted mobility and loss of friendship and family due to illness or death (Wright, 2000). CMC provides 24-hour availability, access to different generations as

well as access to one's own generation and access to a diverse set of information (Adler, 1996; Dickerson, 1995; Noer, 1995, Wright, 2000). All of the advantages of CMC make it very appealing, but there is still evidence to suggest that face-to-face communication is still a trusted and preferred option when it comes communication.

With the introduction of CMC, it was believed that face-to-face communication could disappear (Spender, 1995). There are circumstances, however, within CMC that make face-to-face communication still relevant to individuals for many reasons. First and foremost, access can still be an issue. There are several different types of access (Van Dijk, 2005), but material access is perhaps the biggest barrier to participation in CMC. Individuals may not have a computer or access to an Internet source (Miller, 2011; Caplan and Turner, 2005; Ginossar, 2008; Van Dijk, 2005). Within CMC, there is a lack of non-verbal cues, the inability to keep a consistent group, and lack of physical contact that may result in perceived incomplete or impersonal communicative experiences (Caplan & Turner, 2005; Ginossar, 2008; Sullivan, 2003). Additionally, there is no sense of obligation or cooperativeness with CMC and it can allow people to totally disassociate from reality, resulting in strongly skewed images of reality (Caplan & Turner, 2005; Ginossar, 2008; Miller, 2011; Nayar, 2010). The multiple issues associated with CMC relate to an individual's distorted view of reality or their access to technology.

There seem to be unlimited reasons for individuals to communicate online, however, Armstrong and Hegel (2000) have narrowed down the impetuses to just a few. They describe four types of virtual communities or online spaces where individuals can communicate virtually. The definition of a virtual community is a space taken over by communication technologies that replace the physical spaces associated with people

localizing around a particular cause (Barney, 2004; Miller, 2011). Examples of virtual communities include blogs, online forums, Internet message boards, websites and online chat rooms. These types of virtual communities are centered on transaction, interest, fantasy and relationship. Transaction is a virtual community where individuals are interacting online because they share a common interest and, thus, talk about it online. Fantasy references a virtual community invested in a fantasy, which cannot come true in the reality they live in. Finally, a relationship virtual community is most often associated with online support groups and it refers to a group of people coming together to build relationships with one another in order to find solace, compassion and empathy among those with whom they build relationships (Armstrong and Hegel, 2000). These communities can exist in varied forms, have several ways of luring people online and have multiple benefits.

Virtual communities allow an individual's identity to change. Many believe that having an identity online allows one to disengage from the body in which they live, a notion of disembodiment (Nayar, 2010). Individuals can be disengaged from their physical limitations and being online allows them to totally disregard tangible limitations that they may experience daily. Disembodiment is something that should be celebrated because it allows individuals to transcend geographical and corporeal limitations, making it an augmented body (Rheingold, 1994). Others agree that an online identity can enable an individual to live in a space without boundaries (Turkle, 1995; Rheingold, 1994; Pitts, 2004).

There is an opposing side, however, to the benefits of an online identity. Some believe that disappearing into an online identity is not helpful to the individuals who seek

it. Rather than allowing them to experience disembodiment, by thriving with an online identity, an individual is simply reinforcing their physical limitations (Nayar, 2010). Instead of allowing an individual freedom to participate online, the online identity serves as the reminder that the individual is constricted by physical boundaries outside of their online persona. Despite a minor escape from the problems of reality, their identities are still rooted in their realities and it is unavoidable (Nayar, 2010). Leaving a physical ailment behind is an extremely enticing outlook, yet how does this view differ when individuals are confronted with a health crisis or sensitive health identity and are utilizing the Internet.

With the advent of the Internet, individuals with a disease or rare condition are being drawn to virtual communities. The advantages and disadvantages are many. Yet the idea of identity changes when the Internet is used to talk about health concerns or illness. The concept of identity, particularly for breast-cancer patients illustrates a set of particular challenges. Pitts (2004) and Sandaunet (2007) detail how the emergence of web pages for breast cancer patients are particularly helpful for female patients as they move through their cancer journey. Technology intersects identity and transforms cyberspace into an empowering place. The Internet, particularly, offers a place where corporeal bodies are non-existent and individuals who occupy cyberspace can represent themselves through words, codes, images and symbols (Pitts, 2004). Since the existence of corporeal bodies is not a factor, identities are able to experience greater freedom than before as biological conflicts have disappeared (Caplan, & Turner, 2005; Miller, 2011; Pitts, 2004; Sandaunet, 2007).

This sense of freedom or empowerment has been coined “cyberagency” and carries with it a continuum from skeptics to optimists (Pitts, 2004). Since the physical body cannot be transferred into cyberspace, “cybersubjects” are left to situate themselves as independent from their body, thus, they have the ability to choose what their identity is and how they would like to be addressed (Pitts, 2004). Faith Wilding, a competent feminist scholar (1998), describes one end of that continuum as “net utopianism” which is defined as a free space where gender does not matter and where you can take the shape of an identity regardless of age, sex, race or socio-economic status. There are critics, however, who challenge this notion and suggest that regardless of the freedom the Internet provides, an individual is still connected to their physical body and must attend to the position in which that body puts them in (Miller, 2011; Nayar, 2010). Miller (2011) claims that cyberspace and true biological identities are merging to no longer allow for a break between constructed online identities and biological life. The argument is that people cannot disengage from their corporeal bodies and leave all of that “baggage” in the real world and not incorporate it into their online identities. The feminist concept of identity could benefit or harm a survivor’s concept of his or her own identity when using the Internet.

The discussion regarding empowerment and the Internet is fruitful yet it does not solve every problem. Although the Internet can empower many, it is not inherently empowering and, thus, elements of self-efficacy and motivation emerge as powerful tools that affect the effectiveness of the Internet (Pitts, 2004). Consider Sandaunet’s (2007) research involving breast cancer patients who were participants in an online self-help group. She identified reasons why individuals no longer wanted to participate in the

group and explored those topics further. In her article, she identified five factors that would hinder a breast-cancer patient's participation in an online self-help group. Some of the challenges within the online support group identity with the concept of identity, judgments about online identities and the tension between an online identity and a physical identity. One of the reasons for group withdrawal was the need to avoid painful details about breast cancer. Others included not being "ill enough", finding a legitimate position in the group, organization of everyday life and illness phases that did not motivate others to participate in self-help groups. This echoes Miller (2011) and Nayar's (2010) sentiments that all online interactions are direct results of physical, real-world consequence and that people cannot escape their physical body. Sandaunet (2007) concludes by placing less importance on the role of technology and highlighting people's contingent use based upon their health care needs, and other demographics.

Computer-mediated communication and computer-mediated health communication is multi-faceted. There are several communities with which to associate, multiple advantages and disadvantages and numerous ways to find relief. There are ways that individuals are using computer-mediated communication specifically for health issues and the next section explains these phenomena. The following review of literature highlights how CMC has helped those struggling through illness.

Computer-Mediated Communication and Illness

Within the last 15 years, CMC has created new possibilities for people living with illnesses by allowing them to engage in supportive communication, often with people who are experiencing the same medical issues (Wright, & Bell, 2003). Computer-mediated health communication (CMHC) has expanded to include medical information

sites, sites for health care professionals, support groups for patients, support groups for family or friends of patients and even electronic health records. There are several different relationships evident in health communication where CMC can and does play a role. The most common groups of individuals involved in a health communication situation are: patient-provider, patient-family, family-provider, and provider-provider (Lindlof and Taylor, 2011; Wright, Sparks and O’Hair, 2008). This section of the literature review will focus on the advantages, disadvantages of CMHC as well as describe the social, emotional and information support it offers. Finally, the section will center on the role of CMHC in the lives of friends and family members who are caring for those enduring health crisis.

There are several significant characteristics that make CMC a unique and highly effective solution for people with illnesses. First, as mentioned earlier, CMC can transcend geographical and temporal challenges (Wright, & Bell, 2003). This allows people with debilitating illnesses to log on and chat with a patient or seek medical advice. The second advantageous characteristic is CMHC’s ability for people to disclose stigmatizing health information (Wright, 2000; Wright, 2002). If an illness prohibits someone from seeking medical resources in person, CMC will allow for access to information without fear of marginalization. CMC can also provide better access to diverse health sources, it offers a diversity of supportive relationship and they may find cathartic value in being in control of disclosure in written form (Wright, & Bell, 2003). Patients do not have to obey their health care provider and then do what they are told; health sites online allow for more fluidity. Health information that is available online can allow a patient to look up alternative medicines, read about potential symptoms or seek

support groups for individuals with their same condition.

CMHM also hosts disadvantages. Patients could receive incorrect information regarding their health status, medications or treatments because of the variety of individuals involved with the Internet sites (Glickman, 2011; Reed, Simmonds, & Corner, 2009). Additionally, some individuals do not have access whether it be physical, skill-related, usage-related or simply an issue of motivation (Van Dijk, 2005). There are still critics of the role that the Internet should play in the lives of cancer patients and survivors. Gustafson et al. (2005) note that cancer survivors cannot rely on the Internet alone, there much be long-term vigilance and care implemented for cancer survivors and their friends and families that are supplemented with online CMHC use.

Online support groups are one of the most common types of computer-mediated communication. The amount of online support groups has risen dramatically over the past several years (Caplan and Turner, 2005). Each year online support groups provide new opportunities for patients to communicate with a variety of support systems and different individuals involved in the health profession (Sullivan, 2003). More than 25 million Americans have participated in a support group in their lifetime while 1 million Americans are currently participating (Sullivan, 2003).

Computer-mediated communication offers individuals with a health condition a variety of support. There are a variety of online support groups for people going through a health crisis and their popularity continue to rise because of the amount and type of support they offer (Sullivan, 2003). Online cancer communities have also been studied to find evidence of social support within an online support group (Ginossar, 2008). Previous research confirmed evidence of social support and detailed each type of support type:

informational support (Braithwaite, Waldron & Finn, 1999; White, 2000), emotional support (Braithwaite et al., 1999; Sharf, 1997) and advocacy (Peterson, 1999). The online support groups confirmed concerns regarding some of the aforementioned disadvantages of CMC (Caplan & Turner, 2005; Ginossar, 2008). A variety of social support is further evidence of the benefits of CMC and the comfort it can provide those suffering from a unique health condition.

It is also clear that asynchronous messages providing emotional support are commonly posted online in conjunction with information support (Ginossar, 2008; Heany and Israel, 2008). These findings illustrate that informational support is a crucial part of problem-focused coping throughout online cancer communities. This instrumental support provides tangible aid in the form of taking action by equipping online community members with information related to their cancer concerns. This contradicts previous research that maintained that emotional support is the ideal type of supportive communication (Sullivan, 2003). This is especially encouraging as problem-focused coping is often linked with better health outcomes (Ginossar, 2008). Patients seeking health information using support groups online are finding a variety of support available. Variety in support expands CMHC's reach to more diverse demographics and disease types.

The difference between how patients and their family members think about, receive and respond to care varies greatly. Wright (2002) indicates that patients have higher emotional involvement in online communities than family members; however, Wright does not examine family members and their involvement with online communities. Other research indicates that there is really an overall scarceness of

research about family members who seek information (Northouse, & Northouse, 1997). Some studies posit that family members of cancer patients experience a strong need for information and support as they are interested in patient-focused care and information; however, information is not provided to them first hand nor are they likely to seek additional information from health care providers (Derdiarian, 1989; Northouse & Northouse, 1997; Rees, Bath, & Lloyd-Williams. 1998). Additionally, family and friends also do not want to distract a physician from his or her other patients (Ginossar, 2008). Therefore, it is predicted that family members of cancer patients may turn to computer-mediated communication (CMC) or online cancer communities (OCC) in order to seek the help they were not receiving before as the primary information gatherer (Ginossar, 2008).

Family and friends of patients play a large role in CMHC. Since family and friends feel like they are not receiving adequate information, they are going online to seek additional health-related resources (Hesse, Hanna, Massett & Hesse, 2010; Wright, 2000). Family members appeared to be twice as likely to seek information yet less likely to use online cancer communities like patients in order to exchange information and emotional support (Ginossar, 2008). Overall, family members use online cancer communities to seek information and patients find alternative ways to gather their information. Family and friends are considered “secondary audience” members (Waters et al., 2009). Traditionally, if someone indicated they needed additional informational or emotional support, face-to-face support groups were the recommendation and it was offered through families, friends and individual health professionals (Davison, Pennebaker, & Dickerson, 2000; Deans, Bennett-Emslie, Weir, Smith, & Kaye, 1988;

Sullivan, 2003; Weber, Roberts, & McDougal, 2000). The research to support face-to-face support groups within cancer communities contend that they enhance coping, reduce negative emotional responses to cancer and assist participants in resuming previous life activities (Taylor, Falke, Mazel, & Hilsberg, 1988; Youssef, 1984). Both face-to-face and online support groups have a place in the support group paradigm, when it comes to health concerns; individuals need a variety of support system options.

Recent literature identifies “secondary audiences”, this term includes caregivers, family and friends who may have a better grasp on technology and social media sites. Marketing for “secondary audiences” may have an effect on how individuals use or come into contact with social media or online social support groups (Chou et al., 2009; Ginnsosar, 2008). A focus on “secondary audiences” may lead to a new trend in social media adoption.

Computer-mediated communication is a tool well utilized by those experiencing a health event. Introducing illness makes the advantages and disadvantages of computer-mediated communication more complex. The next section recounts the literature on computer-mediated health communication (CMHC).

Computer-Mediated Communication and Cancer Survivorship

The results are inconclusive as to whether or not CMC will overtake face-to-face support groups as they both offer advantages and both surely have their disadvantages. For many, a social support network that incorporates elements of the traditional, face-to-face contact as well as CMC would be best (Van Dijk, 2005). This section focuses on computer-mediated communication and how it is being used by and developed for cancer survivors. Cancer survivors are a vulnerable group of individuals and therefore, their

utilization of computer-mediated communication are varied even more. This section will provide a brief overview of the elements of computer-mediated communication that should be used in order to successfully support survivors, and how oncologists are using social networking sites to communicate with survivors.

It is important to understand how an online support group measures its success. For cancer care, success is not be measured by financial returns. Success is measured by the opportunity to provide survivors with resources that will accelerate their success and support them if cancer relapses (Hesse et al., 2010). Connecting cancer survivors with appropriate and timely resources is the ultimate goal.

As Gustafson et al. (2005) noted, cancer survivors couldn't rely on the Internet alone, there must be long-term vigilance and care implemented for cancer survivors and their friends and families. The best practices of technology in health care should emphasize user-orientated systems that will enhance a patient's experience, not prohibit patients from realizing their optimal healthcare (Cunningham, 2009; Ginossar, 2008). Cancer patients, who are still receiving treatment, are able to go through their health care providers for first hand, reliable health information. However, once a patient is in full remission, the Internet becomes the survivor's primary resource (Hesse et al., 2010). Other journals indicate that an emphasis on reliability, transparency and accountability are vital in order to improve the coordination of resources among a variety of services and providers (Hesse et al., 2010). Survivorship programs should also be focused on "relationship-based" exchanges versus a more narrowly focused "transaction-based" exchange; this allows for a more fluid and long-term paradigm under which to work with cancer survivors.

Within the arena of computer-mediated communication, social media sites are becoming a useful way to connect with cancer survivors. Large cancer centers throughout the country like M.D. Anderson, Moffitt, Memorial-Sloan Kettering, Vanderbilt-Ingram and the Children's Hospital of Philadelphia have Facebook pages with inclusions for recommendations for treatment, patient comments and cancer news (Dizon, 2012).

Dizon's (2012) work speaks specifically about oncologists and other primary care physicians and their needs and uses for social networking in order to provide the best care to cancer patients. He is quoted in a recent article written for *The Chemotherapy Advisor: Empowering Oncology Professionals*, "Social media can help oncologists focus on the pathways, agents, and targets that are going to be more relevant to the tumor and whatever their patient has" (Hughes, 2013, pg.4). More and more oncologists are using social media to expand their medical knowledge, yet physicians like Dizon have failed to ask if this is where *all* oncology patients feel the most comfortable. The investigation of social media and oncology was concluded by stating "the future will only continue to see an increase in the use of social media for patient engagement, clinical trial recruitment, and professional education" (Hughes, 2013).

Cancer survivorship is a unique location on the cancer continuum. The physical body of a survivor has endured a variety of cancer treatment. The emotional state of the survivors is a mix of joy and fear. Integrating the Internet to support cancer survivors is a valiant effort yet it must be carefully constructed with more traditional communication methods in order to be entirely successful. The next section will discuss social networking as a trend for non-profit organizations and social media platforms as a recruitment tool for clinical trials.

Social Media and Recruitment

Social networking sites are defined as websites that are driven by user participation and user generated content (Tredinnick, 2006). Some examples of popular social networking sites are Facebook, Twitter, Pinterest, Instagram and Tumblr (Pew Internet and American Life Project, 2012). People are going onto social networking sites to connect with peers, locate organizations or programs that interest them or congregate online with those who share similar interests. The age group who uses social networks the most include those aged 18 to 29 years old, as of December 2012, which equates to 83% of Internet users using social networking sites (Pew Internet and American Life Project, 2012). That percentage gradually declines with each age group, 67% of Internet users between the ages of 30 and 49 use social networking, 52% of those ages 50-64 and 32% of those ages 65 and over (Pew Internet and American Life Project, 2012). Even with its varied use among age groups, businesses, non-profits and individuals are using social media daily to connect with others. This section of the literature review will document how non-profit organizations utilize social networking, and how social networking sites have been utilized for clinical trial recruitment. The section will end by addressing the conclusions of previous research done with social networking and clinical trials.

Connecting non-profit organizations and programs such as the HUGS Cancer Survivorship Program and social networking is a new phenomenon (Waters et al., 2009). Organizations are using social media sites such as Facebook as a way to streamline their management functions, interact with potential volunteers and disseminate information about their organization and/or its events. Organizations view social networks as crucial

vehicles for bolstering relationships with a variety of publics (Waters, et al., 2009). The most common use of social networking sites includes posting links to external news items about the organization, its causes, photos, videos or audio files (Carrera et al., 2008). With each post, organizations hope for interaction on their site or interactivity. Interaction on Facebook specifically may include “liking” a post or status (uploading a comment on Facebook as an update on what an individual or organization is currently doing or promoting), commenting on a post or status or “sharing” an organization’s post or status. Interaction or interactivity is vital if organizations want to develop relationships with those who could be stakeholders in their organization (Jo & Kim, 2003). If lack of interactivity occurs on non-health related non-profit organization social media sites, how would the addition of health information impact an organization’s interactivity?

Health care systems are looking to social media tools as part of their comprehensive patient resources and as channels to recruit for clinical trials. Social media sites are promotional sites that allow organizations and businesses to attempt to interact with their target markets, yet there are prohibitive factors. Social media efforts will be most effective when the target population is the younger generation. Those in the older population, of 55 and older, would likely not respond well to networking efforts made online through social media sites (Chou et al., 2009).

The potential influence of social networking sites on the conduct of clinical research trials has been an explored area of research (Glickman, 2011). The Internet is used to help patients connect with relevant clinical trials. While patients are in the clinical trial, social networking sites allow them to remain connected with information regarding their diagnosis or clarification on their condition. The social networking sites Glickman is

referring to, however, are sites where information is specific to the patient, and where they have their own patient portal, not entirely public sites (Glickman, 2011). Glickman's study also highlighted the dangers of social networking sites as a place where health-related information could be easily misinformed due to lack of previous medical knowledge or misinterpretation of medical diagnoses.

Cancer clinical trial recruitment is a fickle task. There are a variety of factors that influence an individual's willingness to participate. Additionally, technology is growing and social media is being utilized as an easily accessible medium for organizations to communicate with large groups of people with similar or diverse interests. Using social media to recruit for clinical trials experienced limited success. The next section will discuss a relevant theoretical approach that has been touted for its use in media use and satisfaction.

Theoretical Approach to Understanding CMC Health Interventions

There have been well-documented instances where survivorship programs or online health support groups have used CMC and CMHC to their advantage and thrived employing the virtues of them. This final section will also offer a theory that will help explain the problems and causes facing the HUGS program.

The theory that best investigates and explains the HUGS program and its problems is Uses and Gratifications Theory (UGT) (Blumler & Katz, 1974). This theory offers a different yet useful perspective on the problem and helps to expound upon this study's research questions. Additionally, this theory has been successfully utilized to explain computer-mediated health communication concepts. Anderson (2011) used the

theory to explain the gratifications earned when authors create and maintain a CaringBridge site for a loved one.

The Uses and Gratifications Theory (UGT) was first used to analyze people's televisions viewing habits, more specifically with political programming (Blumler & Katz, 1974). UGT has since been used with a variety of media types including radio, newspaper, videocassette recordings, cell phones, video games, YouTube, and Facebook. It is a theory that strives to determine why people seek certain media and what needs that media is fulfilling.

The uses and gratifications theory is extremely relevant for the era of the Internet (Ruggiero, 2000). The primary question for UGT is "Why do people use media and what do they use them for" (Ruggiero, 2000). It assumes that the audience is not passive, but rather they are active users and have power over their media consumption and integrating that media into their everyday lives. This theory argues that audience members are responsible for choosing media that meets their needs and desires. UGT contains heuristic value which is vital to communication scholars, to understand the experiences that initiate a media preference.

Katz, Blumler and Gurevitch (1974) outline the assumptions of the UG approach as incorporating "(1) the social and psychological origin of (2) needs, which generate (3) expectations of (4) the mass media or other sources, which lead to (5) differential patterns of media exposure (or engagement in other activities), resulting in (6) need gratifications and (7) other consequences, perhaps mostly unintended ones" (pg.510). The theory suggests that an individuals' motives for media use is impacted by the variety of social and interpersonal factors. This resulted in a variety of studies focusing on demographics

rather than other social and interpersonal factors such as health care or social distance (Anderson, 2011). To focus on health care and social distance offers a different viewpoint as they are characteristics that can change over time, more periodically than gender, age or socioeconomic status. A change in social and interpersonal factors can affect how one uses and is motivated to use media.

Anderson (2011) took UGT further and applied the theory to a computer-mediation health communication context which justifies the theory's use in this study. Anderson (2011) contends that all of the relevant themes found in the Internet studies may not apply to a health situations, but it is likely that some of typologies located in the Internet studies will hold true, for example information-seeking and convenience. Anderson (2011) found that Caring Bridge was a preferred medium during a health care event because it offered various gratifications. The study also found that the online care pages do provide some new media gratifications for Caring Bridge authors and found that spiritual support and emotional support were the two most prominent types of social support. The article also identified 18 other highly valued gratifications from respondents, the most salient gratifications being encouragement from the words or others, cathartic value in writing about difficult situations and providing others with information (Anderson, 2011).

There are also weaknesses to UGT and its use in a health context. It is hard to locate each individual or group and determine why they choose one media type over another. The ability to perceive a group's thoughts on media can mislead or misrepresent groups. Additionally, some criticize the theory for going too far in claiming that people are free to choose their own media sources (Ruggiero, 2000). The theory may not be able

to account for serendipitous moments but is useful in understanding how people use media in order to meet their gratifications. A brief overview of UGT illustrates that the theory can understand the reasons why individuals use media and for what gratifications. The theory cannot, however, apply a mass gratification to a group of people nor can the theory allow for spontaneous moments of media gratifications.

This research study has identified the problem of low clinical trial recruitment, potential causes and its significance. Knowing that the problem is much more complex than low recruitment numbers, this study seeks to answer other questions that include relevant pieces to the overarching question of, “What communication channels do cancer patients and survivors prefer? ”. The more specific questions this research project is investigating are:

RQ1: How are cancer survivors finding cancer resources?

RQ2: What computer-mediated communication tools are survivors using to communicate?

RQ3: Who do cancer survivors trust the most to educate and recruit them for available clinical trials?

The literature outlined computer-mediated communication, computer-mediated health communication, computer-mediated communication and cancer survivorship, and social media clinical trial recruitment strategies. Chapter Three details the method used to carry out the research project. A presentation of data will follow in Chapter Four, Chapter Five includes a discussion of the data and finally, Chapter Six discusses the researcher’s implications and area for future research.

CHAPTER III

METHODOLOGY

This study examines the effectiveness of communication channels within HUGS. This study used in-depth interviews with cancer survivors to better understand the ways the HUGS programs can bolster their communication, their resource dissemination and their recruitment for clinical trials.

Health issues are intimate thus in-depth interviews were found to be the most appropriate method to utilize for this study. This method allowed for rich, detailed responses from a variety of cancer patients throughout different stages of cancer care (Lindlof & Taylor, 2011). This method also allows for serendipitous moments that could not have been gathered without detailed, in-depth, focused and personal investigation (Creswell, 2009; Lindlof & Taylor, 2011). The next section describes the participants.

Participants

Criterion for the sample was any individual who currently has or at one time did have cancer. There were no requirements on tumor type, length of time with disease or without disease, gender, age or experience with the program. An email was sent out to all potential participants in the HUGS email database. The database consisted of any cancer survivor who either a) underwent their treatment at the affiliated cancer center or b) sought the program out and indicated their interest. The database is updated monthly and includes individuals who were diagnosed within the past month to individuals who have

been living in remission for decades. Nineteen of the 20 interviewed participants were female, the age range of the sample varied from mid-30s to late 60s.

The HUGS Cancer Survivorship Program coordinator sent out an email blast to 479 cancer survivors in the HUGS database. The Health Insurance Portability and Accountability Act (HIPAA) of 1966 prohibited the release of patient contact information to the principal investigator, therefore, the HUGS coordinator had to make the first contact. Some of HUGS' members do not provide the coordinator with email addresses, so those who included their email as part of their HUGS contact information were contacted. The email explained the focus of the study and asked interested participants to contact the primary researcher by phone or email (See Appendix D for email script). The email blast requested that survivors contact the primary researcher indicating their interest in participating, thus the sample was also self-selecting.

Twenty-one individuals contacted the researcher, but only 20 individuals followed through to set up a time and place to meet. The 20 individuals who responded were all considered to show no evidence of disease (N.E.D.). A purposive, self-selecting sample of cancer survivors was used. This sample is justified because the depth of each interview is more valuable than the randomization of the sample (Saldana, 2009).

Over several weeks, appointments were made with the 20 participants. Each interview participant determined the location of the interview. Interview participants were not compensated for their time; rather, participants were told that their interviews contributed to the improvement of communication dissemination methods for the HUGS Cancer Survivorship Program and the participation in cancer clinical trials.

Instrumentation

Interviewees were asked between 15 and 20 interview questions. Uses and Gratification Theory and Diffusion of Innovations theory were employed to assist in the line of questioning. The principal investigator edited the interview questions thoroughly after seeking input from a panel of scholars familiar with research methods and health communication.

Interview questions related to each of the main topics of the study's research questions. Questions were asked regarding clinical trial participation, who was trusted to give information about clinical trials, how an individual preferred to communicate about health issues and about their experience was with social networking sites such as Facebook and CaringBridge. Finally, there was a closing question in which participants were asked to comment on any additional communication needs they had as a survivor that they would like addressed (See Appendix F for Interview Questions).

Procedures

This study required Institutional Review Board (IRB) approval by two institutions: the health care facility and the university. The IRBs at a mid-sized, mid-western university and at the health care organization found that this research project involved minimal risk for research subjects and IRB approval was granted by both organizations. The study also received a letter of support from the HUGS program coordinator and founder to conduct research with the program. (See Appendix A and B for IRB approvals and Appendix C for Letter of Support).

The interviews lasted between 25 and 75 minutes and they were recorded to maintain accuracy as recommended from previous qualitative scholars (Whyte, 1984).

The researcher was equipped with the contact information of an emotional support professional in the event of a participant's traumatic disclosure. Interviews were transcribed immediately following the interview and once accurate transcription was accomplished, the audio recordings were erased from the researcher's computer. The researcher's computer was password-protected in order to ensure complete confidentiality and anonymity. Any participant identifiers were coded on the researcher's computer within the transcriptions to ensure complete anonymity and total confidentiality.

All interviews were recorded upon consent of the interviewee. Additionally, informed consent was obtained from all participants. A waiver was submitted with both IRBs so that participants did not sign an informed consent form, further ensuring anonymity. They were given an Informed Consent form to take home and they understood that their participation in the interview was their consent. They were told that they could stop the interview at any time and that after the interview, they could contact the primary investigator to withdrawal their interview from the study. (See Appendix E).

After the interview was completed, participants were free to leave. Participants were emailed three to seven days after the interview to thank them for their participation. No additional follow up sessions were conducted.

After each interview, the researcher took time to write reflections on the interviews and emergent themes that built upon previous interviews or literature. The interviews were transcribed immediately following the interviews and the audio recordings were erased from the computer as soon as accurate transcription could be confirmed. As the interviews were being transcribed, relevant quotes that reflected

powerful sentiment were compiled. As themes began to emerge, significant passages that echoed emergent themes were compiled as well.

In addition to the in-depth interview, the researcher kept detailed notes. As the interviewer asked questions regarding the participants experience with communication channels, clinical trial recruitments and social networking, the researcher also took detailed notes. The researcher took diligent notes detailing the respondents' attitudes, changes in mood or behavior, reactions to particular questions and other miscellaneous observations during the interviews on the interview question form (Saldana, 2009). These notes were used to analyze the authentic human responses of the survivors and these notes were analyzed in addition to audio transcriptions (Saldana, 2009). The researcher also employed pre-coding techniques to highlight rich or powerful participants quotes or passages. After the completion of each interview, the researcher typed up additional notes or immediate reactions to the interview that had just taken place. This compilation of transcriptions of interviews and interviewer notes provided an extremely rich data set from which to contextualize the data (Saldana, 2009).

Data Analysis

Transcription for each interview took between three and four hours and relevant quotes were documented as they were transcribed. A second researcher was involved for data analysis after accurate transcribing and the field notes were coded. Interview responses were organized in a table on Microsoft Word by question number and each participant. Relevant themes were discovered after thorough discussions of interview questions and its responses.

Thematic analysis was used to evaluate each interviewee's response to each interview question individually. The two researchers spent time with the table coding descriptively and hierarchically. Saldana (2009) recommends utilizing descriptive coding when the data addresses structures or processes. Key words and phrases were pulled together to form themes, according to Owen (1984), which resulted in three or more instances of the same or similar sentiment. Each participant's question to each answer was coded. After each researcher coded a question, the codes were checked utilizing the constant comparison method (Glaser & Strauss, 1967). Once an agreement as to the most prominent and recurring elements of each question was decided, the researchers methodically moved on to the next question.

The next chapter documents the answers from each interview question. Chapter Four offers a systematic review of all interview answers with descriptive quotes from participants that further explain their feelings, perceptions and attitudes. Chapter Five dissects the answers to the interview questions.

CHAPTER IV

RESULTS

Interviews were conducted during the months of February and early March in 2013. The interviews resulted in over 18 hours of audio recordings and over 150 pages of interview transcriptions. Additionally, interview notes were compiled throughout the interviews and after each interview as part of reflection; these notes were compiled into over 40 additional pages of notes, commentary and reflections. Nineteen of the twenty interviewed participants were female, the age range of the sample varied from mid-30s to late 60s.

The remainder of Chapter Four documents the responses from the 20 interviewees. This section explains the findings from each interview question. Employing Owens' (1984) concept of identifying themes based upon recurrence, repetition and forcefulness and Saldana's (2009) manual for coding, several relevant themes and categories were identified. A schema of descriptive coding and hierarchical coding was deemed appropriate. Descriptive coding identified key participant passages that emphasized topics or areas of concern. Emergent themes and research questions will be discussed in Chapter Five. Chapter Five will also draw parallels from relevant communication theory to explain emerging phenomena. The first two interview questions accurately obtained demographic information from participants and identified each individual's involvement with the HUGS program. The remainder of the interview questions focused on cancer resources, clinical trials and social networking sites.

Question 1: Where are you currently in your cancer journey?

All of the 20 individuals who participated were considered N.E.D. (no evidence of disease) for varying amounts of time, ranging from six months to over 38 years. Interviewees had varied tumor types and length of evidence of disease yet none of the participants were receiving cancer treatment. One respondent had endured cancer treatment and successfully entered remission on four separate occasions. Fourteen of the participants were diagnosed with breast cancer, three with ovarian cancer, one was diagnosed with melanoma, one with tonsil cancer and finally, one was diagnosed with a type of blood cancer, multi-myeloma. They were seeing an oncologist anywhere from every three months to every year, while two respondents no longer saw an oncologist on a regular basis. Additionally, each interview participant had a different stage of cancer and underwent varying cancer treatments to eliminate the disease. The treatments varied from only surgery, only chemotherapy, only radiation or a combination of any of the three. Additionally, some experiences involved reconstructive surgery for those women who opted double mastectomies as part of their cancer treatment.

Question 2: How did you become involved with or find out about the HUGS program?

All participants had knowledge of the HUGS program although four interview participants did not receive their treatment from the cancer center affiliated with the program. The majority of respondents became involved with the HUGS program through interpersonal communication. This may have included a cancer center volunteer, a nurse, an allied health care professional, or traditional media such as mail or signs posted in the cancer center. Predominantly, however, respondents were finding out about the HUGS program through their health care provider: their oncologist (n=13).

Question 3: What do you know about the HUGS Program?

Respondents knew a wide variety of information. Some people had only joined because they happened to mention he or she were a cancer survivor whereas others were founding members who knew the staff well. Only one person mentioned the term “survivorship” to describe the program. Most others identified education and support as primary functions of the HUGS program (n=5). Many identified the program with its programs or events it hosted; an aspect of the program mentioned 12 times. The programs identified were the HUGS annual picnic, luncheon education sessions, daylong conferences or a “Look Good, Feel Better” program. A few individuals mentioned that they “didn’t really know” what the program was meant to do (n=2). “I couldn’t tell you. I know they try to keep you informed of community things, but I honestly don’t really know a lot about the program.” Finally, others mentioned their understanding of the program as it related to an individual’s cancer timeline. This association of the program with a timeframe, especially after cancer treatment, is evident in the following quote from one respondent:

Well I think from, it’s I suppose I should do more research on it too, it’s for, for me it’s more like aftercare, maybe and I don’t know that that’s, I’m not sure what they do while you’re in the treatment process, um, I guess that part I think when you’re in treatment, that’s all you can focus on, you know at that time, um, but that’s my understanding, it’s kind of resources there for after you’re done because when you’re done, I mentioned that to one of the nurses too when I was getting close with being done like with radiation, you’re almost scared because you’ve done something for 6 months, you’ve been on a daily schedule or you’ve done treatment and then all of the sudden when you know it’s coming to an end, then what? Then you almost feel like you’re, there you are, you know. Fend for yourself.

Question 4: Where are you currently finding cancer resources? (Has the location changed? Where have you in the past?)

The responses mentioned 15 various places where they are finding cancer resources. Overwhelmingly, resources were being sought and found from four distinct places. Additionally, there were three primary forms of support resources being sought: informational, emotional and advocacy support. Within each resource type were specific gratifications being fulfilled and resource types varied depending on the gratification being met.

The first location consistently reported was through an individual's physician. Respondents cited that they went to their oncologist first if they had questions regarding their cancer, diagnosis, treatment options or side effects. This was primarily for information seeking. In fact, here is the response from one interviewee, "um, I don't know, I guess I never thought of anyone else giving me information."

Quotations from two different respondents will provide a more thorough description of the physician as an informational resource.

No. And I guess maybe I'm, maybe somewhat different than some people, I know, I know a lot of people question the hospital or the physician, do I need this drug, I just walk in and say, give me what I need. And, you know, I trust in their expertise to do that. I like to think that when I'm doing what I do for my work, people trust in my expertise and don't second guess everything, I've always had my physician give me the options if there are any, you can do 'a' or you can do 'b'. And, you know, sometimes I ask, well, what do you recommend?

A second type of resource described was an emotional resource. Participants found that physicians were their primary informational resource, yet for emotional resources, they turned to their interpersonal relationships and relied on interpersonal support. Participants did not vocalize the difference among resource and support type, but it became evident throughout participants' responses. To illustrate a reliance on interpersonal communication with family and friends, one participant stated.

I knew one of the things to do was, I put together a team. And my team consisted of, my parish nurse, my cousin who was, is a nurse practitioner but not in that area, I wanted people that would understand the lingo if I had questions. Then I contacted some of my friends to see, two of my friends, to see if they knew of anybody that had cancer and they put me in touch, each of them, with a friend, one that had the cancer I did and one with breast cancer. And then, I have another friend who had gone through breast cancer. So I kind of put that team together. I would say 3 friends who knew somebody and then one friend that had breast cancer. I would say they were kind of like my support group, ah, two, the cancer survivors, they said here is the soap you should be using, ask your doctor about, you should talk to your dentist 'cuz we use different things, like the other side of treatment. So they gave me a care sheet, a checklist, the one lady gave me a checklist of care things to ask about.

The third place most often cited as a cancer resource location was the Internet (n=8). Those who cited the Internet enjoyed their ability to locate resources specific to their tumor type. Specifically, interviewees were locating information on credible local, national or international cancer websites- websites specific to their tumor type. One participant mentioned "Google," the search engine, as a way to obtain information. Using the Internet was a way for participants to locate informational resources as well as advocacy support. Those who used the Internet to locate websites or aspects of websites specific to their tumor type were seeking experiences from survivors who could verify a cancer experience with that specific tumor type. Being able to learn of their own disease and learn the experiences of others allowed them to gather information about their tumor type and play an active role in its management. One participant said:

Um, well when I was diagnosed, I did a lot of online stuff, I mean I was like, grasping for every bit of information that I could, along with my care team, all of the people that were taking care of me, you know at [REDACTED], they have great work, I actually doctor at [REDACTED], but I canceled, [REDACTED] has a great, [REDACTED] is a great program and they just have like a whole set of doctors that would talk to me so that helped. Now, I don't think there is, I don't know, I don't really, I suppose if I want to know anything, I'd look up online or I'd ask at a doctor's appointment. I haven't really joined any groups or anything like that.

Another participant said:

I also went onto a website that you have to be invited on or you can't get on and it's people with just breast cancer from all over the world. And I ask about any triple negative, I'm giving a holler out or do we have triple negatives out there and then they'd all holler back, so then we'd talk back and forth, so that was nice.

The Internet and other resources can be too overwhelming when someone is first diagnosed; this is where the fourth resource type emerged. The fourth area where respondents were finding cancer resources was not a place at all. A quarter of participants cited their need to avoid communication once diagnosed with cancer (n=5). Phrases such as “stay away,” “stopped,” “didn't want to know,” “didn't go online” and “didn't seek” were all emergent sentiments throughout the interviews. In a sense, this cancer resource was a form of emotional support. For their emotional wellness, they avoided communication and cancer resources in order to maintain a controlled outlook on their cancer diagnosis. Here's a clearer understanding of this need to not seek from three different participants. One said:

I'll be very frank here. I didn't investigate anything. I didn't. I didn't want to learn more, I didn't want to give it any energy, so I didn't read about it, I didn't study it. Because I thought the more focus I'd give it, the worse that would be for me. So, quite frankly, I haven't investigated resources at [REDACTED]. [REDACTED] had a, an entire library, um, devoted to cancer resources and references and I walked in there one time during my first days there when I was diagnosed and that was the first and last time I ever went in there, so I, I don't go online. I just don't do that.

Another stated:

Ignorance is bliss, you don't want to go online and see what and I don't want to see this cheery, I survived and blah blah blah.

Yet another commented:

And knowledge is power to me and I have to have that knowledge from a doctor 'cuz like you can't trust the Internet with somebody going on and you know, saying da da da da and it's not true, so during my treatment, um, there wasn't a lot of communication.

And finally, a participant noted:

I didn't want reminders that I was sick, because I never felt sick, and, so I'd get 'get well' cards and I'd throw them away right away. I just didn't want anything, you know some people saved them or wrote in a journal. Someone gave me a beautiful journal, now I wish I would've because it turned out to be so positive. But at the time, it was like I didn't want any reminders that I was sick 'cuz I didn't feel sick. So that was kind of my way of dealing with it. I'd get a 'get well' card and I'd throw it in the garbage right away. And, um, you know or delete messages right away about my cancer and it wasn't, I wasn't mad or anything, but I thought I never want memories of this.

Finally, the Internet played yet another role in the lives of cancer survivors when it came to cancer resources. Two respondents shared their desire to use the Internet, but when they used it, the result was unexpected. Respondents mentioned stories of the Internet "back-firing" on them as a cancer resource. Another individual found that the Internet was not suitable for all of their cancer resource needs. One participant stated:

When I was first diagnosed, I was on the internet a little bit more like the [redacted] clinic website and then I had a, you know the information there is actually kind of scary because I was the early stage and usually with ovarian cancer, you are like late stage when they diagnose it, so everything was like pretty grim and oh, you know you don't usually, only 10% make it 5 years and blah blah blah. So I kind of had a meltdown one day and then my husband came home and he said, I think you should just stop going on the Internet, what do you want all that information for? I said, you're exactly right. It's just bad news. So, I stopped. I did.

Another participated said:

I felt like I was receiving everything. Um, but it was also overwhelming to go in and scary. I, um, when I got my first four treatments, I didn't go online and look at anything. And then I thought, oh, the second four are supposed to be easier, I'm gonna go online and kind of look to see what I'm expecting. The first four treatments were so mind-numbing anyway

that it was like all I could do was go to work and try to go home. That was all I could do. And, so I went online and it was like, OHHHHHHH, all the side effects and I thought, oh my god, this is ridiculous and it was my, I mean the last four were the easiest, so I just didn't, I just took it as it came.

There are a variety of cancer resources that participants mentioned throughout question four. The most prominent answers each provided a different support type to the survivor. A physician offered informational support. Family and friends offered an emotional support system while the Internet provided information and an advocacy outlet for many survivors. With a plethora of cancer resources at their fingertips, a quarter of respondents said they avoided all communication. Those who mentioned communication avoidance revealed their ability to control cancer resource content when they avoided communication. Avoidance of communication is best identified as an emotional support tool to bolster their emotional and mental wellness. Augmenting their emotional and mental health meant selectively associating themselves with only the resources they deemed appropriate.

Question 5: How often do you receive communication from the cancer center or HUGS? If and when you do hear from them, how do they get in touch with you?

Interview participants said that they received information from the HUGS program at a frequency of monthly to quarterly to every six months (n=11). Some participants also cited infrequent communication with the program and the cancer center (n=3). Additionally, the majority of individuals said the only communication they received from the program was the program's newsletter that they received by traditional mail (n=11). One respondent commented on the newsletter's frequency, "I don't even know how often..."

In regards to the cancer center, all respondents said they only hear from the cancer center when they have an upcoming appointment. Participants indicated that the cancer center has recently started an online portal where patients could locate their bill, their appointment history and any upcoming appointments.

Question 6: In your personal life, what types of communication do you use?

There were five communication mediums that interview respondents reported using the most: email, texting, traditional mail, phone and other traditional methods such as news, radio and interpersonal. Email was the primary and mostly preferred way to communicate (n=8). Also mentioned were texting, phone and mail. One participant stated, “I do email the majority of the time. I prefer just to, you know, of course, one email, well people can do it at their convenience, when they have time, they look at it, um, not a big phone person, mail I’ll look at, you know, but, prefer email.”

Other communication mediums mentioned were face-to-face, television news, radio, letter writing and one respondent mentioned CaringBridge. One’s preference for more traditional communication methods was evidenced here, “I am also a writer, I write letters, I write cards, you know I still believe in getting something handwritten in the mail. Love that. Love getting it, love sending it.”

Additionally, three respondents made concerted efforts to mention their dislike for certain communication methods. Respondents discussed that they “don’t do Facebook,” “don’t look at email very much” and “have Facebook but don’t do it.” The question specifically asked about what types of communication the cancer survivors use, therefore, special mention of communication channels that they do not use was deemed worthy of

notation. Here's one participant's response, "I don't do things like Facebook or web stuff very much, I don't like that. I don't Facebook."

Question 7: Do you ever hear about clinical trials?

This closed-ended question resulted in half of respondents saying they hear of clinical trials (n=10). Respondents elaborated on the question to describe where they hear about clinical trials. The primary places where survivors are noticing mention of clinical trials are from their physician (n=7), via traditional mail (n=4), at doctor's appointments (n=1), on the radio (n=3) or on televised news (n=2). The majority of respondents said they hear of clinical trials in a health care setting (n=8). Here is one participant's description of where he or she finds clinical trial opportunities.

You know when I'm sitting in the office I can see them listed or you know they sometimes say, if you have, there's a clinical or whatever, I mean, sometimes I'll see that. Sometimes I'll hear about them on TV, you know you hear some that they talk about, but, I figured if it was something they wanted me to do or knew that I could be a part of then they'd tell me. So I didn't, I didn't bother to check on others.

Question 8: How do you or would you decide on one cancer treatment clinical trial over another?

Cancer survivors offered a plethora of factors that would help them decide on one clinical trial over another. These factors included physician certified or with physician's approval, side effects, adding to cancer research/cancer sciences or required minimal or appropriate work or effort to participate. The majority response was that of altruism (n=5). Specifically, whether or not the clinical trial could potentially save the life of another later on, "It just, um, I guess I didn't hesitate just because I thought if it was something that's gonna help somebody else, you know, I was all for it." Another quote emphasized altruism:

The reason that I said yes to this one was 'cuz it was new, something that they were trying 'cuz, it involved cancer and I thought by me having cancer if I could be of some help of, you know, with this trial. That's how you get to miracles and stuff, you know.

Another participant stated:

I'm more than happy to do one, but I would be a little leery if I was putting something in my body and I didn't know the long term effects or if it wasn't there to be saving my life or possibly saving somebody else's in the long term.

There were additional reasons for participating in a clinical trial. They included convenience, eligibility, specificity to tumor type and a thorough understanding of all potential issues or elements. Finally, there was mention of only participating in a clinical trial as a "last ditch effort." Below are quotes pertaining to these reasons. One participant stated:

Yes. If you have stage 4 or something and you have no other options then you've got to try anything. If you have, you know, the side effects aren't going to make you miserable because your quality of life has got to be important too, not just the quantity. If you are going to live 3 months and be puking your guts out everyday, no, then I wouldn't do something, but if, because I'd rather enjoy what I have then, you know, so, well try this, well if may help you, it may not, but you'll be sick as a dog. No, thank you.

Another respondent said:

If I think, I think is, the only way I would probably ever participate in one was if I had some ailment that I couldn't find relief from then I might try a clinical trial just to see if there's something else out there that, you don't know about you know what I mean.

Finally, a respondent concluded:

I guess it would depend. I mean most of the time when I've seen clinical trials or me, myself or my mother died of cancer also or are patients, I mean clinical trials is usually the, a lot of times what I see is the last ditch effort, so if I was on a last ditch effort, and probably going to die no matter what, you know, I wouldn't be opposed to it, you know, if it could help others at that point. So otherwise I guess if a physician who I trusted

recommended that I try a clinical trial whether or not I'm in the terminal stages of an illness or not, I mean if I trusted them, I'd probably do it

Question 9: Have you ever participated in a clinical trial? If do, how did you find out about it?

Many respondents had participated in a trial (n=12), while eight participants had not. Those who had not participated in a clinical trial cited two reasons as to why they did not. Participants said that they often saw the signs to participate in a trial but forget to ask their physician or did not trust the clinical trial being offered. Here is a response from an individual who did not participate in a clinical trial:

No. I know I see the signs and I think that's something I'm gonna ask when I go in, but I forget to ask her, um, I always thought my doctor might suggest something like that, but it might've been the way my treatment was and my kind of cancer too. But, that is something I would like to do, if I can.

Second, the data revealed that respondents learned of clinical trial opportunities in a few ways, but primarily from their oncologist. Of the 12 who participated in a trial, seven of them learned of clinical trials from their health care provider, more specifically, their oncologist. Other recruitment mediums included a clinical coordinator and a card or sign in the cancer center waiting room.

To better understand the prominent influence of oncologists of clinical trial recruitment, some passages from respondents are listed below. One participant stated:

Actually, the researchers basically had like a mass emails out to all of the oncologists that they were looking for certain candidates with this type of breast cancer and, so, my oncologist actually, told the researchers about me and they then contacted me. A research nurse contacted me and said that Dr. [REDACTED] had referred my type of breast cancer to them and so they said that I was a good candidate for this research.

Another participant said:

Ok. I think I have really only been offered that one and it was very specific to an issue that drives me crazy and that's hot flashes. And she knew that, she knew that, I mean if there's one thing I complain about it's that I'm sick of having hot flashes and so when that trial came up, she of course told me about it right away. Um, so, really, I think I'm pretty certain that is the only one she offered me.

Question 10: Who do you or would you trust the most to give you information regarding clinical trials, aside from your physician?

Although this question specifically asked for other trusted individuals *aside* from a physician, the answers still resulted in an oncologist would be trusted to give clinical trial information (n=4). For example, "If it didn't come from my doctor, I probably wouldn't do it." Another respondent stated, "Basically I put all of my trust into my physician and my nurses. And I would do it again tomorrow. You know, I felt that they had my best interest at heart." Aside from physicians, respondents cited the hospital, cancer center, medical field or nurses as the most trusted individuals. One participant responded:

Well, I just trusted the hospital in general, not only the physician, but the nurses and I think I keep calling them the educational coordinator or whatever their title is for that. And they provided me with a lot of literature and did a little bit of online looking, but I don't trust everything online.

Another participant stated:

I would've trusted the PAs [physician's assistant], any of my team members, you know the physician's assistant or um, the radiologist, oncologist, radiology oncologist, um, even if any of the nurses would've suggested something because you kind of become close to all of them and they know you and you know I think I would've trusted any of them, um, I guess really I'm pretty trust worthy, I'd really want to know probably more from my medical team just because they know me and know what I've been through. I would trust them more.

Second to those in the medical field, participants said that individuals who had previous clinical trial experience would be trusted to recruit them for clinical trials. For example, “Oh, besides my physician. I would see if there was anybody else out there that has gone through clinical trials. Other patients.” Again, emphasizing interpersonal communication.

Finally, participants noted the importance of trust between participant and physician. This individual’s claim that even though an oncologist may tell you about your suggested health route, they must still gain their trust. The interpretation of trust with a physician is listed here:

Well, I think previous history, I mean, um, trust is built with a physician, so if I felt like he’s been open, honest, giving me the information I need, guiding me through my physician when I was diagnosed, I can’t remember what I needed to make a decision about, something about surgery or something else and he said, um, if it were me, this is what I would do. He and I were probably close to the same age and so, I just, you know, that meant a lot, I mean, so...and then that I, I had two really great physicians at the time and both of them just, I really felt that instant that they had my best interests and were not just listening to, ok, here and that’s it, you know where they actually did care about and you know the decisions they made then from then on out determined whether or not I would live or die, so I mean, it’s, I guess it’s just something that’s either there with a physician or not, in my experience, or most health care provider in general for that matter.

Question 11: How would you prefer to receive information from the HUGS program or the cancer center about clinical trials?

There were three primary preferences on how participants would like to hear about available clinical trials: email, phone or via interpersonal communication. Many respondents replied that email notification about upcoming clinical trial opportunities would fit their lifestyles best (n=7). Second to email communication was a phone call because of the individualization that a phone call offered (n=5). Additionally, one person

said they'd only like to hear of a clinical trial during face-to-face communication.

Another individual mentioned Facebook as a viable option and one individual made an effort to say that via the HUGS newsletter would not be appropriate.

I would hope that, again, I would hope the medical team would tell me or even the people that are responsible for this clinical trial that I'm doing. Um, if they knew about something and they know why or when I would want to do it, I would trust, I would think they would could tell me and I would be, you know I would listen to them also. But from outside of that, the newspaper, HUGS, I don't know that I would even do it, if I was interested, I might ask the doctor about it, but, um, I wouldn't just do one just to do one.

Question 12: Do you have a Facebook page? If so, why did you sign up for the page and how often do you log on?

The majority of participants had a Facebook page (n=14). Of those who have a Facebook page, half were logging on daily (n=7). Other respondents logged onto Facebook a few times monthly, every 2 or 3 months or every 6 months. When it came to pinpoint the impetus for joining the social media site, there were a variety of answers. The most common answer was "to keep in touch" (n=9). Respondents detailed their joy in viewing pictures of their Facebook "friends" and their families. Almost all respondents had a story about how the social media giant brought together family members who lived far away. In addition to a communication channel, the reason for joining was also attributed to participants' children who created an online profile for their parents (n=3). The primary reason for joining Facebook can be best summarized as follows, "Well I mean most of Facebook is just kind of to stay in touch with old friends, families, people that you just don't communicate with on a daily or see on a day to day basis."

There were also individuals who did not have Facebook pages (n=6). Those individuals cited their reason for not joining as a way to keep their privacy. Others disliked the social media site because it was “too public”. One participant stated:

My privacy. I’ve got enough stuff to take care of, I don’t want to be taking care of a Facebook and I don’t Twitter and I don’t have, someone in technology, I don’t Twitter, I don’t have an iPhone, we have iPads here at work, but basically it’s like there is so much technology out there, you gotta keep everything.

Question 13: Do you disclose your health status on Facebook? Why or why not?

The issue of disclosing a health status on Facebook garnered an assortment of responses. A little more than half of respondents said, “no” (n=11), they would not disclose a health status on Facebook. The most reported reason for not disclosing a health status was “personal business” or “privacy”. An interesting element to this discussion is the idea that respondents vehemently said, “no”, they would not disclose health information on Facebook, yet they cited a unique position about why they joined Facebook in the first place. These quotes will better explain: “No. I’ve never. I disclose very little personal information on Facebook. Once in a great while, a picture of some trip or something, I’m on there to look at other people’s. Really I am.” and “No. I never wrote anything on there, I was a snoopy one, I just wanted to look.”

Conversely, those who did disclose health information on Facebook reported several reasons why they thought it appropriate to disclose health information (n=7). Equally significant was the idea that respondents were, “open about life” as well as proud of their health milestones and encouraging of health promotions. It was common for respondents to say that they only posted health statuses online when it pertained to an upcoming health milestone, for example, one year without cancer, five years free of

breast cancer or to commemorate the date of a reconstructive surgery (n=2). Finally, interviewees would post health-related information on their Facebook pages if it pertained to cancer awareness, for example, Breast Cancer Awareness Month (n=2). A final reason for disclosing health statuses on Facebook was “to communicate with people wanting to know [about cancer journey]”. One participant responded:

Why I disclosed information? Um, just because I had a lot of friends that don't live around here, so I think we're so into this computer technology stuff versus picking up the phone and calling people that and plus you know because you have so many people wanting to know as far as what's going on and are you 'ok' and this that it's easier to just post something on Facebook so everybody can see it so you don't have to repeat yourself a thousand times.

Another respondent notes:

Oh, I think I did something about when it was my last day of chemotherapy. The boys always posted stuff about, please pray for my mom, things like that and then people would reply, 'You're in our prayers.' on FB because I didn't have a CaringBridge page. And, no, at the time, it's like, I didn't want reminders that I was sick, because I never felt sick, and, so I'd get 'Get Well' cards and I'd throw them away right away. I just didn't want anything.

Question 14: Do you have family or friends on Facebook? If so, why did they sign up and how often do they log on to Facebook?

Similar to survivors' personal motivation to join Facebook, respondents' families and friends were speculated to join in order to “keep in touch” or “socialize” with others (n=16). Participants mentioned that they all knew people who logged onto the social media site daily.

Every respondent indicated that they had friends or family members who had a Facebook page (n=20). The second most cited reason for creating a Facebook page was to look at pictures (n=6). Regardless of respondents' own relationship with the social

media tool, they all knew of friends or family members who utilized the technology often.

Question 15: Do your family or friends “like” HUGS on Facebook?

This question was answered with a resounding, “no.” Very few participants knew that the HUGS program had a Facebook page. Occasionally, this question was followed up with, “I will look it up” (n=5). This question shows the HUGS program’s lack of social media awareness among cancer survivors.

Question 16: Do you have a CaringBridge site? If do, do you use it differently than you use your Facebook page? Please explain.

CaringBridge evoked a wide variety of responses from each respondent, which illustrated its flexibility and utility as an online health site. The majority of respondents did not have a CaringBridge page and cited numerous reasons why they did not join (n=12). Equally mentioned were the responses, “not sick enough,” (n=3) and “too much work” (n=3). Individuals mentioned that CaringBridge was not meant for them, as it was perceived as an online site dedicated to those who were considered “more sick” or terminal (n=3). Individuals also did not know about the online health site and so reported that limitation as the reason why they never joined (n=2).

Finally, individuals mentioned that CaringBridge was too much work to maintain throughout a cancer journey. Quotes further these points: “No, I didn’t I was going to and then I just, you know, like I said, I was lucky I could make it to work.” and “No. I never got that sick my dear, I was so lucky I cannot believe it, I never got sick when I had my treatment.” One respondent stated:

No. I didn’t want. I didn’t know for sure how things were going to turn out and I didn’t’ want this to be and then you know it’s like, this, ah, I don’t

know. Probably just didn't want daily information, I just wasn't ready for that, you know.

Another said:

No. Not really. Once I found out exactly that it wasn't, um, it's serious, but not as, it wasn't full blown, you know, it was localized, my doctor was hopeful that after 3 months of treatment, you know, we could get a good grip on it which he was correct on that and stuff too.

There were advocates of CaringBridge who cited its reach to large numbers of people and its ease to sign in and use (n=4). Below are other examples of reasons why respondents advocated for their use of CaringBridge.

That and CaringBride are, it would just be a very expedient way of getting information out to a large group of people. We used CaringBridge exclusively when I was diagnosed. I had thousands of visits and comments, you know, I, because of where I work, it's a large group of people that I'm in contact with and same with my husband, there was no way we could get the information out without doing like a group thing. So, CaringBridge was awesome for us. Awesome.

Another participant said:

But to me CaringBridge is set up to be a place where you share information about, you know, about, and sometimes kind of personal, intimate details about what's going on in somebody's health journey and so it's expected that there's a lot of detail, just a lot of, a real personal look at what's going on and Facebook is always seems like, from what my experience, it's such, it's almost little teasers, but then everyone has to ask questions like what's going on or what did they say and that just, it doesn't, that seems, Facebook seems more social and CaringBridge is intended to be for those health crises.

Finally, one respondent noted a unique personal connotation associated with CaringBridge, "I think probably intentional, I thought CB sounds like someone's going to die."

Question 17: Any other communication needs you have that I may not have addressed in this session?

The final interview question conjured up a host of communication needs that cancer survivors wanted addressed. Among the most mentioned needs were finances (n=3), support for family (n=2), more continued education and medical updates and more post-treatment communication (n=4). Finances were a significant issue that was cited many times. Respondents commented that the added burden of finances was overwhelming and detracted from their quality of care. One respondent said:

The one piece that I think that was all missing out of that whole thing was the billing piece. The people in the billing office were never as friendly or passionate or caring about their communication with me and I never was one to get behind or not pay, but when, the one time that I didn't call in, you know they tell you to try to get all your, try not to be stressed and you know how you have to let everything go 'cuz you have to, your energy is really used on yourself, I think that was the one piece lacking, was the billing department. They made me so stressed out all the time that I think that if they would be more involved in the whole piece, somehow, I think that would've made me feel more comfortable.

Another noted:

One thing that they have got to do at [REDACTED] is that first time you go in and I realize you are pushed through a bunch of stuff and you've got all those people coming, but they need to have somebody financially come in and visit with people, they really do and they need to talk about different ways of payment.

Another respondent event put off receiving medical attention because of the fear of financial burden:

To be honest with you to start the, I had this lump for quite awhile but I didn't want to go in, I knew what was going to happen with, what has happened with financial and I didn't go in but it started to bleed and I got scared and I went into the emergency room and they wouldn't let me out until I promised to go in and have it checked out.

The second commonly heard communication need centered around additional support for family members. The respondents interviewed were from a wide age range and had families with varying ages as well. Some respondents reported having children as

young at 18 months, while other had fully grown adult children. Not only offspring, but siblings, spouses and extended family were mentioned. One participant said:

I remember one time, one of my sisters made the comment that there was a lot of books out there for how a cancer patient should deal with the issues but as a sister, she had a lot of emotions herself that she never learned how to deal with and it would've been nice if there was something out there for her. So, and when I thought about it, she's absolutely right, um, they're going through a lot of different emotions also, one as a caregiver and also as a family member and then as themselves worrying about, are they going to end up that way, you know. So I think they, there's not a lot and even for my daughter, being 16, there wasn't a lot for her, you know.

Another commented:

I've thought about it and I think this is very important is I think that my husband and I should start a couples group so that he can talk if they have questions or they need to review it because if you've not been through it with your spouse, nobody understands it, you know, they really don't.

Finally, a participant said:

I never really felt like anybody cared about how I was doing or how my kids were doing or, I mean my youngest was 3 and so I mean or so how my husband was doing, and it was just that, I really was disappointed in [REDACTED]. I thought there'd be more support, especially I mean a young mom with stage 4 cancer, I just, that, I was really disappointed.

The last commonly reported areas of communication needs involved continuous updates and constant education and communication post-cancer treatment. Although, HUGS' mission is to educate and support cancer survivors throughout the entire cancer continuum, mention of the idea of left to "fend" for yourself was evident. The following quotations illustrate these points.

I would like to see more and maybe they've done it and I didn't get the emails or maybe, I would like to see more educational, maybe they do it at the lunches, like the lymphedema thing or something, I would like to see a little more here's what's new, would you like some current information, not that you have to follow it, but here's what's out there and they don't have to basically promote it, but they can make it available.

Yet another participant said:

At least for me, that would've been nice, you know, well here's the program or do you want to stop and visit with them today while you're here or something like that. You know and maybe some people aren't comfortable doing that, I don't know, you know, but, maybe they've tried that and it doesn't work. It's not a loss, it's just like, it's just kind of a weird feeling because you've been so connected for so long and then woo, now you're free. It's probably, I suppose like getting out of jail, I don't know.

Finally, a participant commented:

I mentioned that to one of the nurses too when I was getting close with being done like with radiation, you're almost scared because you've done something for 6 months, you've been on a daily schedule or you've done treatment and then all of the sudden when you know it's coming to an end, then what? Then you almost feel like you're, there you are, you know. Fend for yourself.

The results section of this paper systematically identified recurrent themes in each of the 17 interview questions. In some instances, responses were varied in terms of single occurrence of needs or issues. Throughout other questions, however, there were pressing themes that demand attention. In the next chapter, Chapter Five, those themes will be addressed in conjunction with this study's research questions. Chapter Six will follow with a series of implications,

CHAPTER V

DISCUSSION

The ways a cancer survivor prefers to communicate are unique and varied. This study expanded upon previous knowledge of preferred communication channels of cancer survivors. The results identified gaps in the communication preferences of the respondents and begged for a more thorough explanation of media uses and gratifications. Employing Uses and Gratifications Theory (UGT) (Blumler & Katz, 1974) this study identifies ways the HUGS program could become a more patient-inspired and patient-focused program. The following section discusses emergent themes and how they relate to Uses and Gratifications Theory, organized by research question.

RQ1: How are cancer survivors finding cancer resources?

First and foremost, respondents are seeking interpersonal communication from various individuals. Interviewees cited physicians, friends and family among their most utilized cancer resources. Quotations from respondents illustrated their implicit trust in physicians. Cancer resources in family and friends were also a common theme identifying the necessity for human touch, contact and support.

Each interpersonal relationship offered a different type of support. For example, the support a survivor found from a physician was informational, whereas, the support sought and received from family and friends was emotional. Uses and Gratifications theory suggests that people play an active role in the types of media they use based on the gratification that media provides. In this instance, physicians provide a more factual,

informational gratification whereas family and friends gratify cancer survivors emotionally and mentally.

Another facet of cancer survivorship examined was the timing of information gathering from cancer resources. UGT argues that psychological and sociological factors influence the type of media chosen by individual. Additionally, timing seemed to be a salient factor for cancer survivors as they progress through their cancer treatment. One participant noted:

It took me a couple months before I could actually go in and read about things, I just couldn't do it. First of all, you're in shock, and then like I said, when you, if you are reading about someone else it'd be really interesting and I'd want to find out everything but when you're reading about that this is happening to you and this is what could happen and this and this then it's just, it just was too, I just couldn't do it. Tell me what I need to know, that's it because you know 'cuz I have faith in my doctors you know and everybody that they were given the right information and I thought, you know, I'm gonna leave it up to them.

Another participant said:

I mean that, um, because when I got the diagnosis and I can only speak for myself, but when I got the diagnosis, I always thought that if I got cancer, I would want to tell the world and I would want them all to embrace me and instead, I wanted to heal from within and nobody can see my soul, so I needed to start there and go outwards and the best way to do that was to get through the chemo and when I got through that and I looked around and thought about my husband and my support group and myself and my strength in God, I thought I guess I don't need to continue to be around and talk, be around people and talk about cancer all the time because it's just a constant reminder you know it's like revisiting a car accident.

These quotes illustrate two kinds of gratification. First to appear was the fulfillment of information from a physician because the survivor was too overwhelmed. This individual defaulted to receive information from their physician because they were in shock, leaving them in a situation where they needed information, but felt they could not locate it on their own. Secondly, emotional gratification was evident as another individual said they

wanted to avoid communication as talking about cancer less allowed her to receive emotional gratification from within.

The Internet was also identified as a popular way to seek cancer resources. Online, participants could locate resources specific to their own tumor type or from their place of treatment. Using the Internet, survivors could fulfill their informational and advocacy needs. Informational needs were being met because survivors sought material online from informational websites. However, they also sought advocacy support because survivors were looking at tumor-specific sites, reaching out to individuals who experienced cancer with the same or similar diagnoses, treatment and symptoms.

One of the unique characteristics of the Internet is that it can be available to a large group of people yet provide one-on-one communication. This is called demassification. Demassification is the control the individual has over a medium “which likens the new media to face-to-face interpersonal communication” (pg. 12). Individuals’ preference for social media and technology is another way to assimilate interpersonal communication. By using the Internet to locate resources that are specific to one’s tumor type, diagnosis, treatment or survivorship, the survivor is emphasizing their preference of interpersonal communication.

Also of note are the efforts made by interviewees to avoid communication, mainly the Internet. Communication avoidance was not addressed in previous literature and, therefore, is worth further discussion. It draws upon concepts from UGT that suggests that audience members or media consumers can be selective in the type of media they utilize. According to Ruggiero (2000), individuals continue to be analyzed for their social media selection depending on a variety of sociological and psychological factors. It was

evidenced in the interviews with cancer survivors that the difference between when they sought cancer resources and when they didn't depended on their illness. Those who were newly diagnosed felt overwhelmed and bombarded by information and, therefore, avoided it. Those who had partially completed their cancer treatments or felt healthier were more apt to begin to locate resources online. Where a survivor was on the cancer journey continuum affected what types of cancer resources they sought, if any. Depending on an individual's demographics and social and psychological background and, this research shows, health status, avoiding communication may be their way of 'selecting' media through lack of selection.

Additionally, most respondents reported they preferred email as a communication medium and trusted physicians and other health care providers most when being recruited for clinical trials. The interview data related to RQ1 concludes that interpersonal communication with physicians is paramount. The gratification received from interpersonal communication with physicians provided the informational support the survivors needed most. What's more is that a survivor's own physician provided information that was specific to them. Despite the demassification characteristics of the Internet, which emulates interpersonal communication, authentic interpersonal communication when discussing a sensitive topic like a terminal illness trumps all other forms of communication.

RQ2: What computer-mediated communication tools are cancer survivors currently using to communicate?

I use a lot of email, that's how we communicate, our email and our Facebook. Texting. Those are the, you know sad to say, but you know it's nice because we can all multi-task, we can be where we are suppose to be but yet we can still have that connection.

Another respondent answers this question, “Email, probably, I guess that’s the most. I don’t do Facebook, I quit using that about a year ago, um and strangely it was right before I even, before I was diagnosed I just kind of quit.”

Reiterated from RQ1, email was reported as the most common communication used in the personal lives of cancer survivors. In addition to email, survivors reported texting and using Facebook as well. But, how, when and why are they using these CMC tools to communicate?

Cancer survivors responded and indicated that they are hesitant to disclose health information on Facebook. Additionally, they have mixed emotions when it comes to the Internet and other online sources as credible and reliable cancer resources. For some, the Internet provides a safe, streamlined place to locate resources. However, the unregulated nature of the Internet can cause anxiety and fear, especially with sensitive health information. Depending on a survivor’s own interpretation of the Internet, they used the Internet differently to locate cancer resources. Uses and Gratifications Theory anticipates this inconsistent media use because the theory posits that media consumers actively choose what media they utilized based upon the gratification it offers.

Although, email and texting are used in the personal lives of survivors, when it comes to learning and disseminating health information, CMC still has to prove its worth. Uses and Gratifications theory focuses on, “What do people do with media?” Extending that question to read, “What do people do with media when it comes to their health?” begs the question, what’s the difference? UGT says that individuals are actively seeking media based on a set of needs. A cancer patient’s needs look very different from a cancer survivor’s needs and vice versa. An individual’s health status is much more vulnerable

earlier in their cancer journey than after successful treatment. Therefore, computer-mediated tools like email and texting provide different gratifications depending on the type of information being disseminated. Email was mentioned the most because of it encompasses three characteristics found within all CMC tools, which allows CMC to be useful to a diverse group of people.

Current UGT suggests that interactivity, demassification and asynchronicity are traits that must be discussed when talking about the Internet (Ruggiero, 2000).

Interactivity is the degree to which audience members have control over and can exchange roles in their mutual discourse (Williams, Rice & Rogers, 1988). Although, Facebook, for example, is a commonly used CMC tool for survivors, audience members (survivors) don't have control of the content, viewings or responses of other Facebook members. Interactivity on sites tailored for a particular tumor type is vital because they allow for real responses from real individuals. Demassification is the concept that the Internet allows communication to be deconstructed and controlled to result in simulated interpersonal communication online (Ruggiero, 2000). As previously mentioned, demassification on tumor-specific websites allows cancer survivors to interact with others to seek answers to their questions, advocate for themselves and their cancer journey and do it all as if it were face-to-face. Finally, asynchronicity refers to messages that can be staggered in time. Email is considered asynchronous communication. Survivors, who enjoy email because of its ability to help with time management, may prefer a more instantaneous form of communication to accompany their health needs.

This study identified the computer-mediated communication tools that cancer survivors are currently using. The concepts of interactivity, demassification and

asynchronicity influence CMC. When CMC and health information converge, those characteristics of interactivity, demassification and asynchronicity affect an individual's choice in media. It appears that cancer survivors are using CMC differently than they would traditionally, with other, less sensitive, information. The delicate nature of health information influences survivors' preferences in interactivity, demassification and asynchronicity. When talking about health information, interactivity may be sought depending on if the survivor is seeking a specific opinion or wants to join a support group. Demassification is more strongly emphasized when it comes to health information because the interpersonal relationship among friends, family or physicians has been highlighted as the preferred and most trusted cancer resource. Finally, asynchronicity is a useful tool for survivors when it involves social situations, but in health situations, survivors want synchronous, immediate communication.

RQ3: Who do cancer survivors trust the most to educate and recruit them for clinical trials?

Two powerful quotes from two participants answer this research question: "If it didn't come from my doctor, I probably wouldn't do it." and "I don't know, I guess I never thought of anyone else giving me information." Previous literature reported that physicians are the number one, most trusted recruiters for clinical trials (Kaas, Hart, & Rutgers, 2005; Miller et al., 2011). This research study echoes previous work on clinical trial recruitment. Respondents overwhelmingly trusted physicians, nurses and anyone else in the medical field to educate and recruit them for clinical trials. Even when asked to disclose who *else* they trusted, aside from their physician, to give them clinical trial

information, some refused to give an answer different than physician. The amount of trust the physicians incur is overwhelming.

Health crises are intense and survivors want to gather information and be advised by their physician. Instead of asking survivors to look for clinical trials in a different way, health facilities and programs should be meeting them where they feel most safe and comfortable. More research should be conducted on a cancer resource continuum to evaluate when individuals want what types of media available to them. As UGT argues, people are media selective and a variety of factors influence when and how they utilize different media types. Being diagnosed with an overwhelming health status should be added onto the list of factors that influence media selection.

Participants also said they would ask other cancer survivors who had experienced similar clinical trials. There is again an emphasis on interpersonal communication when it relates to cancer resources. The significant trust for physicians, health care professional and interpersonal communication seems to signify that there is no other way an individual would prefer to locate information about clinical trials. Just as in UGT, individuals are choosy about what media they prefer at certain time periods. Adding a health crisis to a media decision only makes the decision more complex and the matter more sensitive.

This section answers the three research questions of the project. It highlighted the fragile nature of health communication and computer-mediated communication. It also described the most trusted individuals in the clinical trial community. Next, Chapter Six will elaborate on the implications of this study and its research questions.

CHAPTER VI

IMPLICATIONS, LIMITATIONS AND FUTURE RESEARCH

This study identified topics that impact cancer survivors and, therefore, has many implications and solutions to offer. First and foremost, this study demonstrated the selectivity survivors exercised when it came to social media and health information. There were certain communication channels they valued and trusted throughout their cancer journey. There were also media outlets that appeared “off-limits” at times during the cancer journey, but once the survivor felt more stable, usually as they reached end of treatment and survivorship, they began to seek more types and different types of media. Uses and Gratifications Theory expounded this phenomenon by explaining that how media is used is dependent on a variety of psychology and sociological factors. This study would also posit that the sensitive nature of health information also influenced media usage.

Before specific practical implications can be discussed, the gap that is evident within this research must be addressed. There is a plethora of new knowledge that is being expanded on every day that entails medical technological advances. In this arena of medical advances, there are groundbreaking diagnostic, treatment, prevention and clinical trial breakthroughs in every issue of the newspaper. These medical advances impact all individuals whether seeking cancer treatment now, will need it in the future or are alongside a loved one as they undergo treatment. A second emerging area of unprecedented growth is in technology and social media. Never before has our society

been so “jacked in” to technology. Constant smartphone and computer usage is commonplace. Smartboards, projectors, tablets and cameras are exploding in educational systems to ensure that students know of the technology, but also to enhance learning with their use. Technology and social media are evolving so much that credible health care facilities not only have websites, but can also be found on sites like Facebook, Twitter or even Pinterest and have links from their websites to these auxiliary social media sites.

Finally, there is a third emergent group. This group grows yearly and thanks to medical advances will continue to grow; this group is that of cancer survivors. Survivors are a multi-dimensional group. They are individuals who have undergone unimaginable trauma. Their narratives revealed that one day they were having coffee with a friend, were at work, or were teaching a class and the next, their world was turned upside down as their health care provider called to tell them of their diagnosis. After their diagnosis, they endured a variety of cancer treatments: chemotherapy, radiation, surgery and in some cases, all three. The treatments made them sick, made them weak for days or weeks, gave them, what they lovingly refer to as, “chemo brain” or resulted in the loss of all of their hair. After successful treatment, these individuals are deemed survivors and sent home. The survivors hope the cancer won’t come back, but can never shake the idea that relapse is just around the corner. They try to find a “new normal”, but feel helpless. They understood how to live before cancer, but struggle on how to do it post cancer treatment. This group of survivors is unique, multi-faceted and frightened. Survivors, through the interviews conducted in this study, are firm in their desire to, at times, avoid cancer resources available on the Internet. They reported that they were bombarded by their diagnosis; so managing new or upcoming communication techniques seemed

impossible. Survivors are also adamant that their physician is their number one trusted clinical trial educator and recruiter. Finally, survivors have been unwavering in their reliance on more traditional means of communication. For survivors, the Internet is not ruling the world; it is being utilized selectively to offer them informational, emotional or advocacy support. The Internet is a valuable place, but, for survivors, only when they want it to be.

Here is the gap. Medical advances are growing, primarily thanks to the work of clinical trials, and influencing how many survivors are enjoying life. Simultaneously, social media is expanding to all facets of life. Everything that consumers do is linked to a social media platform. Cancer survivors are explicit in their preferences for cancer resources and education. The gap is that the advancements in medical advances and social media are not meeting the survivor where they are. Survivorship programs want program participants to discuss very sensitive, private health information via a very public social media platform. Survivors indicated that they only used certain cancer resources depending on the type of gratification being sought. The focus for health professionals should be, “How do medical advances and social media marry to meet survivors where they are?” This will require an evaluation of what gratifications are wanted at each step of the cancer continuum.

First, health care approaches must change. Practices utilized by health care providers, health promoters, clinical researchers and health care facilities must address the survivor first. The use of social media by so many medical institutions may be a unique tool for those who are not sick and seeking medical support; a tool more aligned for job seekers, medical students, friends and family of survivors or health promoters.

Social media however, does not offer information for diagnosis, treatment or symptom management. For sensitive health information, cancer survivors indicated more traditional means of communication. The challenge is to change thinking to be more survivor-centered which will ultimately more appropriately utilize cancer resources.

There are some practical ways to unite these three entities. Offers of clinical trials should change in order to bolster recruitment. Clinical trial education and recruitment is well received from physicians. Physicians, however, are bombarded by time constraints and fatigue as many patients are seen daily. To remedy this, clinical trials must be offered in manageable ways that employ demassification and is translated for survivors, but is expedient in its dissemination.

The social media site could also be promoted primarily to the friends and family of cancer survivors. Those on the periphery have a clearer sense of what the medical plan in and can manage additional communication techniques. For example, health care professionals recommend cancer patients bring a friend or family member to their appointments in order to ensure accurate information dissemination. The same process may hold true for social media promotion.

Limitations

This study has areas upon which it could be improved. The study's researcher had a connection with the cancer center mentioned in this study, which allowed for easier entry into the research environment, which could be interpreted as skewed data. Three of the interviewees had a relative of the researcher as their oncologist. The interviewees who were affected were asked if they still wanted to participate and all consented.

Out of the 20 interview participants, only one man was interviewed. This could possibly mislead the discussion, as there was not an evenly distributed sample of men and women. In addition, the sample included primarily breast cancer survivors (n=14). This did not allow for a wide range of participants. Perhaps those who died because of their cancer diagnosis would have offered a different outlook on cancer resources, clinical trial information and social networking. Additionally, since there is a large national breast cancer awareness campaign, this could have influenced how the majority of the sample thought about their cancer resources, as they may have felt more supported because they could identify with a national program dedicated to their tumor type. Finally, in regards to the sample, the cancer survivors that participated in the study were from one geographic area that has a large northern European population, primarily Scandinavian and Germanic. Participants were representative of the location's population yet they would not be considered a diverse ethnic or genetic sample.

The sample was asked to contact the researcher in order to participate in the study. This protocol, although ideal for HIPAA requirements, may have discouraged more passive, timid or computer-hesitant patients and survivors. The individuals who participated in the study were much more self-motivated and had the initiative to reach out to a study outside of their regular interactions with the HUGS program. Additionally, this recruitment method was limited in that it only reached out to individuals who had their email address on file with the HUGS program. Those who may have been more inclined to traditional communication mediums may not have received the email if it's not a form of communication they share.

The sample also consisted of two individuals who have been in remission for an extended period of time: 18 years and 38 years. These participants were still interviewed as they were involved with the HUGS program, however, their experience with the program was much more limited and infrequent. Their responses to cancer resources, clinical trials and trusted health providers were still considered valuable and were used during data analysis.

Finally, none of the individuals interviewed for this study can be said to be representative of an entire cancer survivor population. They do, however, offer strong voices pertaining to cancer treatment and survivorship in the last decade from the HUGS program and its cancer center. Their narratives are still valuable to the HUGS program even with their known limitations.

Future Research

This research study can and should be expanded upon. This research could be extended to focus on the ways cancer survivors' families and friends use social media to manage information and emotion. Previous scholars noted that family and friends use social media differently (Ginossar, 2008). Could the position of a "secondary audience" member be of value to cancer survivorship programs trying to use social media as a cancer resource?

A focus on oncologists and their understanding of clinical trials would also add to this study. The oncologist plays a significant role in the recruitment process for clinical trials and their adoption of recruitment strategies could influence clinical trial participation. Additionally, an oncologist's knowledge and support of the HUGS program could assist in bolstering the HUGS program's overall participation.

Finally, communication avoidance was a common theme found throughout participants' narratives. Further research on the communication avoidance phenomenon is certainly warranted. Uses and Gratifications Theory could be used to create a new gratification that argues that avoidance is a type of gratification when an individual is too overwhelmed, emotional, confused or fearful. The theme of communication avoidance may be evident throughout health communication research.

Chapter Six presented implications from this study for cancer patients and survivors based upon their experiences with clinical trials, cancer resources, CMC and the HUGS program. The study concluded that health care professionals must adopt a patient-centered approach in order to bolster clinical trial recruitment and effective cancer resources. Communication avoidance was understood as a self-efficacy tool within UGT to selectively choose media. This study sought to explore the preferences and unique experiences of cancer survivors, however as medical technology advances and social media advances, there will always be more exploring to do.

APPENDICES

Appendix A
University Institutional Review Board Approval and Informed Consent Waiver

[REDACTED]

INSTITUTIONAL REVIEW BOARD
c/o RESEARCH DEVELOPMENT AND COMPLIANCE
DIVISION OF RESEARCH

[REDACTED]

January 15, 2013

[REDACTED]

Dear Ms. [REDACTED]

We are pleased to inform you that your project titled, "Communication Channels for Cancer Resources: Addressing Information Dissemination, Clinical Trial Recruitment and Social Networking" (IRB-201301-183) has been reviewed and approved by the [REDACTED] Institutional Review Board (IRB). The expiration date of this approval is January 10, 2014. Your project cannot continue beyond this date without an approved Research Project Review and Progress Report.

As principal investigator for a study involving human participants, you assume certain responsibilities to the [REDACTED] and the [REDACTED]. Specifically, an unanticipated problem or adverse event occurring in the course of the research project must be reported within 5 days to the IRB Chairperson or the IRB office by submitting an Unanticipated Problem/Adverse Event Form. Any changes to or departures from the Protocol or Consent Forms must receive IRB approval prior to being implemented (except where necessary to eliminate apparent immediate hazards to the subjects or others.)

All Full Board and Expedited proposals must be reviewed at least once a year. Approximately ten months from your initial review date, you will receive a letter stating that approval of your project is about to expire. If a complete Research Project Review and Progress Report is not received as scheduled, your project will be terminated, and you must stop all research procedures, recruitment, enrollment, interventions, data collection, and data analysis. The IRB will not accept future research projects from you until research is current. In order to avoid a discontinuation of IRB approval and possible suspension of your research, the Research Project Review and Progress Report must be returned to the IRB office at least six weeks before the expiration date listed above. If your research, including data analysis, is completed before the expiration date, you must submit a Research Project Termination form to the IRB office so your file can be closed. The required forms are available on the IRB website.

If you have any questions or concerns, please feel free to call me at [REDACTED]

Sincerely,
[REDACTED]

IRB Coordinator

MLB/jle

Enclosures

WAIVER OR ALTERATION OF INFORMED CONSENT REQUIREMENTS

IC 702-B
10/19/09

Application for Waiver or Alteration of Informed Consent Requirements

Principal Investigator: [Redacted]

Project Title: Communication Channels for Cancer Resources: Addressing Information Dissemination, Clinical Trial Recruitment and Social Networking

Written documentation of informed consent that embodies all the required elements of informed consent, as described in 45 CFR 46.116, is required for all research subjects. With sufficient justification, the IRB may approve a consent process that does not include, or which alters, some or all of the elements of informed consent provided that it finds and documents specific requirements. Choose **EITHER** option A or B below and complete that section. Sign the form and submit it with your application to IRB.

A. If requesting a waiver or alteration of the requirements to obtain informed consent, justify such in accordance with each of the following four criteria established under 45 CFR 46.116(d) (1-4). (This option not allowed for FDA regulated research)

1. The research involves no more than minimal risk* to the subjects;

[Empty text box for response to criterion 1]

2. The waiver or alteration will not adversely affect the rights and welfare of the subjects;

[Empty text box for response to criterion 2]

3. The research could not practicably** be carried out without the waiver or alteration;
AND

[Empty text box for response to criterion 3]

4. Whenever appropriate, the subjects will be provided with additional pertinent information after participation.

[Empty text box for response to criterion 4]

B. If requesting a waiver or alteration from the requirements for written documentation of informed consent, justify such in accordance with at least one of the criteria established under 45 CFR 46.117(c) (1 or 2).

1. The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality.

In this case, each subject will be asked whether s/he wants documentation linking the subject with the research, and the subject's wishes will govern (this option is not allowed for FDA regulated research); **OR**

2. The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

This research involves minimal risk to subjects. The risks anticipated in the research are minimal and nothing more than encountered on a routine basis. This waiver will allow the PI to be more anonymous in her data collection. Subjects will be able to decline participating in the interview and that will indicate their non-consent. The waiver will provide more anonymity to subjects, as there will be no identifying links between informed consent and raw data.

If requesting a waiver of the documentation of consent, attach a verbal consent script and/or a subject information sheet that describes the study and includes the relevant consent form elements.

(Principal Investigator Signature)

Date:

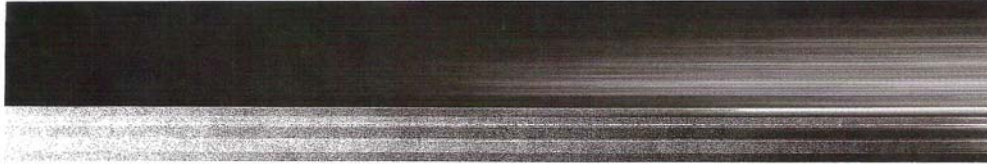
(Institutional Review Board Primary Reviewer Signature)

Date:

**Minimal risk means that the probability and magnitude of harm or discomfort anticipated in the research are not greater than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests.*

***Practicable refers to instances in which the additional cost would make the research prohibitively expensive, or where the identification and contact of thousands of potential subjects would not be feasible for the anticipated results of the study. Practicable would not mean an inconvenience or increase in time or expense to the investigator or the research.*

Appendix B
Health Care Facility Institutional Review Board Approval, HIPAA Authorization and
Informed Consent Waiver



January 28, 2013

PI: [REDACTED]

Project: 03-12-105 Communication Channels for Cancer Resources: Addressing Information Dissemination, Clinical Trial Recruitment and Social Networking

Project Review Level: Expedited Category 6 & 7

Project Risk: No more than minimal

Project Approval Period: 01/28/2013 – 01/27/2014

The study submission for the proposal referenced above has been reviewed and approved via the procedures of the [REDACTED] Institutional Review Board (IRB).

Your study has been granted a Waiver of Documentation of Informed Consent. As a replacement for a signed consent you must provide your subjects with an informed consent document without signature lines. You must document this informed consent process in your study records. Attached is the informed consent that has been stamped with the IRB approval and expiration dates. Please use this original document to make copies for subject enrollment. If appropriate, please give a copy to your subject.

Your project has been granted a Partial Waiver of HIPAA Authorization.

- The waiver will not adversely affect the privacy rights and welfare of the individuals;
- The research could not be practicably conducted without the waiver;
- The research could not be practicably conducted without access to the use of the protected health information;
- The privacy risks to individuals whose protected health information is to be used or disclosed are reasonable in relation to the anticipated benefits if any to the individuals, and the importance of the knowledge that may reasonably be expected to result from the research;
- There is an adequate plan to protect the identifiers from improper use and disclosure;
- There is an adequate plan to destroy the identifiers at the earliest opportunity consistent with conduct of the research, unless there is a health or research justification for retaining the identifiers, or such retention is otherwise required by law; and
- There is adequate written assurances that the protected health information will not be reused or disclosed to any other person or entity, except as required by law, for authorized oversight of the research project, or for other research for which the use or disclosure of protected health information would be permitted.

No alteration to the procedures described in the Application for waiver of HIPAA authorization as reviewed may be instituted unless this IRB has reviewed and approved the alteration.

You have approval for this project through the expiration date noted above. When this study is completed please notify the Human Research Protection Program office. If the study is to last longer than one year, a continuation form is to be submitted prior to the submission deadline in order to assure adequate time for IRB review.

[REDACTED]
January 28, 2013
Page 2

Prior to initiation, promptly report to the IRB, any proposed project updates / amendments (e.g., protocol amendments/revised informed consents) in previously approved human subject research activities.

The forms to assist you in filing your: project closure, continuation, adverse/unanticipated event, project updates /amendments, etc. can be accessed online at [REDACTED].

Sincerely,

[REDACTED]
[REDACTED]
[REDACTED]

Director-Human Research Protection Program

[REDACTED]

- | | |
|----|--|
| 9. | <p>Please explain how your recruitment meets the following criteria:</p> <p>A. Recruitment cannot be practicably carried out without the Partial Waiver of Authorization. Explain: It will be impossible to set up interviews with individuals without knowing their names or how to contact them in order to set up a time and place to conduct interviews.</p> <p>B. Recruitment cannot practicably be conducted without the participants' PHI. Explain: It will be impossible to set up interviews with individuals without knowing their names or how to contact them in order to set up a time and place to conduct interviews.</p> |
|----|--|

By signing this statement, I am providing written assurance that only information essential to the purpose of recruitment will be collected, and access to the information will be limited to the greatest extent possible. Protected health information will not be re-used or disclosed to any other person or entity.

Signature of Principal Investigator

Date:

WAIVER OF DOCUMENTATION OF INFORMED CONSENT

SUBMISSION INSTRUCTIONS: *Submit paper signed original(s) and other required materials and e-mail duplicate electronic documents to appropriate IRB. Form must not be hand written.*

Project / Study Group Number: Project Title: Communication Channels for Cancer Resources: Addressing Information Dissemination, Clinical Trial Recruitment and Social Networking

Principal Investigator: [REDACTED]

Under this waiver, the investigator is still required to provide informed consent to the potential subject, but the subject's signature is not required on the form.

Along with this waiver request, you must submit a consent statement or written script that will be provided or presented to the potential subject. The consent statement or script must contain all the elements of informed consent

Please answer either **1.** or **2.** below and submit with the New Study or other application:

1. Requesting a waiver of written documentation of informed consent based on the following:

A. Is the informed consent the only record linking the subject to the research?

<input type="checkbox"/> No <input type="checkbox"/> Yes: Explain:
--

B. The principal risk is potential harm resulting from a breach of confidentiality.

Explain:

C. Each participant will be asked whether he or she wants documentation linking them with the research, and the participant's wishes will govern. (*in other words, does a participant want to sign a consent form or other document*)

(State how this will be done.)

D. The research is NOT subject to FDA regulation

If your study qualifies for a waiver of documentation of informed consent under this exception, the required elements of informed consent need to be included in an Informational cover letter or, when applicable, consent without signature lines, which includes a statement to the effect that completion of the "questionnaire, survey, participation in the interview" constitutes consent to participate in the study.

2. Requesting a waiver of written documentation of informed consent based on the following:

A. Does the proposed research, in its entirety, involve greater than minimal risk?
(Minimal risk means the probability and magnitude of physical or psychological harm or discomforts anticipated in the research are not greater in and of themselves than those encountered in daily life or in routine physical or psychological exams or tests.)

Yes *(your research does not qualify for a waiver of documentation of consent)*

No:

Explain: The risks anticipated in the research are minimal and nothing more than encountered on a routine basis. This waiver will allow me to be more anonymous in my data collection.

B. Does the research involve procedures for which written consent is normally required outside the research context?

Yes *(your research does not qualify for a waiver of documentation of consent.)*

No: Explain:

If your study qualifies for a waiver of documentation of informed consent under this exception, the required elements of informed consent needs to be included in an Informational cover letter or consent without signature line, which includes a statement to the effect that completion of the "questionnaire, survey, participation in the interview constitutes consent to participate in the study, when applicable.

Principal Investigator Signature: _____

Signature

_____ Date

Appendix C
Letter of Support

[REDACTED]

November 27, 2012

RE: Letter of Support

[REDACTED]

Please accept this letter as acknowledgement of support for [REDACTED] and her thesis work at the [REDACTED]. We support Ms. [REDACTED]'s research and are in communication with her regarding her research questions and goals.

The [REDACTED] Program, under the direction of [REDACTED] and [REDACTED] has worked previously with [REDACTED] and wishes to continue working with her. We understand the nature of [REDACTED] thesis work and we have been asked to provide input and guidance throughout the planning stages.

We anticipate continuing our research relationship with her and look forward to helping her throughout her thesis project. The work Ms. [REDACTED] is completing is relevant to our program and her research will assist us in expanding our program's resources.

Please contact us with further questions at [REDACTED]

Thank you.

Sincerely,

[REDACTED]

[REDACTED]

[REDACTED]

Appendix D
Email Recruitment Script

Email Script:

Hello.

My name is [REDACTED] from the HUGS Cancer Survivorship program at [REDACTED]. I am writing to you today to see if you would like to participate in a study we are conducting about your communication needs and about your preference when learning about cancer clinical trials. We are working with a researcher from the University of [REDACTED] who will interview you. The interviews will take place in a location of your choice and will last about an hour. This research will help Sanford better communicate with cancer survivors. It is voluntary, confidential and you can stop your participation at any time.

So, I am writing to see if you are you interested in working with this study.

If you are interested in participating, please contact the researcher. The researcher's name is [REDACTED]. Thank you for helping us improve our communication with patients.

If you have any other questions about the study please contact Ms. Steen or myself, [REDACTED]. Thank you and have a nice day/evening. If you are not interested, thank you for taking time to read about this research project.

Thank you for your time. Have a nice day/evening.

Sincerely,

[REDACTED]
HUGS Program Coordinator

Appendix E
Informed Consent

INFORMED CONSENT

TITLE: Communication Channels for Cancer Resources: Disseminating Information, Clinical Trial Recruitment and Social Networking
PROJECT DIRECTOR: [REDACTED]
PHONE #: [REDACTED]
DEPARTMENT: Communication

STATEMENT OF RESEARCH

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

WHAT IS THE PURPOSE OF THIS STUDY?

You are invited to be in a research study about Clinical Trials Attitudes and Perceptions within the [REDACTED] Cancer Survivorship Program because you are a participant of the [REDACTED] program and are a cancer patient or survivor.

The purpose of this research study is focused on a cancer survivorship program that is attempting to utilize social networking sites as a vehicle to improve their mission to bring cancer patients, family members and caregivers together in order to address the emotional, physical and financial burdens cancer patients and their families face. Working with cancer patients from the program, the research questions of this project will revolve around how patients use technology and what communication channels they prefer. More specifically, this project will focus on investigating cancer patients' opinions and attitudes regarding reasons why they do or do not participate in clinical trials, how they come to trust individuals that recruit them for clinical trials and, finally, what communication channels they prefer? Within the exploration of communication channels, the research will investigate what barriers stand in the patients' way, what bolsters their communication and observations about communication itself.

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 20 people will take part in this study at the [REDACTED]. Participants will be interviewed; some individuals will be met in person while others will be contacted via email.

HOW LONG WILL I BE IN THIS STUDY?

Your participation in the study will last 30-45 minutes for interview participants and 10 minutes for survey participants. Each visit will last about 30-45 minutes for interview participants.

WHAT WILL HAPPEN DURING THIS STUDY?

During the study you will be asked to honestly respond to a set of questions. Some questions may require in-depth answers while other answers will require shorter answers.

You are free to not answer or leave the interview at any time with no penalty.

WHAT ARE THE RISKS OF THE STUDY?

You may experience frustration that is often experienced when completing interviews. Some questions may be of a sensitive nature, and you may therefore become upset as a result. However, such risks are not viewed as being in excess of “minimal risk”. If, however, you become upset by questions, you may stop at any time or choose not to answer a question. If you would like to talk to someone about your feelings about this study, you are encouraged to contact, [REDACTED] the Principal Investigator of the study and she will locate counseling services for you.

WHAT ARE THE BENEFITS OF THIS STUDY?

You may not benefit personally from being in this study. However, we hope that, in the future, other people might benefit from this study because participants will be contributing to the improvement of the communication dissemination methods of the [REDACTED] Cancer Survivorship Program and participation in clinical cancer treatment trials. Understanding communication channel preferences could allow health organizations to better communicate and inform cancer patients about clinical trials that could be crucial to an improved health status.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will not be paid for being in this research study.

WHO IS FUNDING THE STUDY?

The [REDACTED] and the research team are receiving no payments from other agencies, organizations, or companies to conduct this research study.

CONFIDENTIALITY

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Government agencies, the [REDACTED]

Any information that is obtained in this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of coding data, keeping data safe on a password-protected computer with no links to any identifying information. Interviews will be audio recorded, however, the Principal Investigator will be the only individual that will have access to the data and the audio recordings will be erased after verification of accurate transcription.

If we write a report or article about this study, we will describe the study results in a summarized manner so that you cannot be identified.

IS THIS STUDY VOLUNTARY?

Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Your decision whether or not to participate will not affect your current or future relations with the [REDACTED]

CONTACTS AND QUESTIONS?

The researcher conducting this study is [REDACTED]. You may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact [REDACTED]

If you have questions regarding your rights as a research subject, or if you have any concerns or complaints about the research, you may contact the [REDACTED]

[REDACTED] Please call this number if you cannot reach research staff, or you wish to talk with someone else.

Your participation in this interview indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Appendix F
Interview Questions

**Communication Channels for Cancer Resources: Addressing Information
Dissemination, Clinical Trial Recruitment and Social Networking**

1. Where are you currently in your cancer journey?
2. How did you become involved with or find out about the HUGS Program?
3. What do you know about the HUGS Program?
4. Where are you currently finding cancer resources? (Has the location changed? Where have you in the past?)
5. How often do you receive communication from the cancer center or HUGS? If and when you do hear from them, how do they get in touch with you?
6. In your personal life, what types of communication do you use? Computer, email, Facebook, phone, mail, in-person meetings?
7. Do you ever hear about clinical trials?
8. How do you or would you decide on one cancer treatment clinical trial over another?
9. Have you ever participated in a clinical trial? If so, how did you find out about it?
10. Who do you/Would you trust the most to give you information regarding clinical trials? (Who else aside from your physician?)
11. How would you prefer to receive information from the HUGS program or the cancer center about cancer treatment clinical trials?
12. Do you have a Facebook page? If so, why did you sign up for a page and how often do you log on?
13. Do you disclose your health status on FB? Why or why not?
14. Do you have family or friends on Facebook? If so, why did they sign up and how often do they log into Facebook?

15. Do you or your family or friends “like” HUGS on Facebook?
16. Do you have a CaringBridge site? If so, do you use it differently than you use your Facebook page? Please explain.
17. Any other communication needs you have that I may have not addressed in this session

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