8-1-2012

Social Marketing Approach to Recruit Cancer Survivors for Research and Treatment

Narineh Hartoonian
Loma Linda University

Recommended Citation

Hartoonian, Narineh, "Social Marketing Approach to Recruit Cancer Survivors for Research and Treatment" (2012). *Loma Linda University Electronic Theses, Dissertations & Projects*. 83.
https://scholarsrepository.llu.edu/etd/83

LOMA LINDA UNIVERSITY
School of Science and Technology
in conjunction with the
Faculty of Graduate Studies

A Social Marketing Approach to Recruit Cancer Survivors for Research and Treatment

by

Narineh Hartoonian

A Dissertation submitted in partial satisfaction of
the requirements for the degree
Doctor of Philosophy in Clinical Psychology

August 2012

Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

____, Chairperson

Jason E. Owen, Associate Professor of Psychology

____

Adam Aréchiga, Assistant Professor of Psychology

____

Erin O'Carroll Bantum, Assistant Professor, Cancer Research Center of Hawai'i, University of Hawai'i

____

David Vermeersch, Associate Professor of Psychology

ACKNOWLEDGEMENTS

I would like to express my sincere gratitude to all the members of my committee who have supported me throughout this process. Dr. Jason Owen, who has the attitude and substance of a genius. Thank you for guiding me through this long processes every step of the way. I would also like to thank Drs. David Vermeersch, Adam Aréchiga and Erin Bantum for their valuable guidance and encouragement in helping me finish this project. I would also like to acknowledge the many graduate students and friends who have helped me complete this work: Sarah Ormseth, Eric Hanson, Laura Testerman, and Natalie Kaiser. Without their support and assistance, none of this work would have been possible.

Most of all, I would like to take this opportunity to thank my family who have provided their love and support, and demonstrated what it means to have strength and courage; Mom, Dad, Shara, Charlie, Toby and Meshi, I love you more than I will ever be able to express and I hope that one day I can give back to you the kind loving support that you have provided me; to Jonae, Lynette, Anasheh and Teni, who have put up with me throughout this process, provided me with all their love and encouragement, and shared with me the many hours of laughter. I could not have done this without you.

CONTENTS

Chapter

Appendices

FIGURES

Figures Page

TABLES

Table Page

ABSTRACT OF THE DISSERTATION

A Social Marketing Approach to Recruit Cancer Survivors for Research and Treatment

by

Narineh Hartoonian

Doctor of Philosophy, Graduate Program in Clinical Psychology
Loma Linda University, August 2012
Dr. Jason E. Owen, Chairperson

Recruitment is fundamental to project success and the production of clinically and statistically meaningful results. However, researchers have been challenged to recruit adequate numbers of participants for supportive interventions for cancer survivors (Buss et al., 2008). The purpose of this dissertation was to use social marketing theory as a framework to better understand recruitment for a web-based psychosocial intervention for cancer survivors. The study sample included cancer survivors from the Loma Linda University cancer registry or reached via population-level recruitment efforts (e.g., web and print advertisements). Of the 384 eligible potential participants, 197 fully enrolled in the intervention. Among potential participants, greater distress was associated with younger age, being female and lower SEER score, and study enrollment was higher among individuals with greater distress. Additionally, further progression through the recruitment process (i.e., full study enrollment versus just registration) was associated with higher income, being male, non-Hispanic White ethnicity, and a high level of distress. Consistent with previous research, perceived barriers/costs of enrollment were identified among individuals who declined participation, including personal reasons and health factors. With regard to effectiveness, generalized population-level strategies (e.g., web and print advertisements) were more effective and less resource intensive overall, but did not yield a representative sample. The results of this study may serve to guide selection of appropriate strategies in recruitment and intervention design in future cancer research. This study also demonstrates the feasibility of using social marketing theory as a framework within which to evaluate existing recruitment and intervention data.

CHAPTER ONE

INTRODUCTION AND LITERATURE REVIEW

In research and public outreach efforts, recruitment is foundational to project success and production of meaningful results. Recruitment of adequate numbers of participants to supportive interventions for cancer patients however is difficult (Buss et al., 2008). In view of the importance of effective recruitment and the challenges associated with recruitment of cancer patients, it is critical that recruitment efforts are planned and carried out in a systematic and organized manner. Use of effective recruitment strategies alone however is not enough in that these methods cannot compensate for an intervention that was not designed to address participant needs or expectations. A continuous feedback loop of research and revision is necessary to enhance recruitment and to design interventions that are of high quality, efficacious, and appealing. Social marketing is a promising theoretical framework for understanding, designing, and implementing recruitment efforts and interventions. In research, the "four Ps" of marketing are product, price, place, and promotion and are expanded to include participants and partnerships (Nichols et al., 2004). Social marketing theory also provides a framework for a continuous feedback loop in which strategies may be evaluated as precursors to interventions as well as during the interventions to identify major gaps that would lead to refinement of promotional materials and revision of methods to increase participation. Likewise, this information could be used to design programs that are appealing to participants. The purpose of this dissertation is to use the social marketing model and its principles as a theoretical framework to better understand recruitment activities for cancer patients with a goal of identification of effective and appropriate strategies to guide recruitment and intervention design in future cancer research and outreach.

Although information pertaining to recruitment and program design is essential to ensure that the purpose of the intervention is not compromised and treatment efficacy jeopardized, psychologists do not, nor should be expected to, have expertise in matters of marketing and business. Also, in general, resource and time constraints make it unreasonable for psychologists to perform full-scale prospective surveys and analyses for explicit purposes of exploration of information related to intervention recruitment and design. Therefore, the goal is to demonstrate the use of the social marketing model using accessible data pertaining to participant variables that characterized the potential participants and provide information for marketing mix decisions (the four Ps), including existing recruitment and intervention data and selected secondary data. Furthermore, the feasibility of the social marketing model as a theoretical framework for psychologists to systematically develop, implement, and evaluate recruitment and intervention strategies will be explored.

Research Fidelity and Cost Association

The National Institute of Health (NIH), Research Portfolio Online Reporting Tool results showed that in the year 2009 a total of $35,452,267.00 of funding was granted to research institutions in the U.S for projects that fall within the following categories of risk, prevention and health behavior research: 1) Behavioral Medicine: Interventions and Outcomes Study Section [BMIO], 2) Psychosocial Development, Risk, and Prevention Study Section [PDRP], 3) Psychosocial Risk and Disease Prevention Study Section [PRDP], 4) Risk, Prevention and Intervention for Addictions Study Section [RPIA], 5)

Social Psychology, Personality and Interpersonal Processes Study Section [SPIP], 6) Psychosocial and Developmental Processes, Personality, and Behavior Fellowship Study Section [F11], and 7) RPHB C-10 (B) SBIRSTTR: Risk Prevention and Health Behavior across the Lifespan (U.S Department of Health & Human Services [USDHHS], 2009). In consideration, examining and improving the reliability, validity and clinical applicability of health behavior intervention research is vital, such that these studies should be generalizable or produce equivocal results when replicated in other clinical settings. Millions of taxpayer dollars are being provided for intervention studies (USDHHS, 2009) that are underpowered (Maddock & Rossi, 2001). The Treatment Fidelity Workgroup of the National Institutes of Health Behavior Change Consortium has identified strategies to improve treatment fidelity in behavioral intervention research (Bellg et al., 2004). In addition, the authors describe the importance of consistency in using improved methodological strategies, including study design, training, and treatment delivery. They also encourage reviewers, editors and funding agencies to make this process a standard part of the evaluation process.

Participant attrition (leaving or withdrawal after entering a research study) is a major threat to the completion of intervention studies, such that attrition alone will reduce statistical power and limit the generalizability of study findings (Ribisl et al., 1996) resulting in systematic error or selection bias (McGregor, Parker, LeBlanc, & King, 2010). Therefore, it is imperative that our intervention studies have enough power to yield meaningful results. In order to accomplish this, enough subjects are needed in studies to have power to detect effects. However, having enough subjects is not the only method to improve power. A need for a more superior methodological knowledge base is needed to enhance power without just simply increasing sample size. Maddock & Rossi (2001) calculated the power for 8,266 statistical tests in 187 articles that were published in the 1997 volumes of Health Psychology, Addictive Behaviors, and the journal of studies on Alcohol. The power analyses detected the following results for the three journals (power to detect small, medium, and large effects): Health Psychology, .34, .74 and .92, Addictive Behaviors, .34, .75, and .9, and Journal of Studies on Alcohol, .36, .77 and .91, respectively. According to Cohen (1988) recommended value of 0.80 is needed to detect effects (J. Cohen, 1988). Using this criterion alone, these journal articles have adequate power to detect medium and large effects. Studies that examine small effects, such as intervention studies are still underpowered. This becomes a critical issue, since most interventions effects in the field of health psychology are small (Maddock & Rossi, 2001). Furthermore, non-significant results are also less likely to be published than significant results, and for this reason the power of tests conducted in studies are likely overestimated.

How can we improve our methodological knowledge in order to have greater power to detect effects in our intervention-driven studies? As mentioned before, in research and public outreach efforts, recruitment is fundamentally the building block to project success. However, difficulties in recruiting participants to supportive interventions remain a huge barrier (Buss et al., 2008). In spite of the challenges of recruitment and unsystematic execution, recruitment effort alone is not enough. Interventions that are not fundamentally designed to clearly address the needs or expectations of participants can be quite useless and can affect the outcome of study results, and most importantly the quality of care. Researchers need to be cognizant of these factors and put forth better effort in enhancing recruitment and interventions quality.

Data describing or testing recruitment strategies are limited and oftentimes study investigators do not report recruitment experiences carefully (Hunninghake, Darby, & Probstfield, 1987). Although recruitment is essential to program success, it is often one of the most challenging elements of research (Appel et al., 1999; Blumenthal, Sung, Coates, Williams, & Liff, 1995; Steinhauser et al., 2006; Swanson & Ward, 1995). Therefore, the goal of this study is to demonstrate the use of social marketing techniques to help researchers identify potential markers that influence recruitment. Additionally, the feasibility of the social marketing model as a theoretical framework to systematically develop, implement, and evaluate recruitment will be examined.

The order of information that will be covered in this paper is as follows: (a) brief overview of the *social marketing theory* using the classic publications of Kotler and Zaltman (1971) and Lefebvre and Flora (1988) who applied the concept of the social marketing model to the public health segment, (b) *The Academy for Education Development* (AED) social marketing framework and its application to this study, (c) information regarding who the *target audience* is, what the audience wants, and the *behavioral determinants* that drive the target audience to engage in behaviors similar to those we want them to take, (d) research study plans, activities and methods of implementation that will aid in maximizing the benefits and minimizing the barriers to participation (*Marketing Mix*), and lastly, (e) pilot study and feedback (*Execution*).

Social Marketing Theory/Framework

The discipline of Social Marking began in the 1970’s, with the first publication by

Kotler and Zaltman (Kotler & Zaltman, 1971). In 1988, social marketing was introduced to the public health sector (Lefebvre & Flora, 1988) where it has been most widely used for health behavior change programs to improve the welfare of the community at large. The concept and methods of social marketing are, in part, derived from the traditional marketing literature. Nonetheless, there is a clear distinction between the two methods, such that the emphasis of social marketing is more on "non-tangible" products, ideas, lifestyles and attitudes, whereas the traditional business marketing method is more focused on "tangible" products and services.

The theory of social marketing also provides an informative framework for systematizing recruitment activities inherent to clinical research. It identifies constituent parts that can be modified to increase the achievement of recruitment objectives. In addition, the success of recruitment will depend on the use of the strategies of both the matching model (Levkoff & Sanchez, 2003) and the participatory action model (Travers, 1997). The basic principle of the matching model proposes that in order to achieve recruitment success the perspective of participants and researches must match (Levkoff & Sanchez, 2003). The participatory action research model focuses on strategies geared towards developing community partnerships to enhance recruitment efforts (Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004; Travers, 1997). These consumer-centered models provide strategies used by the social marketing framework as a supplement to further develop recruitment campaigns, identification of impending problems and cost, and appropriate allocation of resources (Nichols, et al., 2004). The foundation of the social marketing principal is the feasibility of the techniques, the analysis and the planning, the execution, and lastly the evaluation of the program/

interventions to influence behavior of the target audience for the purposes of improving overall health (Andreasen, 1995). Although, the fundamental use of this theory is to change behavior and improve the welfare of the target audience and society in general, the use of its principles are also designed to enhance recruitment efforts, with the ultimate goal of improving research study success (Nichols, Malone, Tarlow, & Loewenstein, 2000). The social marketing principal has eight fundamental components that were originally listed in Lefebvre & Flora (1988) article. These components, include: 1) a consumer orientation to realize organizational goals, 2) an emphasis on voluntary exchanges of goods and services between providers and consumers, 3) research in audience analysis and segmentation strategies, 4) the use of formative research in product or message design and the pretesting of these materials, 5) an analysis of distribution (or communication) channels, 6) use of the "marketing mix"-that is, utilizing and blending product, price, place, and promotion characteristics in intervention planning and implementation, 7) a process tracking system with both integrative and control functions, and 8) a management process that involves problem analysis, planning, implementation, and feedback function. Adequate attention given to these components could result in recruiting a greater number of participants in a more cost-effective way (Lefebvre & Flora, 1988). Each of these eight components is described in more detail below. *These descriptions are adopted from the original Lefebvre & Flora (1988) article that addressed the social marketing theory with particular reference to the field of public health intervention.*

Consumer Orientation

The social marketing theory was developed from business marketing practices. There are two main orientations used in business, “production orientation” and “sales orientation.” The former orientation is geared towards increasing overall output and reducing costs. The latter orientation is predominately characterized by a selling and promotional effort aimed to generate more sales and greater profits. Notice that both of the business driven orientations are more agency-centered and do not give much attention to the consumers’ needs. As opposed to being sales or product driven, health marketing refers to programs that are geared towards consumer needs or satisfaction that uses strategy to reach a target audience who is in need of the program, for reasons specific to improving overall health (Lefebvre & Flora, 1988). The consumer driven model not only emphasizes efforts that are intended to respond to audience needs, but also considers 1) the implementation to meet the needs of the audience, 2) use of effective strategies to meet those needs, and 3) identification of new or changing needs. The key message in this particular component is that “needs assessment” is not the end but rather a means to an end.

In addition to the necessary steps required to meet the needs of the audience, some barriers may hinder the implementation and maintenance of consumer-oriented practices. These obstacles include the following: lack of clear objectives or inadequate needs assessment, failure to identify the key target audience, organizational pressures that place professional ideas or objectives above the needs of the target audience, organizational biases that practice programs that are mainly expert-driven, and situations in which the organization partners with an intermediary, who may alter delivery of the information or the message to the target audience (Lefebvre & Flora, 1988). Hence, it is important to recognize these barriers prior to the onset of program development to ensure success during program implementation.

Exchange Theory

While the underlying foundational principles of marketing are classified as consumer oriented, the mechanism in which it operates is rooted from a fundamental understanding of the exchange theory. Basically, the exchange theory bounds the social world as a continual series of exchanges. These exchanges can involve many different types of transactions, such as monetary means, products or services, or the exchange of communication or ideas. Nevertheless, in order for these transactions to be considered marketing transactions, it must involve, ideas, products or services that are being introduced deliberately. The exchange is also described as follows: “at the heart of exchange is the notion of profits. Profits can consist of benefits (or rewards) with less cost (or punishments). Rewards may be material (economic) or symbolic (such as attention, advice, or status). They are generally things defined as something that either has “value or bring satisfaction and gratification to the individual” (Robbins, Chatterjee, & Canada, 1997, p. 337). The resources that individuals have available to them for exchange in a health promotion setting include, money, time, physical efforts (i.e. exercise), cognitive efforts, psychological factors (i.e. self efficacy, coping skills), lifestyle and social contacts. Organizations in return typically offer technical expertise, money, ideas, products, and services. Consequently, individuals who comply with such programs benefit by improving health, quality of life, improving self-efficacy, better coping, overall well-being and increasing their number of social contact. As a result of individual involvement, organizations benefit tremendously from outside funding for research studies and therefore have the ability to continue conducting studies that benefit the society at large. Lastly, professionals need to be cognizant to the resource exchange that is intrinsic in dissemination of ideas, product use, and service delivery. Professionals need to capitalize on the benefits rather than solely attempt to address or emphasize on cost reduction (Lefebvre & Flora, 1988).

Audience Analysis and Segmentation Strategies

The concept of audience analysis and segmentation into meaningful subdivisions is a direct manifestation of the consumer-oriented schema. The main philosophy of this type of analysis is to identify consumers' needs and perceived cost and benefits of the program for both the organization and the consumer. There are two main goals in conducting an audience analysis. First, the organization needs to identify homogeneous subgroups for the purposes of designing messages and products. Secondly, the organization must identify segments for distribution and different communication channel strategies (Lefebvre & Flora, 1988). Examples of segmentation variable are, geographical region, demographics, social structure, and individual factors such as, personality, readiness level, needs, lifestyle, etc.). Various methods can be used for audience and segmentation analysis. These methods could be either direct or indirect. Direct methods include, but are not limited to the following: questionnaires, sampling surveys, or interviews (focus groups). Indirect methods are more available to organizations and therefore are utilized much more than the direct methods. Indirect methods are more cost effective (more affordable) and more readily available so organizations are more likely to use secondary sources such as, census data, reports from the Chamber of Commerce, national pools, etc. In fact, the use of more qualitative analysis such as focus groups can be extremely useful and beneficial in designing programs that are more effective, since this type of analysis can aid in understanding specific needs of the consumers that have had past experience and knowledge about the program. In fact, this helps organizations further understand characteristics of the targeted audience or segmented groups with respect to the behavior change process (Lefebvre & Flora, 1988).

Formative Research

The necessity of market and consumer research is often key to program success. Testing concepts, content and design, new products or services before dissemination is essentially one of the most important components of social marketing. This involves a pretest phase before full study implementation. It includes pretesting ideas, methods, and messages with the given target audience. Often times this is a critical weakness in social marketing, as many fail to properly execute the necessary steps prior to full implementation of program or dissemination of products and services. Commonly professionals view techniques such as focus groups, pilot studies, and interviews as luxuries, rather than provisions or necessities that are critical to program success (Lefebvre & Flora, 1988). This is particularly important in studies that have a lower level of funding. The use of these techniques will improve the effectiveness of the program, and help avoid costly and unsuccessful interventions before its full dissemination or implementation to a bigger audience.

Distribution Channel Analysis

Delivery of messages, services or products through various communication channels is an essential part of reaching the target audience about the various interventions or programs the organization has to offer. Channels may vary from mass electronic to print media, Internet, institutional access to a specific or definable population, schools, worksites, social organizations, churches, physicians' offices, nonprofit agencies, etc. In addition, several other techniques are also available for providing ways to reach the target audience. These methods include the following: public events, personal sales, direct mail and telemarketing. In order to determine which of these communication channels will best serve the organization's needs to reach the desired target audience, a thorough channel analysis will be required (Lefebvre & Flora, 1988). Despite the efforts needed to track the most influential selection of communication channels, it is imperative that the organization understands the channels in which the target audience most often comes in contact with, and gives adequate attention to the form of message or service it is disseminating. An individual's decision making process can be highly influenced by his or her interpersonal network. Hence, early efforts to aim for, and utilize a group of intermediaries for dissemination purposes are important to strengthen the communication process. Additionally, respected and credible sources of information can also support the adoption of new attitudes and behaviors (Rogers, 1983).

Lastly, communication channels can vary in a number of ways or through various other relevant dimensions, including: ability to convey complex messages, its medium (visual, print, electronic, auditory), its costs, frequency and continuity, number of intermediaries it may require, oversaturation, its ability to build multiple effects via building on one another and the level of perceived credibility.

Marketing Mix

Originally, the core planning, design and implementation of programs through marketing involved the combination of 4 distinct constituents, including: product, price, place and promotion. These four elements, also known as the “4Ps,” have been used in business and commercial sectors (Kotler & Zaltman, 1971), but have now been adopted by the health promotion field. More recent organization of the marketing mix model uses six key components, including: identifying the target audience (participants), developing the research intervention (product), managing the cost/barriers (price), improving accessibility (place), promoting the study (promotion) and working with partners (partnership) (Nichols, et al., 2004). As mentioned earlier the marketing of interventions promoting health can be extremely difficult, since many products that are being promoted are intangible. For example, an individual cannot buy a “healthier life” or a “better quality of life.” Hence, the challenge is to make these intangible goods more tangible (Lefebvre & Flora, 1988). The details of all the constituents will be further discussed in later chapters of this paper. Marketing a research intervention study is critical to ensure that the purpose of the intervention is not compromised due to ineffective recruitment strategies. Moreover the failure in planning, designing and implementing the six elements of the marketing mix could jeopardize recruitment and increase attrition rates in any study.

Process Tracking System

The ongoing activities in health marketing should be tracked. This provides a comprehensive control processes for an organization. It will help the organization track longitudinal data of utilization trends. This includes information such as ethnicity of participants, age, gender, and marital status- that will help the organization target segments of the population that are underrepresented. In addition, it will help track activities, identify elements of the program that are either underutilized or not being offered enough by the organization. If organizations do not manage its process tracking system, it will fail to recognize its own strengths and weaknesses of its marketing plan.

Managing Process-Feedback

Use of effective health marketing strategies alone will not be enough to compensate for an intervention that was not designed to address the target audience needs or expectations. A continuous feedback loop of research and revision is necessary to enhance efficiency and to design interventions that are of high quality, efficacious, and appealing. Despite the fact that health professionals are open to, and often times advocate the use of marketing principles, the truth is that these activities are poorly understood and not appreciated by many administrators/professionals in non-business fields (Lefebvre & Flora, 1988). In both business and not-for-profit sectors, there is a strong belief that when an organization uses marketing principles they become solely market-driven. If continuous feedback and revisions are made, then not only will the consumer benefit from health programs but so will the organization as a whole.

The Academy for Education Development (AED)

BEHAVE Framework

The Academy for Educational Development has established a simple method in organizing and understanding key elements that will advise organizations in better managing a marketing campaign. The BEHAVE Framework (see Figure 1), is a four-step framework that includes the following elements: target audience, action, determinants and marketing mix. This framework encompasses four simple questions, and encourages researchers to answer them. The first question is, *"who is your target audience, and what is important to that audience?"* the second question is, *"what do you want your audience to do?"* Third, "*What are the factors or determinants that influence or could influence the behavior and are they determinants that a program can act upon?"* Lastly, once the first three questions have been answered, *"what interventions will you implement that will influence these determinants so that the determinants, in turn, can influence the behavior?*" (Academy for Education Development [AED], 2008, p. 15). The answers to these sequential questions make up the fundamental steps of this framework. Most importantly, one must clearly understand the wants and needs of the segment audience in order to inform meaningful interventions, and must decide upon the target audience and action in order to move forward in identifying, addressing, and promoting the interventions desired for the potential participants to act upon. The BEHAVE approach is deceptively simple, however it requires a great deal of informed decision-making. Our study will use the social marketing BEHAVE framework as a way to develop, implement and evaluate all of its research study recruitment strategies.

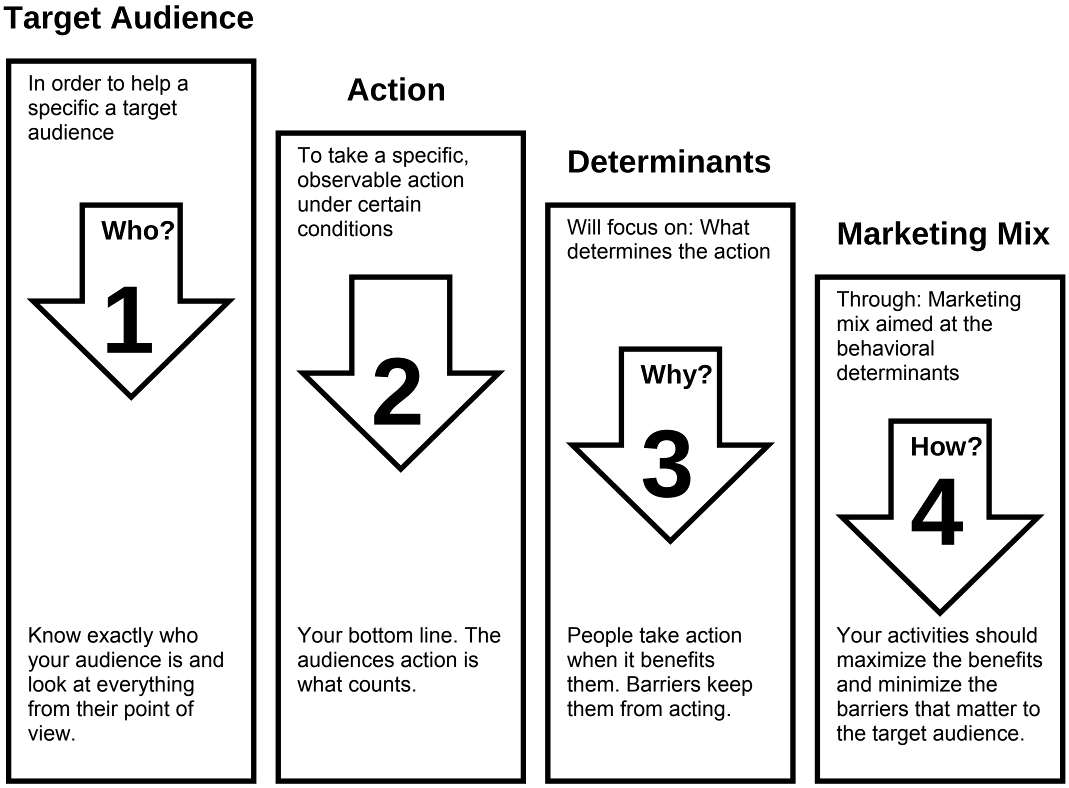


Figure 1. The BEHAVE Framework

BEHAVE Model Marketing Plan

In addition to developing the BEHAVE framework, the AED has developed a BEHAVE model marketing plan (See Table 1, AED, 2008). The plan is an eight-step process addressing the needs (why the program is being developed?), outcomes (What actions do the researchers want participants to engage in?), strategies (formative research, specifying the determinants of behaviors [benefits and barriers]), tactics (constructing the marketing mix), prototypes and pretesting (pilot study with potential participants), implementation, evaluation (is the marketing plan working), and feedback (further recommendation for the next stage of program development). This framework is a way of planning social marketing initiatives and it will be used for this study as well. Through a thorough literature review we will determine, 1) the wants and needs of our target audience (cancer survivors), 2) what it is that we want our potential participants to do (engage in psychosocial services online to lower cancer-related distress), 3) identify the barriers and benefits that could potentially influence the level of interest in participating in online psychosocial services, 4) implement or construct the right tactics that would influence their behavior, 5) pretest our initial study design, 6) implement program material and recruitment strategies, 7) evaluate the pilot study to make further recommendation for the next stage of implementation, and lastly 8) implement the new revised strategies to enhance recruitment and design interventions that are of high quality.

Social Marketing Logic Model

Finally, the social marketing logic model incorporates the eight-step marketing plan in a logical flow to demonstrate the process of the social marketing theoretical framework to methodologically develop, implement and evaluate intervention strategies. This social marketing logic model is illustrated in Figure 2 (AED, 2008) for the purposes of clarification and logical order of events that will need to take place throughout the stages of developing, implementing and evaluating our current research study.

Table 1.

BEHAVE Model Marketing Plan

	Audience +	**Action**	**Determinants**	**Marketing Mix**
Step 1: Needs	What's the social benefit? Why is the program being developed?			
Step 2: Outcomes	Define the audience (primary and secondary) and the actions you want each audience to take.			1-page description of each audience and action using existing research. Pose questions you need to know next.
Step 3: Strategies	Conduct formative audience research.	Based on research, determine key benefits and barriers. Define the potential change (e.g. Make helmets seems fashionable).	Chose the specific strategies to make that happen (e.g. Associate helmets with coolness).	A logical, research based written strategy that can be summarized in three or four brief bullet points. Suggest tactics. (see below)
Step 4: Tactics	Review audience research.	Review perceived benefits and barriers.	Chose tactics (e.g. Get sexy TV stars to wear helmets). Create materials.	Materials for audience (TV spots, posters, brochures, sticker, earned media placement, etc.)
Step 5: Prototyping	Gather audience in focus groups, one-on-ones, etc.	Test impact on perceived benefits and barriers.	Test pilot product, services, messages.	Research report.
Step 6: Implement	Possible ongoing research of audience awareness, attitudes and actions to determine the effect of the interventions.	Ongoing measures of perceived benefits and barriers, including appeal.	Initiate program (reproduce and disseminate materials, buy media, etc).	Program materials.
Step 7: Evaluate	Assess actions (are you changing the behavior).	Assess awareness, attitudes, perceptions, (precursors to behavior change).	Assess dissemination effectiveness.	Research report.
Step 8: Refine Program Question Everything	Are you in touch with audience? Did you pick the right audience: Is the audience changing?	Have you chosen the right barrier and benefits? Are attitudes changing? Are there unintended consequences?	Is your message getting through? (e.g. Is the creative "breaking through"?)	List of recommendations for the next stage of the program.

Note. Adopted from AED, 2008

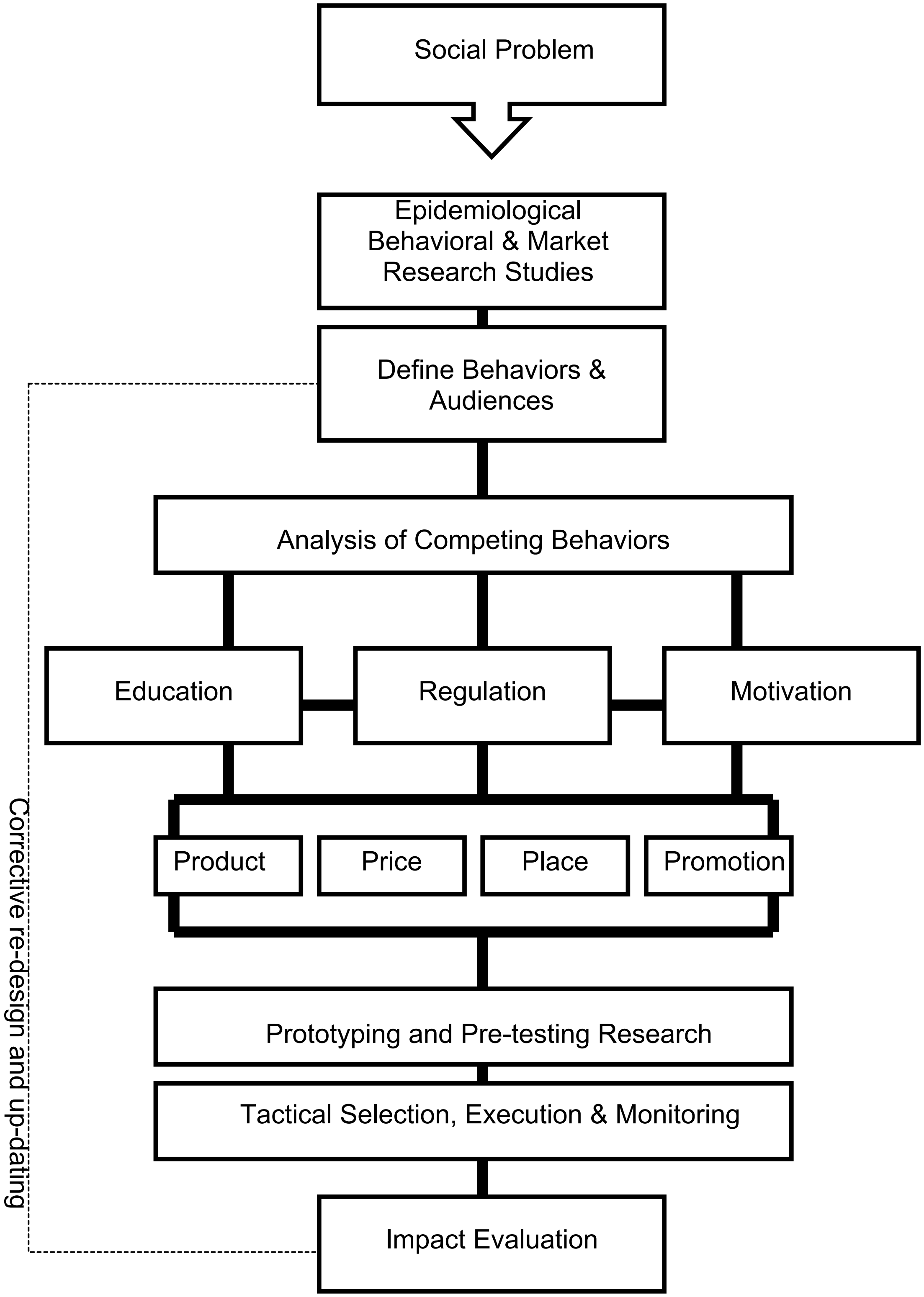


Figure 2. Social Marketing Logic Model

Thus far a brief overview of the classic studies on the topic of social marketing theory has been presented. Additionally, the social marketing theories application and applied value has been addressed. Subsequently, a thorough literature review is performed to address the following topics related to the audience and their behavior: 1) the *target audience* for this study, 2) what the target audiences' wants and needs are, and 3) the *behavioral determinants* that drive the target audience to engage in behaviors of interest.

Audience Research: Target Audience & Behavioral Determinants

Cancer Population

There are more than 11 million Americans living with a personal history of cancer (American Cancer Society [ACS], 2009). This chronic illness is not only a major public health problem in the United States (U.S.) but is also a huge problem in all parts of the world. Reports indicate that in the U.S, one in four deaths is caused by cancer. Statistics on incidence, mortality, and survival are estimated on a yearly basis by the ACS, based on data from the National Cancer Institute (NCI), Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), and the National Center for Health Statistics (NCHS). The estimated rates of new cases and death rates in the U.S. in 2009 are 1,479,350 and 562,340, respectively (ACS, 2009). Overall, reports indicate that there has been a reduction in the rate of cancer deaths over a 15-year period, including lower rates of prostate, lung and colorectal cancer in men, and breast and colorectal cancer in women (Jemal et al., 2009). However, cancer mortality could be further reduced by increasing knowledge across all domains of the general population and improving strategies for early detection, supporting discoveries, as well as, treatments.

Cancer treatment often times includes enduring various medical treatments such as chemotherapy, hormone therapy, surgery, radiation therapy, etc. Undergoing these medical regimens can weaken the quality of life even years after completing cancer treatment (Ganz et al., 2006). The psychological sequelae following a cancer diagnosis are poorly understood, and there is a great need to decode the dynamic complexity of this prolonged disease trajectory. While consequences of the cancer diagnosis may typically adopt an intransient set of assumptions, the transitory nature of the disease may need to be considered along a nonlinear spectrum both phasically and temporally. Studies indicate that level of distress severity not only increases subsequent to the cancer diagnosis and during the course of treatment (Harter et al., 2001; Stanton, Danoff-Burg, & Huggins, 2002), but this particular condition is also evidenced during the late stages of the disease trajectory (Ayres et al., 1994; Bloom, 2002; Deimling, Bowman, Sterns, Wagner, & Kahana, 2006), as well as years after treatment (Deimling, et al., 2006). In a study looking at quality of life of breast cancer patients at the end of primary treatment concluded that patients who underwent treatment improved emotional function but reported to have lower physical function. This was more commonly seen is patients who underwent chemotherapy or reported having had a mastectomy (Ganz et al., 2004).

In the general population, depression significantly impairs social, physical and emotional functioning (Hasin, Goodwin, Stinson, & Grant, 2005; Kessler et al., 2003; Williams et al., 2007). Major depressive disorder impacts approximately 13 million individuals living in the U.S. The Behavioral Risk Factor Surveillance System (BRFSS) lifetime prevalence of depressive disorder were greater in women than men, 20.2% and

11.1%, respectively (McKnight-Eily et al., 2009). Several studies have reported greater estimates of lifetime diagnosis of depression in Whites compared to the minority population (Riolo, Nguyen, Greden, & King, 2005; Strine et al., 2008; Williams, et al., 2007). However, higher point prevalence of current depressive symptoms has been reported in racial or ethnic minorities (Strine, et al., 2008). Other predictors of depression in the general population include: lack of comprehensive primary care services and insurance coverage (Das, Olfson, McCurtis, & Weissman, 2006), unemployment, lower educational attainment, divorced or never married (Strine, et al., 2008), and comorbid medical problems (Das, et al., 2006; Strine, et al., 2008). Several studies have also documented that the prevalence of depression in the general population decreases with increasing age (Beekman, Copeland, & Prince, 1999; Karel, 1997; Kessler, et al., 2003; Pirkola et al., 2005; Regier et al., 1988; Trollor, Anderson, Sachdev, Brodaty, & Andrews, 2007). Additionally, prevalence estimates drawn for the 2006 BRFSS data showed that unadjusted estimates of smoking, physical inactivity, obesity, heavy drinking, cardiovascular disease, diabetes and asthma were all significantly associated with lifetime diagnoses of depression (Strine, et al., 2008).

Cancer Distress

Although distress is thought to be relatively common in cancer survivors (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001), the scope of the problem is poorly understood. As noted in a “state of the science” conference evidence report by the Agency for Healthcare Research and Quality (U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, 2002), prevalence estimates for depression/anxiety in cancer are markedly varied- ranging from 10% to 25%. Estimates derived from single studies of the prevalence of meaningful distress, depression or anxiety has ranged from as low as 0% to as high as 61% (Massie, 2004). Additionally, estimates revealed that 64% of those diagnosed with cancer survive five or more years post-diagnosis (Rowland et al., 2004). Understanding the prevalence of distress is critical for allocation of necessary resources for screening, prevention, and treatment efforts.

Distress has been defined as a multifactor unpleasant emotional experience of a psychological, social and/or spiritual nature that can interfere with the ability to cope with cancer and its sequelae (National Comprehensive Cancer Network [NCCN], 2010). Emotional distress refers more specifically to the psychological experience of anxiety and depression, symptoms of which often overlap with physical problems associated with cancer and its treatment. Cancer distress studies have shown relevant association with overall outcomes, such that untreated distress in cancer survivors has been linked with lower treatment adherence (Ayres, et al., 1994; Colleoni et al., 2000; DiMatteo, Lepper, & Croghan, 2000), poor quality of life (Somerset, Stout, Miller, & Musselman, 2004), poor health behaviors, and higher mortality (Antoni et al., 2006; Spiegel & Giese-Davis, 2003). Several studies, including more recent ones, have documented an association between depression and cancer mortality (Hamer, Chida, & Molloy, 2009; Hjerl et al., 2003; Kaplan & Reynolds, 1988; Onitilo, Nietert, & Egede, 2006; Pinquart & Duberstein, 2010; Satin, Linden, & Phillips, 2009; Zonderman, Costa, & McCrae, 1989). Psychological distress has also been linked to poor prognosis in individuals with prior cancer diagnosis (Chida, Hamer, Wardle, & Steptoe, 2008). Furthermore, psychological distress is more robustly correlated with mortality in individuals with a history of cancer than those without a history (Hamer, et al., 2009), and the relationship between psychosocial distress and cancer mortality is mediated by both behavioral and physiological secondary factors (Sephton & Spiegel, 2003; Yang & Glaser, 2003). Consequently distress-lowering interventions targeting this particular population could potentially prolong survival, increase quality of life, improve treatment adherence, and result in better health behaviors, and overall outcomes.

Cancer Worry

Many cancer survivors experience both emotional and cognitive disruptions. These include symptoms associated with anxiety and the loss of control over the illness. These psychological effects of cancer manifest at any point in treatment and persist long after the initial diagnosis (Fredette, 1995; Gotay & Muraoka, 1998). Additionally, studies have shown that cancer survivors who were not in complete remission report higher levels of cancer-related worry when compared to cancer survivors in full remission (Lampic et al., 1994). The majority of emotionally experienced symptoms reported by survivors are anxiety and worry about the fear of recurrence (Cella & Tross, 1987; Fredette, 1995) and worry about general physical health (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997). Death anxiety is also commonly reported following the cancer diagnosis and has been shown to be more commonly experienced among those individuals with Hodgkin’s and testicular cancer (Cella & Tross, 1987). In part, beliefs about recurrence may be the driving force responsible for the persistent worry even during post-treatment. A study assessed the physical, psychological, and social function status of breast cancer survivors ranging from 6 months to 32 years post-surgery. Results indicated that survivors continued to experience thoughts about recurrence and nervousness associated with health check follow-up (Polinsky, 1994). In another study, women who had a previous cancer diagnosis reported more worry and greater belief about having more susceptibility to the risk of cancer when compared to women with no history of cancer (Easterling & Leventhal, 1989). Additionally, in this same study the authors found a positive correlation between worry and reporting of greater number of overall symptoms.

Although psychosocial stressors are thought to be relatively common in cancer survivors (Zabora, et al., 2001), the extent of the problem is poorly understood. Since distress is associated with lower adherence to treatment recommendation (Ayres, et al., 1994; Colleoni, et al., 2000; DiMatteo, et al., 2000) and poor prognosis (Chida, et al., 2008), many healthcare providers face challenges in dealing with psychological distress in cancer survivors, and the inability to attend to the needs of this population is generally demonstrated by the poor detection of psychological mood disturbance in health care setting (Lefevre et al., 1999; Schwenk, Coyne, & Fechner-Bates, 1996). Thus, understanding the extent of this problem is critical and necessary for the purposes of screening, prevention, and treatment.

Healthcare Utilization Among Cancer Survivors

Cancer survivorship is associated with a higher prevalence and severity of mood disturbance than exists in the general population (Kaiser, Hartoonian, & Owen, 2010) and is associated with poor quality of life (Somerset, et al., 2004). With respect to prevention or treatment, healthcare providers face many challenges in attending to psychological distress in cancer survivors. These challenges are demonstrated by studies showing poor detection of psychological mood disturbance (Lefevre, et al., 1999; Schwenk, et al., 1996), providers' concerns about distress management and with psychosocial coordination (Institute of Medicine report [IOM], 2007). Studies have shown that mood disturbance contributes greatly to increased health care expenditure. In fact, some studies have shown that mood disorders, comorbid with other chronic conditions are risk factors for increases in health care cost (Kalsekar et al., 2006). In the general population, mood disturbance is associated with increased utilization of a variety of healthcare services (Buck, Teich, & Miller, 2003; Ford, Trestman, Steinberg, Tennen, & Allen, 2004; Haas, Spendlove, Silver, & Holmberg, 1999; Kalsekar, et al., 2006; Katon et al., 1990). It has been postulated that the underlying factors that govern treatment-seeking behaviors may, in part, be associated with mental illness and not necessarily with the primary perceived condition the individual is seeking treatment for. An example would be that an individual with an anxiety disorder would persistently utilize the healthcare system for further reassurance about their fears of their perceived health condition (Ford, Trestman, Tennen, & Allen, 2005). Providing proper treatment is complicated by the fact that those with mood disturbance may at times seek inappropriate or excessive care due to unmet mental health needs (Bernstein, 2006).

Dissatisfaction with healthcare providers is also commonly seen in the general population and as a result of this dissatisfaction, the frequency of Emergency Room (ER) visits has generally increased (Sarver, Cydulka, & Baker, 2002). In regards to ER visits, state and national level data show that individuals, (and in particular, those with mental illness) utilize the ER as a primary choice of healthcare due to its convenience, accessibility, and affordability (Bernstein, 2006). Ragin et al. (2005) argued that the inappropriate ER use is in part an "affirmative choice" for care, rather than the only remaining option (Ragin et al., 2005). This inappropriate ER use by individuals with mental illness becomes a secondary phenomenon associated with unmet health needs and not necessarily a "provider of last resort," (Bernstein, 2006). Other studies have also shown that ER utilization has become a site for primary care treatment of mental health issues (Fuda & Immekus, 2006; Jones, Ames, Jeffries, Scarinci, & Brantley, 2001; Poveda Monge et al., 2000; Rassin, Nasie, Bechor, Weiss, & Silner, 2006). Studies on person level data show that 54.5% of ER frequent users (users that utilized the ER more than 5 times during a one-year period) made at least one visit in which a diagnosis associated with a mental health condition or substance abuse was given compared with 12% of infrequent users (users that utilized the ER less than 5 times during a one-year period) (Fuda & Immekus, 2006).

Andersen's Theory of Healthcare Services Utilization provides a theoretical framework that is potentially useful for identifying the individual determinant of healthcare utilization (Andersen, 2008). According to this behavioral model of health services use, utilization is likely to be associated with Predisposing factors (i.e., gender, age, race/ethnicity and marital status), Enabling factors (i.e., income, education, insurance coverage), and Need factors (i.e., time since diagnosis, BMI, smoking status self-reported health status and comorbidity). Self-reported health status and comorbidity are considered as indicators of perceived need and evaluated need, respectively.

A recent preliminary (unpublished) study used Andersen's Theory of Healthcare Services Utilization to examine the relationship between distress and healthcare utilization in breast cancer survivors after adjusting for various predisposing, enabling, and need factors. In this study, of particular interest was the effect of distress on utilization of healthcare services beyond that explained by the factors of evaluated need (as diagnosed by a healthcare professional) and perceived need (personal subjective evaluation of health status; Ormseth, Hartoonian & Owen, 2009). Population-based data were drawn from the combined years 2003 through 2005 Sample Adult Component of the National Health Interview Survey (NHIS). Predictor variables included the theorized factors of utilization and non-somatic depression. *Predisposing factors* were age (years), ethnicity (Caucasian, Hispanic, Black, other ethnicity), and marital status (married, single, separated/divorced, widowed). *Enabling factors* included insurance coverage status (insured, uninsured) and education (less than high school, high school, beyond high school). *Need factors* were time since diagnosis (years), BMI, smoking status (smoker, nonsmoker), self-reported health status (excellent to very good, good, fair to poor), and comorbidity (determined by an adaptation of the Charlson Comorbidity Index). Self-reported health status and comorbidity were considered as indicators of perceived need and evaluated need, respectively. The Kessler 6 was used as a marker of distress. The outcome consisted of measures of health care utilization over the prior year for the following medical services: emergency room, general practitioner, medical specialist, and mental health. Multivariate logistic regression was used to evaluate the effects of non-somatic depression on healthcare utilization after controlling for those predisposing, enabling, and need factors that showed univariate significance.

The results of this analysis concluded that distress remained significantly associated with likelihood of seeing a general practitioner in the past year ($p < .05$) after adjusting for the effects of age, insurance coverage, BMI, health status, and comorbidities. Furthermore, both evaluated and perceived need were shown to significantly predict having visited a general practitioner as a greater number of comorbidities and lower reported health status remained significant in the multivariate model (*ps* < .05). Likelihood of the use of mental health care services was significantly associated with distress after covarying for the effects of age, marital status, smoking, and reported health status (*p* < .05). Additionally, the perceived need variable of reported health status remained a significant predictor of use of mental health care in the multivariate model, with poorer reported health status associated with utilization of services (*p* < .05). After controlling for predictors of ethnicity, insurance coverage, smoking, health status, and comorbidities, distress remained marginally, but not significantly, associated with use of ER services (*p* < .10). Evaluated and perceived need did retain multivariate significance with ER utilization associated with a greater number of comorbidities and poorer reported health status (*ps* < .05). Though significant in the unadjusted analysis, after adjusting for the effects of age, ethnicity, education, marital status, time since diagnosis, insurance coverage, BMI, reported health status, and comorbidities, likelihood of use of medical specialist services was not associated with distress in the multivariate analysis. In contrast, evaluated and perceived need remained significant in the multivariate model with a significant association between greater number of comorbidities and poorer reported health status and medical specialist services utilization (*ps* < .05).

Despite the excess need for such services, cancer survivors are not receiving the proper attention to manage their level of distress. Challenges such as poor detection of mood disturbance (Lefevre, et al., 1999; Schwenk, et al., 1996), the concerns that providers have about how to manage distress, and poor coordination with psychosocial support services remain. It has become evident that cancer survivors are not receiving the proper psychosocial support services that they need, and as a result may be seeking services from their provider hoping to alleviate their level of distress. Additionally, the healthcare system in this country is changing, the quality of care has been falling short of expectation (McGlynn et al., 2003; Schuster, McGlynn, & Brook, 1998), and this has become a major challenge for many individuals who are facing a life-threatening illness, such as cancer.

Access of Healthcare Information on the Internet

In the past decade or so there have been recent changes to the overall healthcare system. Managed care organizations are enrolling more individuals (Block, 1997; National managed care companies increase share of HMO enrollment, 1996), providers are spending less time with patients, and costs are being more carefully monitored (Dugdale, Epstein, & Pantilat, 1999). In addition, more effort is put forth in transitioning care from an inpatient setting to more of an outpatient setting (Scutchfield, Lee, & Patton, 1997). The United States healthcare system has maintained a fairly stable position as the most expensive healthcare system in the world (The World Health Report, 2000). Surprisingly, as healthcare expenditure has increased in the past few decades, the enhancement of quality of care has been decreasing (The World Health Report, 2000). Another major concern that impacts both the cost and quality of care is the availability of access to care. These three factors, cost, quality and access are interrelated, and are extremely important to consider during any change in the healthcare system. What accounts for the majority of U.S. healthcare costs is the nature of the healthcare delivery system. A recent study from the University of California, San Francisco reported that the average U.S. patient-physician face-to-face time is about half the average of that in New Zealand and one-third of that in Australia. This has impacted the management of chronic conditions and helps to explain why Americans have poorer overall health outcomes compared to citizens of other countries (Bindman, Forrest, Britt, Crampton, & Majeed, 2007). The U.S. healthcare system does not meet the preventative, acute and chronic needs (medically and psychologically) of its population, leading to increased utilization and expenditure. The low relative ranking of our healthcare system shows there is an inverse relationship between quantity and quality. Consequently, our model has been moving further and further from one focused on quality.

While all these changes have been taking place, the Internet is becoming the main source of health information delivery system. Overall, this has given the consumer more control of their own health care and has allowed consumers to seek health care information via this particular medium (Pennbridge, Moya, & Rodrigues, 1999). Additionally, consumers are now more informed and they are taking charge of their own health care (Marietti, 1998). According to the Institute for the Future, Five-Year forecast report, the health care system has discovered the Internet and it is rapidly growing. In fact, there are “strong” and “unstoppable” driving forces that are pushing the Internet to become increasingly integrated in our health and health care. The Internet is used as a channel for disseminating health information, provides diversity of health care information, provides online global network communities for individuals with common interest and support, e-mail, e-commerce, forming sites for consumers to share stories and experiences and also delivering the information and resources at a very low-cost (Mittman & Cain, 1999). Studies have also reported that in addition to using the Internet for health information, of those who use it, approximately 10% of them participate in online social support groups associated with a medical condition (Pew Internet & American Life Project, 2009). Furthermore, the internet is now widely used for purposes of recruitment (Leveille, Huang, Tsai, Weingart, & Iezzoni, 2008) and intervention delivery (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006).

In contrast, many barriers exist when integrating the Internet into health and health care. These barriers include, but are not limited to the following: security concerns, weakness in web browser and search engine technologies, poor-quality of information on numerous websites, the uncertainty and uneven quality of publically-available information, and also low physician acceptance of its use. In addition, the disarray of information and the lack of universal standards for communications and transactions may also act as barriers (Mittman & Cain, 1999).

Theories of Internet Usage

Many theories of Internet use have been proposed in the past couple of decades. In fact, some have used Bandura's social-cognitive theory including the enacting learning as an important model in understanding how interactions with media environment influence media exposure. This interaction is explained by continually altering expectations about behaviors pertaining to future media consumptions (LaRose, Mastro, & Eastin, 2001). The gratifications sought-gratifications obtained formulation has been a parallel model that seems to be indistinguishable from the underlying mechanism governing the social-cognitive theory. The reciprocal relationship between the individual, his or her environment, and behavior is explained by Bandura's social-cognitive theory (A. Bandura, 1963; Albert Bandura, 1977, 1986; A. Bandura, 1989, 2004) and is represented similarly in the gratification model- the reciprocal relationship between gratifications sought, media behavior, and gratifications obtained (LaRose, et al., 2001; Palmgreen, Wenner, & Rayburn, 1980; Palmgreen, Wenner, & Rosengren, 1985). In principle, a distinction between gratification sought and gratification obtained may be drawn by the expectations one has about the content formed prior to exposure and the satisfaction gained from the utilization of the content (Katz, Gurevitc.M, & Haas, 1973).

The gratification approach has been traditionally used in media research. The core question of such research is why do individuals use media and what do they use it for? (McQuail, 1983). The gratification approach suggests that individual's needs tend to influence their choice of media, its use, and the gratification obtained. The gratification approach emphasizes the individuals' choice by evaluating the reason behind why one media content is picked over another, as well as the predictors of gratification obtained. An individual chooses information and integrates the content to either satisfy his or her needs or gratify his or her own interest (McQuail, 1983).

Furthermore, with increased usage of the Internet, many have developed models that better define patterns and predictors of use (Jackson, Ervin, Gardner, & Schmitt, 2001a, 2001b). Jackson et al. (2001a,b) proposed the idea that many psychological factors play a key role in determining patterns of use, including: motivational, affective, and cognitive. Individuals use the Internet to satisfy their motives and to increase positive affective response. Internet use may also alter social motivation, positive affect, and attitude towards technology in general (Jackson, et al., 2001a). Findings also indicate that there are distinct differences between Internet usage among males and female, such that males are more likely to use the Internet for information and women are more likely to use the Internet for communication (Jackson, 1998). In a study examining the use of the Internet for information and support in breast and prostate cancer patients, it was concluded that communication focused on cancer-related information was more commonly seen in prostate cancer patients. In contrast, study results also concluded that breast cancer patients were more likely to use communication focused on emotional support (Demasio, 2003). Usage also varied in ethnic minorities, for whom it is believed that the use of the Internet is lower (James et al., 2007). Furthermore, studies have shown that online support group use is also lower in ethnic minority women (Im & Chee, 2005; Im, Chee, Tsai, Lin, & Cheng, 2005). Im et al. (2005) reported that only 24 out of 546 online cancer support groups were intended for minorities and the participation of minority women in women-only online cancer support groups were as low as 1% (Im et al., 2005).

What Kind of Information are They Looking For?

Despite the obstacles that many face with the healthcare industry, individuals are using the Internet to obtain health-related information. The use of the Internet for purposes of seeking health information has become increasingly pervasive worldwide. Health Information Technology research has shown that 74% of U.S. adults use the Internet, and of these users, 61% have used the Internet to access health or medical information (Fox & Jones, 2009). In this same study, it was also found that 49% of adults who searched the Internet for health information were looking for information about a specific medical condition. Additionally, studies examining the use of the Internet for health information have shown that there is increasing knowledge about the type of information sought (James et al., 2007), and that the informational needs of individuals can change over time (Rozmovits & Ziebland, 2004). The same study also reported that "access to practical and experiential information from other patients was highly valued" (Rozmovits & Ziebland, 2004), and that there is clear preference for non-commercial sites when looking for health information (Rozmovits & Ziebland, 2004).

Estimates derived from the Health Information National Trends Survey 2003-2005 provide useful data to better understand Internet usability and trends in retrieving health-related information. In 2003, 50.7% of participants reported using the Internet to look for health information. In 2005, 58.4% of participants reported using the Internet to search for health information (Rutten, Moser, Beckjord, Hesse and Croyle, 2007). In addition, women (58%) were more likely than men (43.4%) to use the Internet for health related information. Of these adult online users, women (4.1%) were more likely to use online chat groups than men (2.5%) to learn about health topics (R. A. Cohen & Stussman, 2010). Furthermore, a study confirmed that 81% of young adults of average age of 22.9 years reported that they used the Internet for research for school or work, 80% reported that they use it to access email or chat groups and 43% looked for health information. Among those who accessed the Internet for health information, 52% looked for information related to diet and nutrition and 43% for fitness and exercise (Hanauer, Fortin, Dibble, & Col, 2003).

Many individuals are utilizing the Internet to obtain health related information. This is also true for cancer survivors. Questions related to the type of information sought, and why that type of information is important for individuals with cancer will help highlight salient factors for study investigators to capitalize on for this study. The needs of the target audience are one of the most important questions that will have to be answered in order to develop and implement effective programs and recruitment strategies for study success.

Why is Information Seeking Important For Individuals with Cancer?

Over the past several years, communication, exchange of practical information, and health related information has been considered extremely valuable in helping individuals to cope with cancer (James, et al., 2007). When faced with a potentially life threatening disease, such as a cancer diagnosis, knowledge about the illness, treatment, and prognosis may provide some support for the patient and facilitate coping by alleviating feelings of uncertainty and symptoms of anxiety (Derdiarian, 1987). Providing input about care and having information about prognosis, treatment options and general information about diagnosis is fundamentally important for those who have been diagnosed with cancer. The process of active patient involvement in decision making about their own medical condition and treatment has been increasing over the past decade (Dutta-Bergman, 2005). Studies have shown that the need to seek information goes beyond simply the need to make decisions. It is important for many other reasons, including greater satisfaction with the choice of treatment (Luker et al., 1995), better coping skills, and lower levels of anxiety (Rees & Bath, 2001). Information and successful communication is vital to meet the needs of cancer survivors, however defining specific informational needs still remains a complex phenomenon yet to be uncovered. The informational needs of cancer survivors vary depending on the course of the illness or patterns of informational needs, and Internet use may differ across the illness trajectory (Ziebland et al., 2004). In one study, those who used the Internet for health information expressed preference for sites that were affiliated with well-known universities or medical centers, and non-commercial sites. In addition, respondents expressed that they evaluated and compared information from a number of sources before fully trusting it (Rozmovits & Ziebland, 2004). A thorough exploration of influential factors that effect information seeking behaviors in cancer survivors is important for developing communication-based interventions (Mayer et al., 2007).

Models of Information Seeking Behaviors

Many models of health behavior change consider variables such as beliefs, awareness and knowledge as important factors that contribute to the understanding and support in health behavior change. Conceptual models have been proposed to link information seeking behaviors to models of health behaviors. Numerous information-seeking models have been proposed to describe causal pathways of the delivery of health information. For the most part though, these models focus primarily on factors related to the communicator or sender of information. With cancer survivors, increasingly engaging in motivated information seeking behavior it is also necessary to consider health information communications from the perspective of the recipient.

One widely used model that does precisely this is Johnson and Meischke (1993)

Comprehensive Model of Information Seeking (CMIS; See Figure 3). The Johnson and Meischke's (1993) CMIS model is based upon the synthesis of three theoretical research areas, which include uses and gratification, the Health Belief Model, and a model of media exposure and appraisal. These authors propose that individuals' selection of media is goal directed. This model looks at how demographic characteristics, direct experiences with cancer (symptoms and social network), salience (perceived applicability of information), and beliefs (individuals' beliefs in the efficacy of procedures) along with the characteristics (the attributes of the content or carrier of the information) will affect the utility (does the information directly relate to the individual) of the information. Both the characteristics and utility of the information will directly affect the actions taken by the individual (Johnson & Meischke, 1993). In Johnson and Meischke's (1993) study of their CMIS model, they postulated that antecedent factors, such as demographics, direct experience, salience and beliefs motivate cancer survivors to seek information in magazines. Originally, the CMIS was used to study breast cancer information seeking in magazines. Because the CMIS is amenable for use to model cancer information seeking in populations, research has often focused on the unique information needs of cancer survivors.

Despite the usefulness and the attributes of the content or carrier of information, information seeking behaviors may be either active, passive or just simply avoided (Case, Andrews, Johnson, & Allard, 2005; Mayer, et al., 2007; Miller, 1995). In the literature, Miller (1995) reports two basic modes of coping with medical stressors. These modes are defined through either monitoring or blunting. Monitoring is when the individual gives attention to, scans for, and amplifies the threatening cues. Whereas, blunting is the avoidance of the potentially painful, threatening cues (Miller, 1995). Information seeking or avoiding have shown to potentially moderate perceived severity and susceptibility, help provide cues to action, and alter both psychological and behavioral outcomes (Czaja, Manfredi, & Price, 2003; Dutta-Bergman, 2004). In fact, studies are providing a framework to tailor information about cancer to best-fit patients' attentional coping styles (Gattuso, Litt, & Fitzgerald, 1992; Mayer, et al., 2007; Miller, 1995; Watkins, Weaver, & Odegaard, 1986). Cancer survivors who are characterized as monitors tend to be more distressed about their cancer risk and are commonly more concerned about their care than blunters. For example, Miller (1995) reported that those who are characterized as monitors are more knowledgeable about their condition, have more demand for their care, report higher levels of discomfort (side-effects) and are generally more dissatisfied. However, blunters are more likely to adhere to treatment recommendation and are more likely to be passive in decision- making. In addition, when faced with cancer-related threats, they are more likely to experience psychological distress (Miller, 1995).

In 1981, Wilson (1999) developed a basic framework explaining information seeking behaviors and different characteristics of information behavior. However, after proposing several models that address issues at different levels of behaviors related to information seeking, Wilson then integrated complementary models originally proposed by him. After integrating complementary models with other information seeking models, he presented this basic framework explaining information seeking in his more recent publication (Wilson, 1999). In this model, he presents three theoretical ideas including, the stress/coping theory (Folkman, 1984), risk/reward theory (Murray, 1991; Settle & Alreck, 1989) and social learning theory (Albert Bandura, 1977). The stress/coping theory provides information to help better understand why some individuals' needs do not demand seeking information. The risk/reward theory helps explain why some individuals are more likely to use certain sources of information over other sources (Murray, 1991; Settle & Alreck, 1989). And finally, the Social learning theory helps explain how self-efficacy plays a critical role in better understanding how ones beliefs about executing a behavior successfully is an important factor needed to generate the desired results (A. Bandura, 1977). Figure 4 depicts Wilson's 1995 model. In addition, to the three basic theories serving as activating mechanisms in this model, the intervening variables such as, psychological, demographic, role-related or interpersonal, environmental and source characteristics have both a supportive and preventative impact on information-seeking behaviors. Information seeking behaviors, either passive or active can have an overall impact on information processing and use, which in turn can affect satisfaction of informational needs (Wilson & Walsh, 1996).

Some earlier findings have demonstrated that those who are information seekers (monitors) experience lower level of distress when given a higher quantity of preparatory information when compared to those who were given less (Miller & Mangan, 1983). In studies looking at the relationship of coping style to cancer treatment side-effects, the authors showed that blunting or distraction-oriented coping style was correlated with lower levels of anticipatory anxiety, and lower level of depression and somatic symptoms (Lerman et al., 1990). More recent findings suggest that tailored health messages that are salient could contribute to the increase in early detection behaviors (Latimer, Katulak, Mowad, & Salovey, 2005). Moreover, this study suggested that strategies such as psychologically tailored materials should be used to support the usefulness of cancer information services. In general, matching patients' coping style (monitor vs. blunter) to the quantity of information given, the content of the information and the type of psychosocial intervention is important, and may be useful for improving overall outcomes (Manfredi, Czaja, Price, Buis, & Janiszewski, 1993; Mayer, et al., 2007; Miller, 1995; Miller & Mangan, 1983).

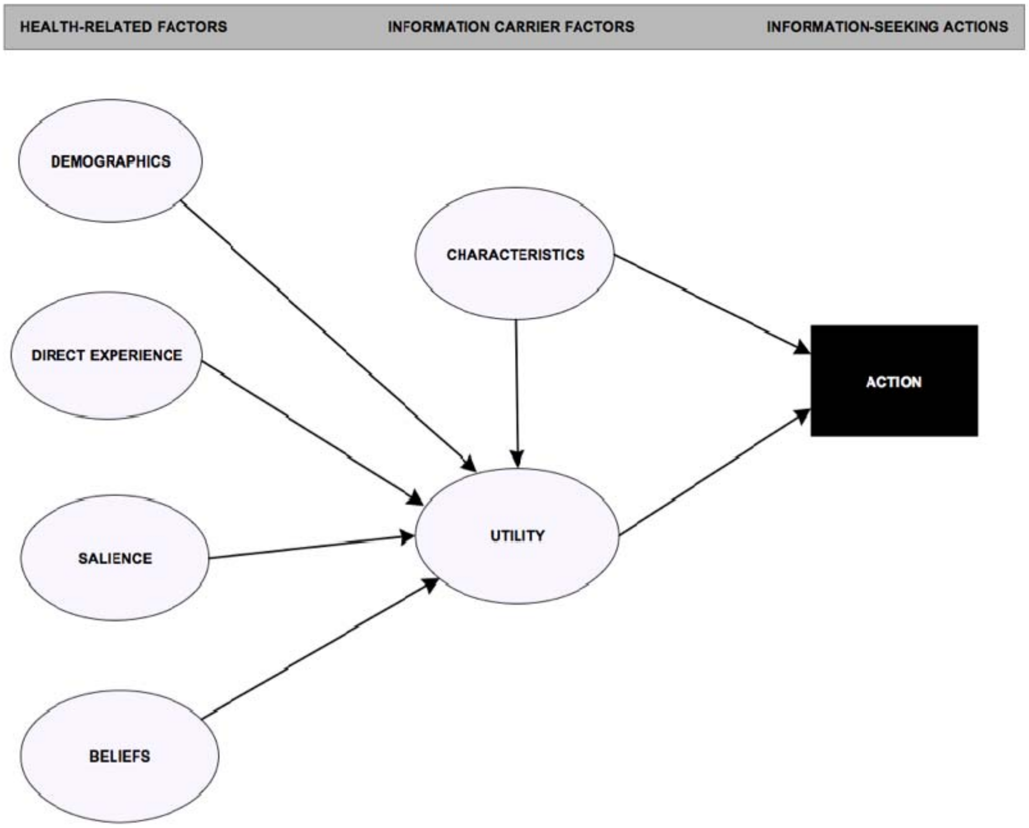


Figure 3. Johnsons Comprehensive Model of Information Seeking

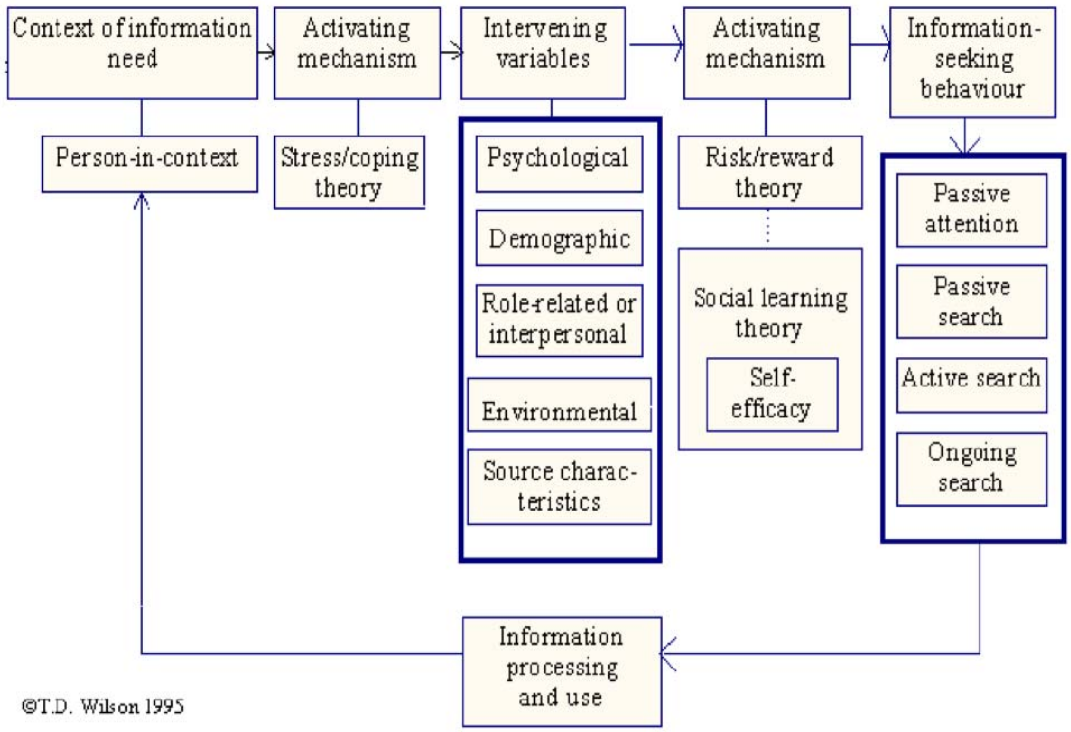


Figure 4. Wilsons Model of Information Seeking Behaviors

The knowledge of theories and frameworks that govern the fundamental understanding of information seeking behaviors is important for promoting studies that require high levels of participation and engagement. The two above theories reflect why the target market is seeking specific types of information and what determinants are drivers of such behaviors. By using information derived from these theories in an *a priori* fashion, it may influence decision making about what problem to tackle, how to segment or subdivide the audiences, what objectives are best to be used during program development, how to effectively develop strategies and tactics for the program, how to test the strategies and manage the implementation and dissemination processes, which messages are salient enough to resonate with the target audience and how to best promote our services.

Using Internet For Social Support

A review of the literature shows that approximately 58% of cancer patient use internet support services (Monnier, Laken, & Carter, 2002). Monnier et al. (2002) attempted to understand and identify the needs for, the overall interest in, and the feasibility of employing web-based cancer support site. The results of this particular study showed that both cancer patients and caregivers display interest in using web-based services for information, making contact with physicians, and accessing online social support groups. In addition to the high level of interest, 70% of both patients and caregivers reported that they would use these services. However, older age, lower education attainment, and being a minority contributed to a lower likelihood of using the Internet (Monnier, et al., 2002). Utilization of Internet services has shown to increase levels of social support, decrease loneliness, and lower symptoms of depression and anxiety (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Lieberman et al., 2003). In a fairly recent study, Beaudoin & Tao (2007) demonstrated that the Internet may potentially be a positive cyber venue for cancer survivors who are in active treatment and are seeking out social support (Beaudoin & Tao, 2007). Moreover, implicit to their original model of how Internet use impacts health outcomes (Thorson & Beaudoin, 2004), the authors propose that lower distress and an increase in coping may aid to cancer recovery (Beaudoin & Tao, 2007).

Other studies have looked at the impact of Internet cancer support communities on emotional support (Wright, 2002). Wright (2002) reported that emotional support and stress were inversely related. Web-based support groups allow individuals to maintain contact with a large network of people who may share the same medical condition. These large networks provide individuals the opportunity to turn to others during crisis or simply offer a common place for daily support (Braithwaite, Waldron, & Finn, 1999). Furthermore, since cancer patients' may face negative social stigma (Koller et al., 1996; MacDonald & Anderson, 1984), they develop a greater need for interpersonal relationships with other cancer survivors (Wortman & Dunkelschetter, 1979). MacDonald and Anderson (1984) investigated the effect of social stigma on outcomes, and results of the study indicated that stigma is associated with many factors of health related maladjustment, including, restricted physical, emotional and social adjustments. Often patients report that after facing a life-threatening illness like cancer, many individuals in their social group or network withdraw despite their need for support (Cluck & Cline, 1986). Cancer survivors seem to show great interest in using web-based social services related to their illness (Monnier, et al., 2002) and efforts to make social support websites available for this population are important and may extend the ability of psychosocial interventions to improve psychosocial functioning in this population. It is important to also make special efforts to meet the needs of ethnic minorities, older individuals, and those with lower educational attainment when implementing internet-mediated social support programs.

Efficacy, Feasibility and Limitations of Online Psychosocial Interventions

Understanding factors that are associated with increased participation in psychosocial intervention is essential in further improving its effectiveness.

Factors Influencing Participation in Psychosocial Intervention

Owen et al. (2004) reported that three factors contribute to participation in psychosocial interventions and may, in part, be a function of the following: perceived interest (stage of disease, time since diagnosis, existing support, etc.), availability (what support services are available in the community, awareness of these support services, individual vs. group support options, etc.), or accessibility (time constraints, distance from the individuals home, lifestyle responsibilities, etc.). In one study, investigators looked at the level of participation and interest in women with breast cancer. Several factors were reported to influence individual participation were surgery (those who have had surgery in the past 12 months), higher levels of anxiety, greater distress and those survivors between the ages of 50-65 (Fukui et al., 2001). Investigators also reported that among the 58% of non-participants, 73% were interested in the intervention, and those who did not have interest and did not participate reported significantly greater level of anxiety compared to those who showed interest but did not participate (Fukui, et al., 2001). Conversely, studies have concluded that the refusal to participate in psychosocial interventions is often due to lack of family support or encouragement in joining these psychosocial interventions and progression of disease (Gustafson, Taylor, Thompson, & Chesney, 1993). It is important to bridge the gap between patients' interest to participate and the process of becoming an active participant in these psychosocial services. The social marketing theory will help bridge the gap between individuals' interest to join psychosocial services and actual participation. This paper plans to investigate the wants and needs of potential participants to better inform study coordinators about potential key elements that will help improve the design and implementation of recruitment strategies and intervention. Individuals with a cancer diagnosis who express interest in psychosocial services may also need services outside of the psychosocial domain and providing such support services is central to their recovery process.

Traditional Face-to-Face Versus Online Psychosocial Interventions

Traditional face-to-face cancer support groups have been evaluated and well documented in the literature, showing positive outcomes on overall quality of life in survivors (Bramsen et al., 2008; Cella & Yellen, 1993; Grassman, 1993). Support groups can provide emotional support, assist with psychosocial adjustment, and help patients cope with their life-threatening illness (Cella & Yellen, 1993). Cancer patients may be vulnerable to experiencing a high level of cancer-related distress, feelings of anger, worry about prognosis, uncertainty about the future, physical and cognitive impairments, fatigue, pain, and mood disturbance (Galloway & Graydon, 1996; Gaston-Johansson, Fall-Dickson, Bakos, & Kennedy, 1999; Gaston-Johansson, Ohly, Fall-Dickson, Nanda, & Kennedy, 1999; Zabalegui, 1999; Zabora, et al., 2001). Though many individuals with a cancer diagnosis experience illness-related distress, studies have documented the beneficial effects of psychosocial interventions on improving quality of life and mood in cancer patients (Cella & Yellen, 1993; Meyer & Mark, 1995; Newell, Sanson-Fisher, & Savolainen, 2002; Spiegel, 1994, 1995, 1997; Spiegel & Kato, 1996). Evaluations of such programs have shown promising results, despite the arguments against its effectiveness and lack of methodological validations (Coyne, Lepore, & Palmer, 2006). A large literature on psychological treatment has documented decreasing feelings of isolation, increasing affective expression (Samarel et al., 1998), increasing positive functional performance, elevating mood and satisfaction (Coward, 1998), better coping related to illness (Shapiro et al., 1997), decreasing distress and making fewer physician appointment related to their illness (Stanton et al., 2000), and prolonging survival by 18 months (Spiegel, Bloom, Kraemer, & Gottheil, 1989).

The Institute of Medicine has also concluded that, "there is statistically significant, clinically relevant evidence to support the effectiveness of psychotherapeutic interventions in helping to manage anxiety or depression in adults with cancer- across disease sites, treatments, and types of interventions" (IOM, 2007, p.75).

Despite the effectiveness of face-to-face psychosocial interventions, the benefits are not experienced by most of cancer survivors. Many cancer survivors are unable to attend these services due to poor overall health (Gustafson et al., 1994) or living too far from the facilities that is offering the psychosocial treatment (Owen, Klapow, Roth, Nabell, & Tucker, 2004). Therefore, feasibility of these interventions becomes an important topic of discussion. In fact, a more popular alternative to traditional face-to-face support groups is the Internet-mediated support groups, which have become highly popular over the past several years.

Internet support groups have potential to overcome some potential drawbacks of the traditional face-to-face support groups. For example, time and distance can be a major barrier, and convenient meeting times do not suite all attendees equally (Klemm et al., 2003; Klemm, Reppert, & Visich, 1998). Online support services also provide anonymity (Finfgeld, 2000), information and support (Fernsler & Manchester, 1997; Sharf, 1997). In fact, several studies on internet-based psychosocial interventions have concluded early support of its effectiveness and success (Fernsler & Manchester, 1997; Gustafson et al., 2001; Gustafson et al., 2002; Lieberman, et al., 2003; Owen et al., 2005; Sharf, 1997; N. Weinberg, Schmale, Uken, & Wessel, 1996). An evaluation of an Internet coping group for women with breast cancer examined the effect and mechanisms of action of an internet-based coping-skills training group on quality of life in women with early-stage breast cancer (Owen, et al., 2005). No main effects were found, but women with poorer self-perceived health status showed greater improvement in perceived health over time when assigned to the treatment condition.

Since only a few studies have shown promising effects of Internet-based psychosocial interventions, we will examine more closely the positive outcomes reported by the successful working models used in these studies. The Comprehensive Health Enhancement Support System (CHESS) is a computer-based health promotion and/or behavioral change system intended to assist patients and their families to become more active in their treatment process. The Comprehensive Health Enhancement Support System intends to offer health information, to provide social support services and decision-making support, to help address issues regarding health behavior change and to increase social networking with individuals who are facing similar life threatening illness with the ultimate goal of improving individuals' quality of life (The Center for Health Enhancement Systems Studies [CHESS], 2006). The first pilot test of CHESS was conducted in 1989 with this particular system including topics like Breast Cancer, Living with HIV/AIDS, Adult Children, Stress Management, Sexual Assault and Academic Crisis (CHESS, 2006). In 1987, Dr. David Gustafson built CHESS and conducted several studies on the effectiveness of this system on overall quality of life. In one of his studies, Gustafson et al. (2001) assessed the impact of home-based computer intervention, or

CHESS, on quality of life in women with breast cancer. The intervention included decision-making support services, informational content, and emotional support. The study concluded that CHESS improved social support, significantly improved information competence, increased participation in health care and quality of life; however, the effects of CHESS were reported to be stronger in the short run and less consistent five months after implementation (Gustafson, et al., 2001). In contrast, the study results of the 5-moth follow up reported null finding with respect to health care participation (behavioral involvement, level of comfort and confidence in doctor) and quality of life (social/family well-being, emotional well-being, functional well-being, and breast cancer concerns; Gustafson, et al., 2001). Another study evaluated the effects of online support groups on psychological distress in women following a diagnosis of breast carcinoma. Study investigators evaluated a 12-week structured online support group in a randomized clinical trial that was geared for women with breast carcinoma. The intervention was aimed to improve coping skills and lower distress. Results showed that Internet-based psychosocial intervention significantly reduced participants' level of distress, perceived stress and cancer-related trauma (A. J. Winzelberg et al., 2003). The effect size of this study ranged from 0.38 to 0.54 and is known to be one of the best methodologically sound studies thus far in the literature looking at Internet based support group for cancer patients.

Feasibility

Online support groups are a cost-effective method for delivering psychosocial support and education to cancer patients (Gustafson, Bosworth, Hawkins, Boberg, &

Bricker, 1992; Lieberman, et al., 2003). Internet-based support services are available to individuals during all hours of the day. It also eliminates the need for a meeting location and the need for those who are interested in participating to have to travel from their home to the treatment facility (N. Weinberg, Schmale, Uken, & Wessel, 1995; A. Winzelberg, 1997). This enables individual's 24-hour access to the services, enabling participants to access services outside of typical clinic hours

(Finn, 1995; N. Weinberg, et al., 1996). More than half of online posting in an online group occur between the hours 6 p.m. and 7 a.m. This suggests that online support group users have better flexibility in accessing services outside of the usual clinic hours (Finn, 1995). Additionally, Internet-based support allows individuals living in rural areas the opportunity to participate in psychosocial interventions or just simply take advantage of support services who otherwise would not be able to attend the traditional face-to-face support groups due to living far away from the treatment facility, lack of transportation or transportation cost (Sullivan, Weinert & Fulton, 1993). One of the advantages characterizing Internet-based support services is to give potential participants living in disparate geographic locations the opportunity to engage and benefit from support services (Danaher, Hart, McKay, & Severson, 2007; Gustafson et al., 2005). Even though the level of distress of cancer patients from rural area is similar to those individuals living in urban areas (Lancee et al., 1994), rural communities are underserved medically (Herman, Lengerich, & Stoodt, 1996), socially isolated leading to poor coping skills (Rowland, 1994), and have poor health related outcome. These factors are noted to be amplified by geographic isolation, limitation to resources and lack of transportation (Sullivan, et al., 1993).

Women with breast cancer express higher levels of interest in Internet-based support groups than for face-to-face groups (Owen, et al., 2004). Moreover, lung cancer patients have also expressed interest and great need for supportive care services. In fact, one study reported that 91% of participants expressed interest in supportive care service (Curran et al., 2008). The physical demands of cancer treatment may have severe side-effects, making attendance of a traditional face-to-face support group very difficult (Fernsler & Manchester, 1997). Individuals with potentially life-threatening diseases, such as cancer, may be more willing to discuss sensitive issues and self-disclose personal information online rather than face-to-face (White & Dorman, 2001). A more recent study has documented the feasibility of online support for women with breast cancer (Owen, et al., 2004). The goal of the study was to better understand factors that contribute to interest in participation and identify factors that could increase the efficiency of recruitment. Greater levels of interest in participating in an online psychosocial treatment were associated with women under the age of 65, higher need to offer social support to other participants, and greater preference for Internet over face-to-face support. Study results also indicated that the effects of social support, perceived difficulty sharing feeling and the effects of social support where mediated by outcome expectancies. In contrast, the stage of disease and time since diagnosis were not associated with the level of interest in participating in an online psychosocial intervention (Owen, et al., 2004).

This promising body of evidence examining the efficacy and feasibility of Internet-based psychosocial interventions suggests that cancer survivors express comparable levels of interest in Internet-based support groups than for face-to-face groups. Second, the physical demands of disease treatment may have severe side effects, making attendance of a traditional face-to-face support group very difficult. Third, cancer patients may be more willing to discuss issues and self-disclose personal information online rather than face-to-face. Lastly, social support can play a role as a mediator to enhance the efficacy of the intervention among cancer patients.

Limitations of Online Social Support Sites

Despite the fact that majority of the online intervention studies have reported promising results, there have been some major limitations. The earlier studies were limited in its availability of technological advances contributing to the low level of online interactivity, and most of the studies were limited to women with breast cancer. Thus far, studies have looked at the level of distress across all cancer types but online interventions have mainly focused on using women with breast cancer as their target population. Zebora et al. (2001) concluded that individuals with other types of cancer experience greater amount of distress compared to women with breast cancer. Furthermore, in this particular study we postulate that the greater the distress the more likely they are to join our online interventions. Furthermore, the use of more advanced technology to improve social-networking website features may help increase individuals interactivity with the website features (Gustafson, et al., 2002). Additionally, studies with more technological advances will have better tracking of participants overall interactivity with the website and will provide the researcher the opportunity to track behavioral engagements, interactivity with different features of the websites and overall health quality outcomes.

These advantages have the potential to create continuous feedback loops allowing strategies to be evaluated and reevaluated. The ability to evaluate previously used strategies may help identify major gaps in study development that was not initially designed to address participant expectations. This will allow study investigators to revise study methods to increase recruitment and participation, improve program design; making it more appealing to the participants, and identify more effective strategies to guide future cancer research and outreach. The information gathered from technologically advanced social-networking websites in which the infrastructures allows for advanced storage and gathering of data, will help researchers monitor flow and identify specific predictors of audience participation and retention. An example of an effective strategy that may help with participation may be the use of a “needs-matching strategy” (Owen, et al., 2004). Needs-matching strategies use distinct types of interventions to match the individual participants’ needs, such as tailoring educational strategies to the needs of the participants.

Recruitment and Enrollment For Online Supportive Clinical Trials

Despite the promising effects of these psychosocial interventions on quality of life and distress in cancer patients, and the endorsement of these clinical trials as a way to provide care, several issues still exist in enrolling patients into these clinical trials (Benson et al., 1991; Cockburn, Redman, & Kricker, 1998; Klabunde, Springer, Butler, White, & Atkins, 1999). Even though clinical trials are accepted as a part of clinical care, the ones that center around supportive care tend to face greater recruitment challenges (Buss et al., 2008). Cancer patients with poor functional status or who have a limited life expectancy are less likely to participate (L. J. Fallowfield et al., 1998). Additionally, physicians are less likely to make a referral to these types of services, hence lowering patient participation (Benson, et al., 1991; L. Fallowfield, Ratcliffe, & Souhami, 1997). Furthermore, the physicians' attitudes substantially influence patients' enrollment into clinical trails, such that the relationship between the physician and patients or 'patients' trust in the doctor' is a significant predictor of enrollment (Albrecht, Blanchard, Ruckdeschel, Coovert, & Strongbow, 1999; Jenkins & Fallowfield, 2000). In a recent publication looking at patient enrollment (CHESS) concluded that despite their thoughtful recruitment efforts, the rate of enrollment to CHESS did not meet targets. To ensure that the study had adequate power the time allotted to study enrollment was extended for more than a few months (Buss, et al., 2008). The leading causes of reason for declining to participate in the study included: factors related to computer use (usability and accessibility), part of a study (not wanting to fill out surveys, concerns about privacy, wording of consent form), personal issues (time, overwhelmed, copying style, timing of the study), and lack of interest (Buss, et al., 2008). However, the top three reasons for decline was, lack of interest, no reason given, and personal issues. It is important to note that this CHESS study offered a large amount of incentives to its participants. Participants' Internet cost was covered, participants were allowed to keep their laptops after they completed the study, and all participants received cash payments after completing the surveys. However, despite all the incentives and the study recruitment efforts, the study did not meet its target enrollment rate (Buss, et al., 2008).

Lastly, according to Buss et al. (2008), "Supportive care trials do not offer any chance of modifying the course of disease, so many patients may perceive their benefits to be ancillary and therefore may be less inclined to participate" (p. 173); and since the physicians may share this belief as well, partnering with local physicians/oncologists may be beneficial in implementing recruitment strategies more successfully.

One of the most important elements of a recruitment strategy is to determine who the target audience is and identify their needs and expectations that the program can act on (Nichols, Malone, Tarlow & Loewenstein, 2000). The target audience for this study includes cancer survivors who are experiencing distress related to their diagnosis, and who may be in need for psychosocial services and support. The product of this study is providing online psychosocial interventions for cancer survivors. The different components of the intervention will be further discussed later in this paper. However, in order to develop successful recruitment strategies for cancer survivors, study investigators must also implement an external market analysis to better understand the target market. Additionally, many factors influence the target market, such as regulatory issue, economic trends, technological trends and others. Earlier in this paper, the social marketing logic model was proposed illustrating how regulatory factors, motivational factors and education can influence the "4Ps" of marketing, and how such factors can influence development of recruitment strategies and program design. Described below is an analysis of the external market for the online social-networking website with the goal of better understanding majority of the issues and its potential bearing on recruitment for the online supportive care study.

External and Internal Market Analysis: Recruitment for HealthSpace.net

The external market research analysis is aimed at developing a better recruitment strategy for an online social-networking website for cancer survivors. For purposes of registry-based recruitment, the target market will be mainly Southern California, including San Bernardino, Riverside, Ventura, Los Angeles, Orange, San Diego, and Imperial Counties. In view of the geographic boundlessness of the World Wide Web, a secondary target market area is the United States since online advertising efforts will be nationwide in scope. Trends in healthcare utilization, availability of online educational materials, social support services, and health status are critical factors examined in this analysis. The essential foundation for use of an online social-networking website for cancer survivors is access to and knowledge of computers and the Internet. However, many barriers exist that limit the accessibility and usability of these services. Demographic trends, broadband technology trends, Internet usability, economic trends, and regulatory issues also influence the target markets and therefore are important to consider in this analysis.

Demographics

A three-year analysis, 2005-2007, of population-based data from the American Community Survey revealed that approximately 84% of individuals 25 years and older graduated high school. Of those individuals, 27% had received a bachelor's degree or higher. Forty-four percent of individuals reported that they did not speak English "very well." The analysis also indicated that 20% of individuals in the target area did not use English as their primary language at home. In contrast, state-based data in California revealed that 42% of individuals did not use English as their primary language at home (U.S. Census, 2007).

Race, education, income, and language are critical predictors of Internet use for health-related material. African Americans and Latinos continue to be limited in both access to and proficiency in use of the Internet (Fox, 2003). Furthermore, lower income is associated with a decreased likelihood of Internet use, particularly to search for health-related material (Fox, 2003). Lower rates of online health information seeking behavior are also related to lower educational attainment. Sixty-nine percent of college educated Internet users search for health information online as compared to only 33.8% of Internet users with less than a high school education (Rutten et al., 2007). The reported trends clearly indicate that Latinos are at a disadvantage. Adequate knowledge of different cultures is needed to increase the accessibility of resources to underserved populations (Berkowitz, 2006, pp. 168-169).

Cancer

Cancer is the second leading cause of death in the United States (National Center of Health Statistics, 2009) and within the state of California (ACS, 2009). Over 1,168,500 California residents have a history of cancer (ACS, 2008). The effects of this disease are not limited to just physical symptoms but also the impact of cancer on overall quality of life (Aaronson et al., 1993). Therefore, understanding the prevalence of distress in cancer patients may, in part, be critical for the dissemination of necessary resources for prevention and treatment (Kaiser, et al., 2010)

Healthcare Utilization

In 2006, a total of 38,008 cancer cases were reported in Los Angeles County. The second highest number of reported cases in California came from San Diego County, with a total of 13,825 cases. Orange County reported 12,456 cases, Riverside County 8,253 cases, and San Bernardino County 6,594 cases (California Cancer Registry, 2006). Healthcare utilization in these areas is also reported to be high. Cancer centers in Southern California include: City of Hope National Medical Center, Jonsson Comprehensive Cancer Center, USC/Norris Comprehensive Cancer Center, The Burnham Institute, Salk Institute Cancer Center (National Cancer Institute, n.d.), and Loma Linda University (LLU) Cancer Center. As a result of its cutting-edge proton therapy, people from all over the world seek cancer treatment at the LLU Medical Center (LLU Chamber of Commerce, 2009).

Broadband Technology

There has been major progress in transitioning Internet users from a dialup connection to broadband technology. Since broadband is traditionally more expensive than dialup, price is a major factor for many people in choosing their service providers (“Moving Towards Establishing a Usage,” 2007). However, the discrepancy between dialup connection and broadband technology is closing. Internet service providers are offering broadband connections at lower rates. Rurality is another barrier to access to broadband since cable and DSL Internet services are generally not as accessible in remote areas (Lo, 2006). About 71% of the adult population has a home Internet connection. Approximately 47% of those individuals have a broadband connection (Center of Disease Control and Prevention, 2008).

Internet Usability

Estimates derived from the Health Information National Trends Survey 2003-2005 provide useful data to better understand Internet usability and trends in retrieving health-related information. In 2003, 50.7% of participants reported using the Internet to look for health information. In 2005, 58.4% of participants reported using the Internet to search for health information. Interestingly, only 3.9% of the same respondents from 2003 and 2005 reported using an online support group (Rutten et al., 2007). The essential foundation for use of an online social support group for cancer survivors is accessibility and usability of computers and the Internet.

Social-Networking Website

Evaluation of the top websites and most popular social-networking websites is critical in identifying trends in site preferences (Rutten et. al., 2007; Alexa Internet, 2010). The top ranked global sites include: Google, Facebook, YouTube, Yahoo!, Windows Live, Baidu.com and Wikipedia. Facebook and Twitter are the two social-networking websites used most frequently by individuals of all ages. However, males, individuals who are 45 years and older and lower educational attainment (no college) are underrepresented at both sites (Alexa Internet, 2010). This trend is critical for advertisement and recruitment. There are also preexisting social-networking websites for cancer patients. The Wellnesscommunity.org, Organizedwisdom.com and The Medical Blog Network are among the top sites adapting to new interactive technology (Landro, 2006).

Availability of Web-Based Resources

Cancer patients utilize online resources provided by government agencies, scientific organization, company websites, and other public foundations. These resources include the following sites: the National Cancer Institute, California Cancer Index, American Cancer Society, OncoLink, Cancer Care, and Centers of Disease Control and Prevention. The National Cancer Institute and the American Cancer Society are the top-ranked sites for cancer information (Alexa Internet, 2010). However, resources available to cancer patients are not tailored to specific individual needs. This trend is critical in the design and dissemination of intervention materials for the cancer population.

Health Status

Involvement in physical activity is recommended to increase quality of life of cancer survivors. Physical activity will reduce fatigue and increase the overall quality of life in cancer survivors (Knols, Aaronson, Uebelhart, Fransen, & Aufdemkampe, 2005). Physical activity is also associated with reduced risk for recurrence and mortality (Holmes, Chen, Feskanich, Kroenke, & Colditz, 2005). A study of health-related goals of female cancer survivors, who recently completed treatment, showed the following as their top three goals: physical activity, losing weight and eating more healthfully (Lauver, Connolly-Nelson, & Vang, 2007). Providing tailored interventions and educational materials to cancer survivors via the Internet may be beneficial for increasing physical activity and overall quality of life.

Economic Trends

Approximately 91.5% of individuals report using a vehicle as their primary means of transportation (U.S. Census, 2007). Economic concerns about gas prices have raised consumer awareness around fuel conservation by driving less. Recent surveys showed that 56% of individuals report driving less after the increase in gas prices. In December 2008, the U.S. Department of Transportation reported that the total miles driven decreased by 3.8 billion miles from 2007 to 2008 (ConsumerAffairs.com, 2009). This economic trend impacts cancer patients' ability to utilize integrated oncology and support centers outside of their homes.

Regulatory Issues

The Institutional Review Board (IRB) in an academic institution has the right to approve, request modifications to, or disapprove proposed research activities conducted by the institution. Under university sponsorship, these regulations must be implemented in order to protect the rights and welfare of all participants affiliated with the institution. In order to recruit participants for the social-networking study, it is necessary that the LLU IRB committee approve the proposed recruitment process. It is the responsibility of the investigator to make certain that women and racial/ethnic minority groups are included in the study as well. If the investigator decides to recruit from other institutions and cancer centers, the primary institution with which the patient is affiliated will also need to undergo the IRB review (LLU, 2003). This may impact the ability to effectively recruit cancer patients to the study.

Critical Trends

The trends that may highly impact the process of recruitment are the accessibility and usability of Internet services. Many barriers have been identified in using Internet services. Broadband connection, Internet usability, and demographic variables contribute to participants' attrition rates. Those individuals with lower income, lower educational attainment and language barriers may be limited in utilizing these services. Economic trends, such as lower driving rates, have forced many to utilize in-home services. Individuals with cancer who live far from treatment facilities report higher interest in online support groups as opposed to face-to-face support groups (Owen, et al., 2004).

SWOT Analysis

Appendix A lists the organization's strengths, weaknesses, opportunities, and threats. The major strengths of the Behavioral Oncology Lab (BOL) include its affiliation with LLU and its approach to patient care. Some weaknesses of the organization include limited number of facilitators and its barriers in usability. Partnering with the National Cancer Institute (NCI) is a potential opportunity for BOL while its integrity may be threatened by competitors or funding limitations. The organization's SWOT analysis provides information that will help with future planning (Berkowitz, 2006).

Competitor Analysis

There are many social-networking websites that provide resources similar to those offered by the BOL. However, the BOL has developed a social-networking website that will provide intervention materials that can be tailored to the individual. Since 2007, it has been implementing similar interventions to help cancer survivors cope better with their high levels of distress. The table in Appendix B illustrates how the BOL compares competitively with four other social-networking websites. The competitor analysis includes the following sites: The Cancer Support Community, OncoLink, Cancer Care, and Cancer Compass. Even though Cancer Compass has the largest number of members, the Cancer Support Community seems to be the strongest competitor with respect to the resources available to its members.

This preliminary research analysis, as well as the extensive literature review provides some insight into the recruitment/enrollment challenges we may face in this particular study. The majority of the issues discussed have potential bearing on recruitment for online supportive care study. The most important factors could simply be accessibility and usability of computers and the Internet. However, computer and Internet use has been increasing over the past several years. Due to the increased use of the computer and the Internet, the resistance may lessen even more when technology further integrates into the everyday life of individuals, as well as, culture. Many cancer patients believe that computer and Internet access are valuable resources to them, especially during times when it becomes difficult for them to leave their home due to the physical demands of cancer treatment. In fact, studies are concluding that those who refuse to enroll into online-support group studies because of the inability to use a computer are of older age. Moreover, in Buss et al. (2008) study, those who refused to take part in their study believed that they “were too old” (p. 172) to use a computer or Internet for an online study.

Research Plan

Recruitment is foundational to program success and production of meaningful results. Resources and time constraints make it difficult for researchers to perform full-scale prospective surveys and analyses for the explicit purpose of exploration of information related to intervention recruitment and design. However, researchers must ensure that the fundamental basis of the intervention is not compromised and that the treatment efficacy is not jeopardized due to methodological flaws and poor program design. Although recruitment is essential to program success, it is often one of the most challenging elements of research (Appel, et al., 1999; Blumenthal, et al., 1995; Steinhauser, et al., 2006; Swanson & Ward, 1995). Data describing or testing recruitment strategies are limited and oftentimes study investigators do not report recruitment experiences carefully (Hunninghake, et al., 1987). Recruitment of adequate numbers of participants to supportive interventions for cancer patients is also challenging (Buss et al., 2008). In view of the importance of effective recruitment and the challenges associated with recruitment of cancer patients, it is critical that recruitment efforts are planned and carried out in a systematic and organized manner.

The purpose of this study is to demonstrate the utility of the social marketing model to better understand recruitment activities for cancer patients with a goal of identification of effective and appropriate strategies to guide recruitment and intervention design in future cancer research. Furthermore, this study will demonstrate the use of this model using accessible data pertaining to participants' variables that characterized the potential participants and provide information for marketing mix decisions. In this study, the "4 Ps" of marketing: product, price, place, and promotion, are expanded to include participants as well.

Furthermore, the feasibility of the social marketing model as a theoretical framework for researchers to systematically develop, implement, and evaluate recruitment and intervention strategies will be explored. Once researchers understand the key marketing concepts, program objectives, and their role in their project form a more market driven perspective, they can develop better strategies to meet organizational goals. Audience analysis will help the organization specify goals. Formative research will help define and test strategies, potential points of resistance of the strategies proposed, and help researcher identify ineffective use of resources. Channel analysis will help researchers identify cost-effective ways to reach the potential participants and focusing on the "4 Ps" of marketing in addition to an effective process tracking system can provide valuable feedback that can help fine-tune strategies to optimize efficiency of overall program objective and design.

This study is aimed to evaluate the effects of distress and participants characteristics on the effectiveness of different recruitment strategies, the assessment of the congruence between distress and the perceived benefits associated with participation in intervention on recruitment effectiveness, to identify the perceived costs and sociodemographic correlates associated with study enrollment, to evaluate the effectiveness and cost effectiveness of various communication channels, and to asses sociodemographic characteristics of distressed participants to inform more targeted promotional strategies.

Marketing Mix

The “4Ps,” of the marketing mix have been used in business and commercial sectors, but have now been adopted by the health promotional field. As mentioned earlier, a more recent organization of the marketing mix model uses six key components (see Table 2), including: identifying the target audience (participants), developing the research intervention (product), managing the cost/barriers (price), improving accessibility (place), promoting the study (promotion) and working with partners (partnership) (Nichols, et al., 2004). In health marketing it can be difficult to promote products, since the products are intangible. Hence, the challenge is to make these intangible goods more tangible. The marketing mix focuses on what interventions will be implement that will influence determinants so that the determinants, in turn, can influence the behavior (AED, 2008).

Table 2

The “4Ps,” of the Marketing Mix in addition to two extra elements

Marketing Mix	Descriptions
Participants	Defining and identifying the target audience (potential participants): The identification of the target audience (potential participants) is intertwined with the identified need or problem (who has the problem?) and the development of the intervention to address the problem (what intervention will this group accept?).
Product	Developing the product (research intervention): Interventions are designed to address a problem, which must be serious enough for potential participants to be interested in the intervention. Embarrassing or taboo problems may be more difficult to address because participants may not admit having the problem. The intervention must also be socially and culturally acceptable to the participants.
Price	Managing the price: Participating in the intervention and making any behavior changes have a cost to the participant, costs that could include time and effort, as well as financial costs. Minimizing costs increases the likelihood of successful recruitment and retention and implementation of the intervention by the participants.
Place	Improving accessibility (place): Improving accessibility to the place or places where recruitment occurs and where participants receive information about, or engage in, the intervention improves recruitment and retention. Accessibility can involve location, convenience or cultural acceptability.
Promotion	Promoting the study: Marketing techniques must be designed to reach the target audience.
Partnership	Working with partners: Community partners in formal and informal organizations can provide assistance in recruitment, including referrals, space, screening, and credibility.

Adopted from Nichols et al., 2004

Participant

Defining and identifying the target audience. The identification of the target audience is intertwined with the identified need or problem and the development of the intervention to address the problem.

Product

Interventions are designed to address a problem, which must be serious enough for potential participants to be interested in the intervention. Embarrassing or taboo problems may be more difficult to address because participants may not admit having the problem. The intervention must also be socially and culturally acceptable to the participants. The product in this research study is the online psychosocial intervention that is being provided to participants. The intervention is designed to provide for participants ways in improving coping skills, lowering distress, and improving overall quality of life. The fundamental framework of health-space.net consists of the following features: (a) online cancer support group (OCSG) intervention, (b) intervention framework for health-space.net, (c) professional facilitation, and (d) social interactive website features.

Price

Participating in the intervention and making any behavior changes have a cost to the participant, costs that could include time and effort, as well as financial costs. Minimizing costs increases the likelihood of successful recruitment and retention and implementation of the intervention by the participants. The price of an intervention in social marketing is defined as the cost perceived by the potential participants. This can be members’ time, money, effort and other factors that cost them if they comply with the intervention program. Managing the price is very important and may be the single most important factor that needs a great amount of attention from social marketers. Any behavior that is being altered or introduced has a cost associated with it. Minimizing that cost will increase the likelihood of successful recruitment and longer retention rates in the intervention. Cost is typically inversely proportional to recruitment success, member retention (lower attrition rates), and greater likelihood of intervention implementation by participant (Swanson & Ward, 1995). Several potential cost variables have been identified in this study.

An example would be the consent form. Despite all the important information given to potential participants, there are some obstacles some might face when reading the informed consent. Although one might think that revealing less information may be correlated with inducing less anxiety, there is clear evidence of the interaction with knowledge. Edwards et al. (1998) discussed the interaction between knowledge and anxiety. In their study, the authors showed that irrespective of consent method, high levels of knowledge is significantly associated with lower levels of anxiety (Edwards, Lilford, Thornton, & Hewison, 1998). The greater amount of information the potential participant knows prior to participation in the clinical trial, the more prepared they are to cope with the consent procedure. This evidence does offer insight about the informed consent procedure, suggesting that in order to enhance potential participant understanding and reduce anxiety, an optimal amount of information is necessary for participants to consent to treatment (Edwards, et al., 1998).

Place

In a research milieu, the place is the location where the potential participants receive information about the intervention, or the location where they engage in the intervention. Improving accessibility to the location where both recruitment and dissemination of information takes place will improve recruitment and retention (Nichols, Malone, Tarlow & Loewe, 2000). Accessibility can involve location, convenience, or cultural acceptability.

Promotion

This refers to promoting the study via the use of marketing techniques. Techniques must be designed to reach the target audience. Earlier under the "Place" section different potential locations were discussed that will serve as vehicles for promoting the study. However, strategies that are used to disseminate the information to the target audience include, flyers, tear off flyers and tailored flyers for colleagues (physicians, oncologist and social workers), newspaper advertisements, links on cancer-related web sites, Google advertisement, television, targeted mass mailings, magnets and business cards and other promotional items.

Aims and Hypothesis

Aim 1 (Participant)

To evaluate the effects of self-reported distress and participant segmentation variables (characteristics) on the effectiveness of individual-level recruitment to a web-based psychosocial support intervention.

Hypothesis 1a

In individual-level recruitment, self-reported distress will be associated with potential participant segmentation variables. Specifically, greater distress will be associated with the following potential participant segmentation variables: younger age, female gender, residence in census areas of lower income levels, greater RUCA-measured rurality of residential address ZIP Code, and lower average SEER 5-year survival rate associated with cancer type.

Hypothesis 1b

Web-based support group enrollment will be associated with potential participant segmentation variables. Specifically, greater likelihood of enrollment will be associated with the following potential participant segmentation variables: younger age, female gender, residence in census areas of higher income levels, greater RUCA-measured rurality of residential address ZIP Code, lower average SEER 5-year survival rate associated with cancer type, and greater level of distress.

Hypothesis 1c

Distress will mediate the relationship between Web-based support group enrollment and potential participant segmentation variables. Potential participant segmentation variables include, age, gender, income levels, RUCA-measured rurality of residential address ZIP Code, and SEER 5-year survival rate associated with cancer type.

Aim 2 (Product)

To assess the effects of congruence between the identified problem (i.e. distress) of the target audience and the perceived benefit associated with participation in the web-based social support intervention on recruitment effectiveness.

Hypothesis 2

Of potential participants screened and determined to be eligible, greater distress will be associated with greater likelihood of registration, consent to participate, and completion of baseline questionnaire (full enrollment).

Aim 3 (Price)

To identify the perceived costs and the sociodemographic correlates associated with enrollment in the web-based psychosocial intervention, particularly among potential participants with significant self-reported distress.

Hypothesis 3a

Among those who declined participation in individual-level recruitment, potential participant segmentation variables will be associated with the stated reason participation was declined. In particular, the following reasons for refusal of participation will be associated with the specified potential participant segmentation variables: *Health factors* (i.e. poor health, illness-related functional limitation) will be associated with older age, being female, residence in census areas of lower income levels, and lower average SEER 5-year survival rate associated with cancer type; *Personal factors* (feeling overwhelmed, lack of time) will be associated with younger age, being female and lower average SEER 5-year survival rate associated with cancer type; *Perceived lack of need* (i.e. excellent health and lack of distress) will be associated with being male, residence in census areas of lower income levels, higher average SEER 5-year survival rate associated with cancer type, and other ethnicity; *General lack of interest* will be associated with younger age, lower average SEER 5-year survival rate and lower income.

Hypothesis 3b

In individual-level recruitment, self-reported distress will be associated with the stated reason participation was declined, with greater distress associated with reasons related to *health factors* (i.e. poor health, illness-related functional limitation) and *personal factors* (feeling overwhelmed, lack of time).

Aim 4 (Place)

To evaluate the effectiveness (including yield of a representative and/or diverse sample) of the communication channels utilized for recruitment of cancer patients to a web-based psychosocial support intervention.

Hypothesis 4a

Differences will be observed in the general effectiveness of the recruitment via various communication channels. Individual-level strategies will be more effective as compared with population-level strategies.

Hypothesis 4b

Differences will be observed in the yield of a representative sample of the different communication channels utilized for recruitment of cancer survivors to a web-based psychosocial support intervention. As compared to the representative of the cancer survivors currently living in the United States, the yield of representative and/or diverse sample will be more effective (better representative sample) in population-level strategies than individual-level strategies.

Aim 5 (Promotion)

To assess sociodemographic characteristics of participants accessible via various communication channels as well as characteristics of those with significant self-reported distress to inform more targeted promotional strategies.

Hypothesis 5

Participant segmentation variables will be differentially associated with the recruitment communication channels. In particular, and as compared with average sociodemographic characteristics of cancer survivors, the following participant segmentation variables will be associated with the various recruitment communication channels: *Registry-based recruitment* (older age, lower average SEER 5-year survival rate associated with cancer type, more recent time since diagnosis and greater distress); *Web-based Registry recruitment* (younger age, residence in census areas of higher income levels); *Print Media* (older age, residence in census areas of lower income levels); *Cancer Websites* (younger age, greater distress, more recent time since diagnosis and lower average SEER 5-year survival rate); *Cure Website* (younger age, greater distress, lower average SEER 5-year survival rate, residence in census areas of higher income levels, and more likely to be female); *Facebook* (younger age, lower distress, residence in census areas of higher income levels); *General Internet Sites* (older age, lower distress, more likely to be male, lower average SEER 5-year survival rate).

CHAPTER TWO

METHODS

Participants

The research analysis is aimed at developing a better recruitment strategy for an online social-networking website for cancer survivors who may be experiencing cancer-related distress. For purposes of recruitment, the target audience is anyone who has ever been diagnosed with cancer, is experiencing distress and is over the age of 18. Potential participants must also be willing to interact with the health-space community on a daily basis, take several surveys, and be willing to be randomized to either an active online support group or a waitlist group, which would necessitate a 12-week wait before joining the health-space community.

Procedures

Participant recruitment and enrollment is characterized by a multistep process, including (a) project overview (i.e., initial contact during which potential participants are provided general information about the study), (b) eligibility screening, (c) registration, (d) informed consent, (e) baseline survey, (f) randomization to intervention or waitlist control, and (g) administration of additional surveys according to randomization condition (see Figure 5). Specific details of this recruitment process vary somewhat as a function of use of individual- or population-level recruitment strategies.

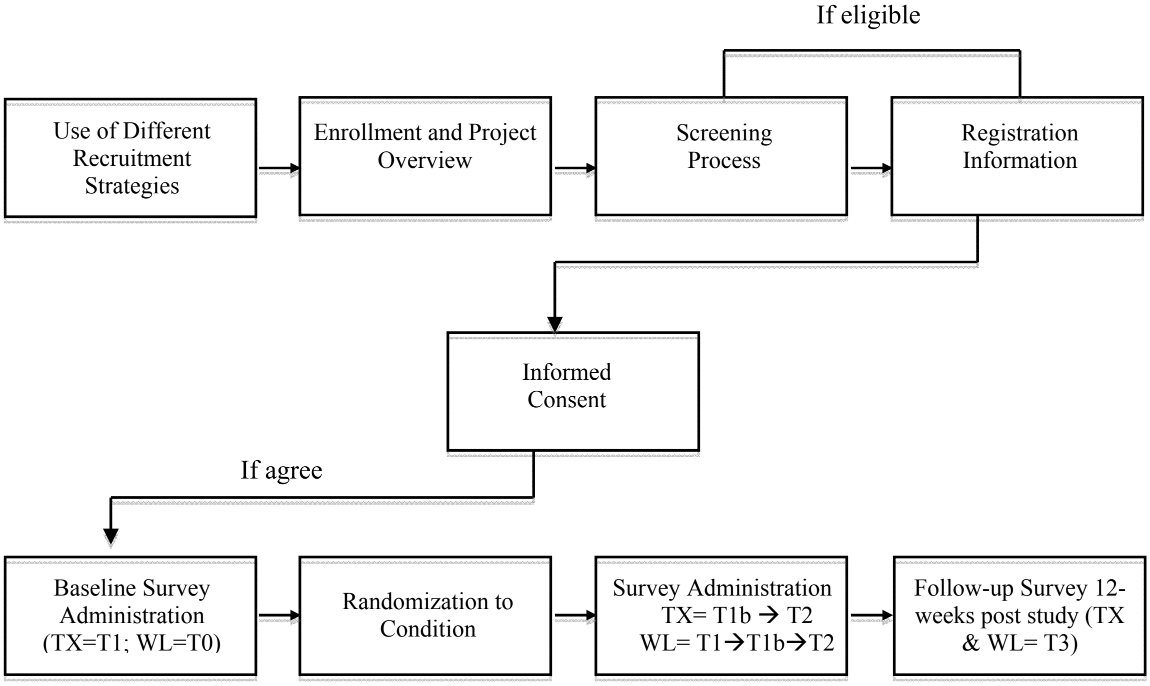
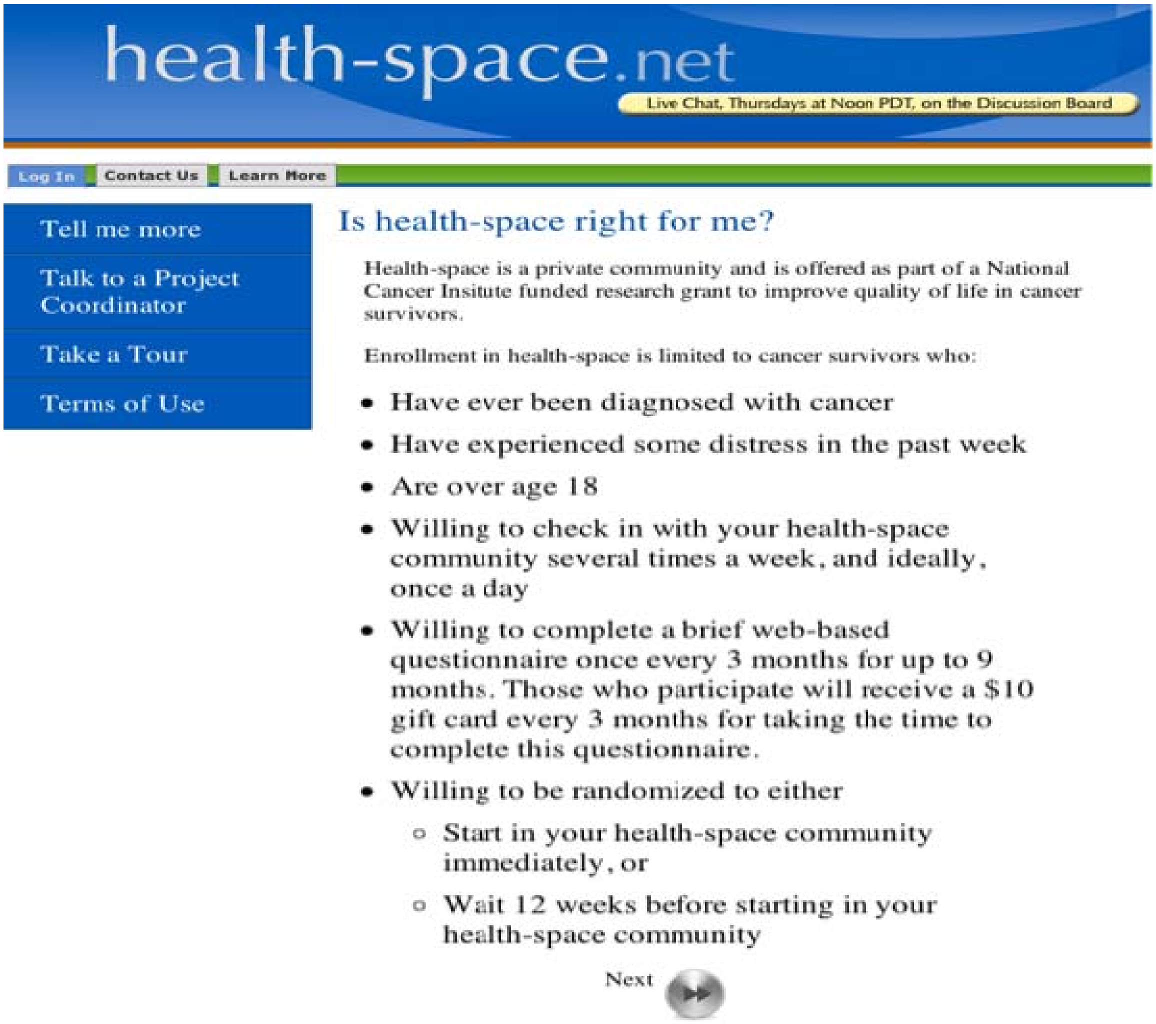


Figure 5. Recruitment Methodology

For individual-level recruitment (i.e. registry-based recruitment), potential participants will be identified using Loma Linda University cancer registry and mailed an information packet. This packet includes a tailored letter describing the study details, flyers, business cards, and information regarding how the researchers identified them. The packet also includes information about how to enroll into the study via the Internet. If potential participants do not opt out of the study within 3-weeks, the research coordinator will contact them by telephone. Population-level recruitment efforts (e.g., web and print advertisements) will inform potential participants about the study and guide them directly to the health-space.net website to complete the enrollment process. Additionally, potential participants will have the option of contacting project coordinators for enrollment, if they are not comfortable enrolling directly from the study website. This contact information will be provided on flyers, business cards, magnets and other promotional and advertisement materials.

Potential participants targeted via individual-level recruitment who do not opt out, as well as those targeted via population-level who do not wish to enroll directly from the study website, will be contacted by project coordinators. The informed consent process (see Informed consent section for further information), brief screening regarding accessibility and usability of the internet and assessing potential participant's current distress levels will be conducted by project coordinators through a brief telephone screening process. Only those potential participants with regular access to the Internet and those whom exhibit clinically meaningful levels of distress (i.e., a Distress Thermometer Score of ≥ 4) will be eligible for randomization. Potential participants who are eligible after the initial screening process will be asked if they have an interest in participating in the study. After providing registration information, namely email address, name, phone number, zip code, address (for purposes of mailing gift cards earned for participation in the study), username, password, and how they heard about the study, participants will then consent to the study, and be emailed a personalized username and password. Potential participants targeted via population-level recruitment, as well as those targeted via individual-level who prefer to enroll directly online, complete a four step enrollment process on the study website (see Figures 6-9).



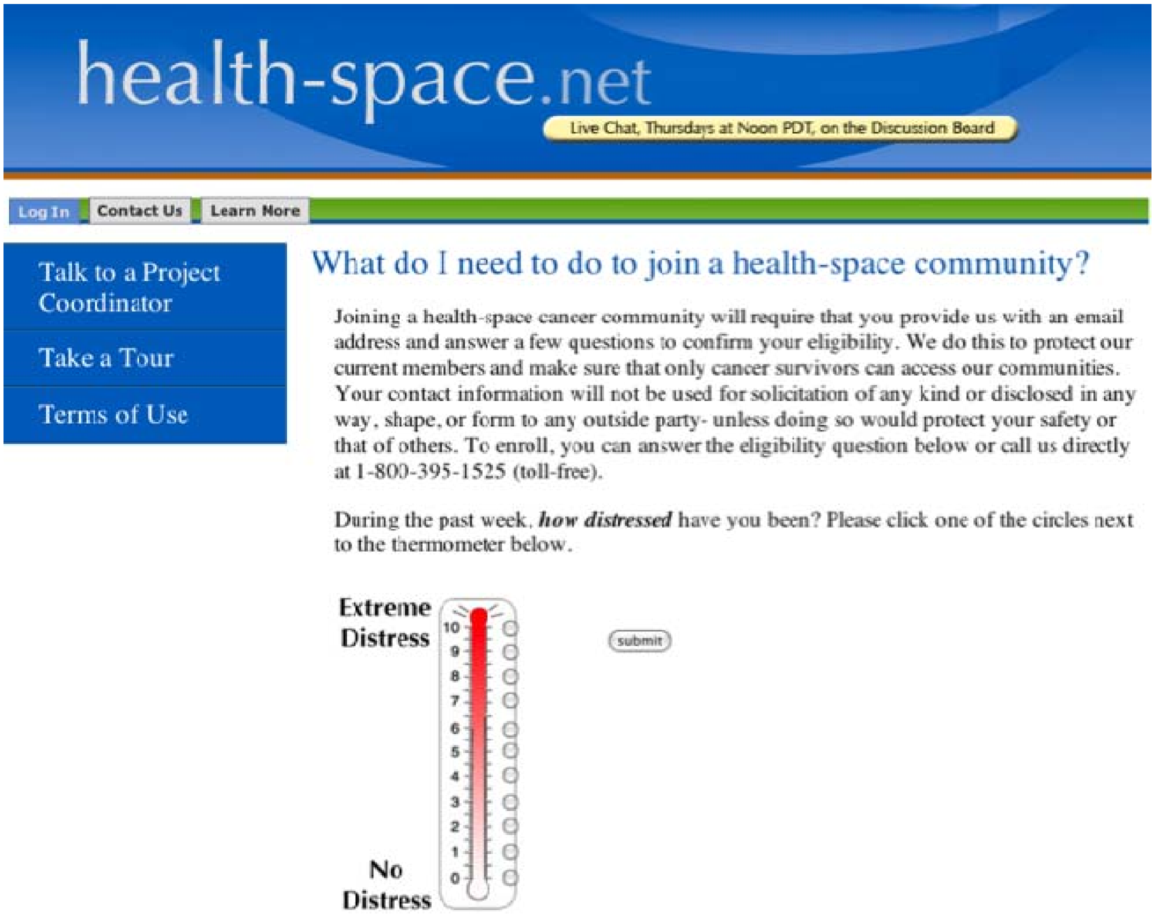
Is health-space right for me?

Health-space is a private community and is offered as part of a National Cancer Insitute funded research grant to improve quality of life in cancer survivors.

Enrollment in health-space is limited to cancer survivors who:

- Have ever been diagnosed with cancer
- Have experienced some distress in the past week
- Are over age 18
- Willing to check in with your health-space community several times a week, and ideally, once a day
- Willing to complete a brief web-based questionnaire once every 3 months for up to 9 months. Those who participate will receive a $10 gift card every 3 months for taking the time to complete this questionnaire.
- Willing to be randomized to either
  - Start in your health-space community immediately, or
  - Wait 12 weeks before starting in your health-space community

Figure 6. Is helath-space.net right for me?

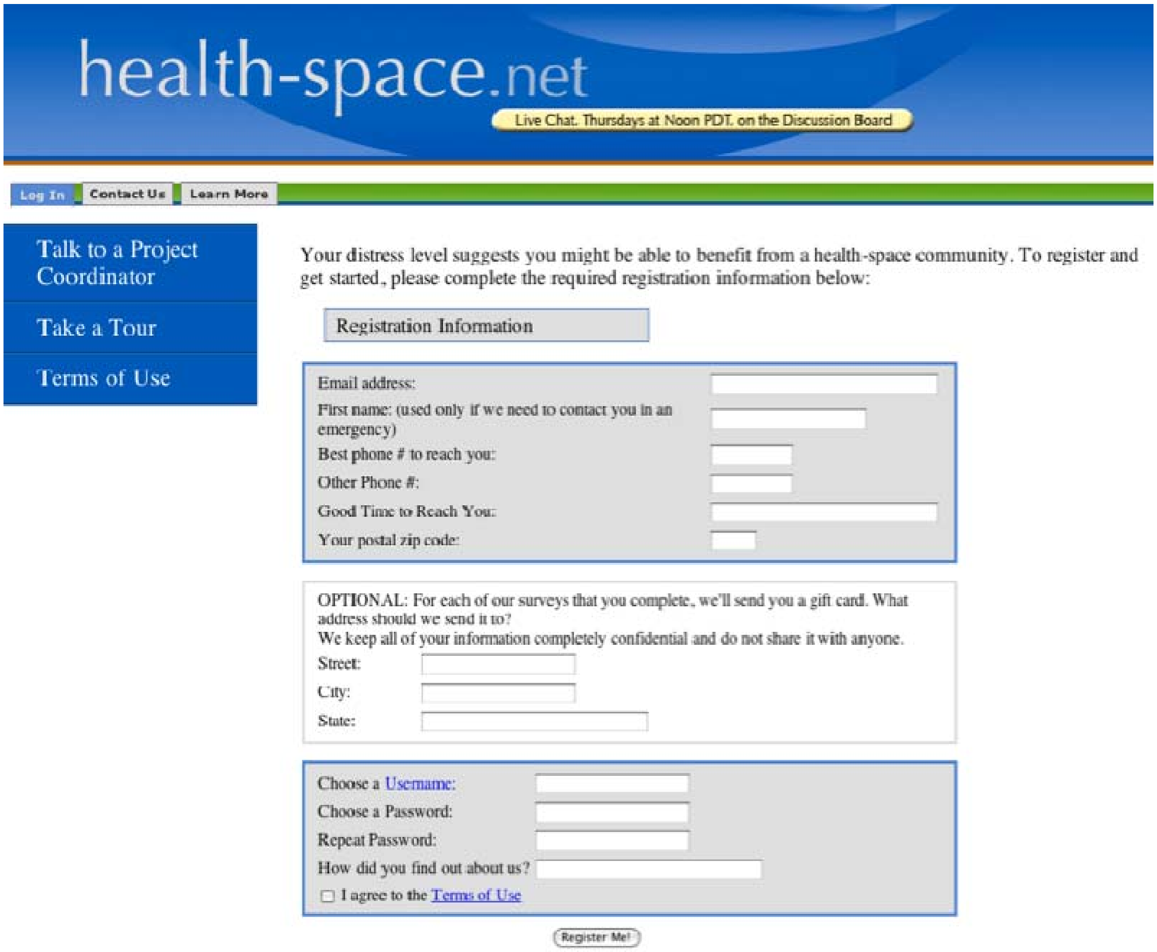


What do I need to do to join a health-space community?

Joining a health-space cancer community will require that you provide us with an email address and answer a few questions to confirm your eligibility. We do this to protect our current members and make sure that only cancer survivors can access our communities. Your contact information will not be used for solicitation of any kind or disclosed in any way, shape, or form to any outside party- unless doing so would protect your safety or that of others. To enroll, you can answer the eligibility question below or call us directly at 1-800-395-1525 (toll-free).

During the past week, ***how distressed*** have you been? Please click one of the circles next to the thermometer below.

Figure 7. Screening for level of distress



Your distress level suggests you might be able to benefit from a health-space community. To register and get started, please complete the required registration information below:

Registration Information

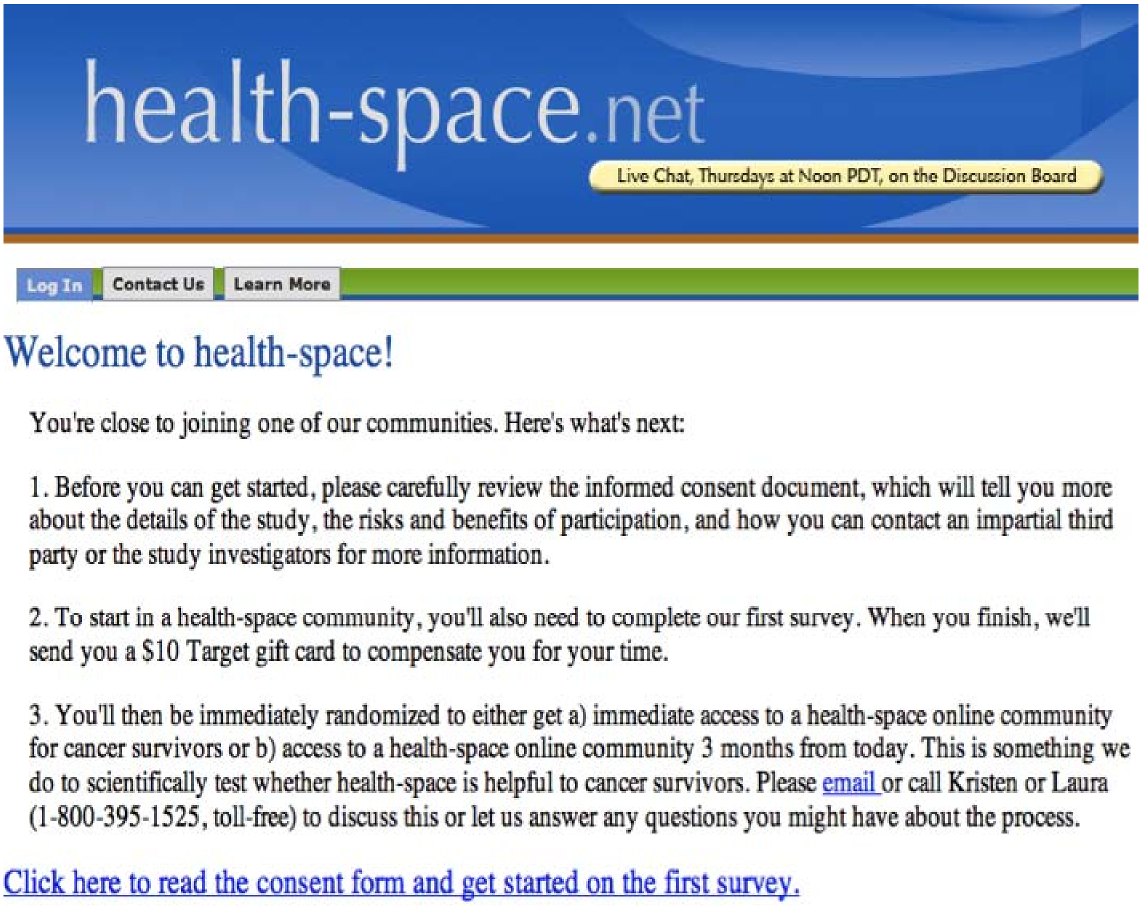
Email address:
First name: (used only if we need to contact you in an emergency)
Best phone # to reach you:
Other Phone #:
Good Time to Reach You:
Your postal zip code:

OPTIONAL: For each of our surveys that you complete, we'll send you a gift card. What address should we send it to?
We keep all of your information completely confidential and do not share it with anyone.

Street:
City:
State:

Choose a Username:
Choose a Password:
Repeat Password:
How did you find out about us?
☐ I agree to the Terms of Use

Figure 8. Enter registration information



Welcome to health-space!

You're close to joining one of our communities. Here's what's next:

1. Before you can get started, please carefully review the informed consent document, which will tell you more about the details of the study, the risks and benefits of participation, and how you can contact an impartial third party or the study investigators for more information.

2. To start in a health-space community, you'll also need to complete our first survey. When you finish, we'll send you a $10 Target gift card to compensate you for your time.

3. You'll then be immediately randomized to either get a) immediate access to a health-space online community for cancer survivors or b) access to a health-space online community 3 months from today. This is something we do to scientifically test whether health-space is helpful to cancer survivors. Please email or call Kristen or Laura (1-800-395-1525, toll-free) to discuss this or let us answer any questions you might have about the process.

Click here to read the consent form and get started on the first survey.

Figure 9. Consent to treatment.

After completing all aspects of enrollment, registration and consent, participants can log onto the website to fill out the baseline questionnaire. Randomization will be to either directly to an online support group (intervention group) or the wait-list group (control group). In addition to the baseline questionnaire, participants will be administered questionnaires at the end of study (Time 2) and 12-weeks post study (Time 3). In addition, participants will be asked to complete a brief measure two weeks (Time 1b) after they gain access to the online intervention. The questionnaires include measures of quality of life, emotional functioning, health behaviors, and attitudes about the intervention. All participants who enroll into the study and fill out the questionnaires will be reimbursed with a $10 gift card for completion of each survey at each time point (maximum of $50). Information regarding the monetary compensation is only provided on the health-space.net website.

Informed Consent

The consent form includes the purpose and procedures of the study, risk and discomforts, benefits, members' rights, findings of study, alternative to participation, confidentiality and costs to participants. The purpose and procedure section includes the purposes of the research and the expected duration of participation. It also includes a thorough description of all the procedures. Any reasonably foreseeable risks and/or discomforts must be listed for the potential participants. All reasonable benefits must be listed and disclosure of alternative procedures that might be advantageous must be provided for the potential participant. Information regarding confidentiality of records and a description of the extent to which confidentiality will be maintained must be provided. Contact information for answers to pertinent questions about the research study and the participants' rights, and the individual to contact in the event of a research related discomfort or injury to the participant must also be provided. In addition, the cost of participation must be noted and consequences of a participant's decision to leave or withdraw from the study. Participants will be provided with several ways to opt out of the study, including a toll-free number for the study, a confidential pre-paid postcard, website address, and email address.

Recruitment Strategies

Before the initiation of the study, members of the research team will be assigned to several different recruitment tasks with a projected completion date. For all recruitment methods, potential participants will be provided with a brief overview of the research study and will be given several sources of information guiding them with ways to contact research coordinators or the principal investigator of the study. As previously discussed, internet-driven recruitment methods have ways for potential participants to directly link to Health-Space.net for a more extensive overview of the study and to find out more about the eligibility requirements. However, all strategies provide for the potential participants various methods in contacting research coordinators or the link to the website to find out more about the research study. In addition, a toll free number and an email address are provided.

Recruitment Channels

The essential foundation for use of health-space.net for cancer survivors is access to and knowledge of computers and the internet; in view of the geographic boundlessness of the World Wide Web, the target market area is the United States since online advertising efforts will be nationwide in scope. The members of the research team identified several individual-level and population-level recruitment strategies. Cancer-registry recruitment (i.e., phone calls and mailings to patients from the Loma Linda cancer-registry) was the primary individual-level recruitment strategy. Population-level recruitment methods include: (a) print and other media sources (e.g., newspaper advertisements), (b) targeted mass mailing to oncologists and social workers (c) internet (e.g., Google campaign, listserv, and online communities such as Facebook, cancer related sites, Cure website, and Craigslist), and (d) direct referrals by physicians and nurses from Loma Linda Medical Center Family Medical Group. Please see Appendix C for examples of all promotional materials.

Cancer-Registry

Majority of recruitment was conducted by contacting potential participants by obtaining their information from the Loma Linda Cancer-Registry. Thousands of potential participants will be sent a mailing packet with a personalized letter, some promotional material and flyer with detailed explanation of how to enroll into the study. Please see the Procedures section for a more detailed description of this process.

Print and Other Media Sources

Information about the study was disseminated through several newspaper ads. The newspaper ads were generated in both local and non-local media. In addition, public service announcement was made on local cable channel by the principal investigator.

Flyers and other promotional material (tear-off flyers) were placed at medical offices (e.g., Loma Linda Family Medicine Group), community bulletin boards, oncology clinics, physician offices and in other public arenas.

Targeted Mass Mailings

Several targeted mailings were conducted throughout the course of the study. Social workers and oncologist all around the United States was contacted by mail and/or email and received promotional material with information regarding the study. The goal of this strategy was to have oncologists and social workers, who work directly with cancer survivors, refer their patients directly to the research study. The targeted mailings packets to social workers and oncologists included the following promotional material: (a) personalized letter, (b) tear-off flyer, (c) magnets, (d) business cards, and (e) flyer tailored for colleagues. This information included detailed step-by-step instructions for directing patients to either the study website or helping them make direct contact with research coordinators.

Internet

Advertising listings was placed on key cancer listservs, websites such as Craigslist, Facebook, Cure, Google, and cancer support group websites (see Figure 10).

> If you are 18 or over and have experienced any distress associated with a cancer diagnosis, we invite you to join our supportive online community by enrolling in our paid clinical trial. Our confidential site offers personal pages, a live community forum, and tips for living beyond cancer.
> Spaces are limited— sign-up today at www.health-space.net!

Figure 10. Example of statement included in internet site advertisements

Listserv administrators from acor.org were contacted for approval to post message according to the rules and specifications as defined by the ACOR organization. The above recruitment strategies would direct the interested participant to access the health-space website to enlist, as well as give informed consent, to participate in the research study. In addition, advertisements were posted on Craigslist, and administrators of over 700 cancer-related websites were contacted and asked to post the Health-Space.net link on their site to help those cancer survivors who are in need for psychosocial services.

Facebook advertisement was executed in two different forms. First, a health-space.net profile page was created and members of Facebook were asked to join. Information related to the study and a link to the study website for enrollment was provided on the main administrative page for all interested audience. Second, other cancer support group administrators on Facebook were contacted and asked for approval to post advertisement about health-space.net clinical trial on their main support group profile page. The administrators of the groups were sent a personal message via the Health-Space Facbook profile page, and if interested, they were provided with some promotional material to post on their main site. Additional, other cancer support group sites were contacted either via email or via the actual website comment page and asked to post the Health-Space.net link on their site to help those cancer survivors who are in need for psychosocial services.

Additionally, a Google campaign was launched for advertisement. The Google campaign will not only help with advertisement but also help the study gain insight into consumer trends, better identifying and understanding what the target audiences' wants and needs are and identifying health-space.net's traffic patterns. The Google campaign has several elements, including: the main headline, lines of text, the display URL and the destination URL. An example of a Google AdWords text ad is presented in Figure 11. The headline is the first line of the ad and it acts as the main link to health-space.net. The lines of text briefly describe the service health-space.net is advertising. The display URL, which is the last line shows the website that is being promoted (health-space.net); and finally, the destination URL is the exact page that the audience is directed to. This component of the ad is not visible but it links to the exact page within health-space.net which potential participants are sent to.

Fight Cancer Distress
Worried? Tired? Blue? On your own?
Join a private support community.
health-space.net

Cancer got you Down?
Fight back. Join a free,
private, support community.
health-space.net

Figure 11. Components of a Google AdWords text ad

In addition to the different Google campaign elements, keywords are used to target the ads to the potential participants. These are words or phrases that the potential participant would use when searching for services similar to the ones health-space.net offers. The most relevant portion of this particular feature is that it allows targeting the ads to the desired audience. Some examples of the keywords that were used for health-space.net are presented in Figure 12.

1) Survivor Support Group
2) Natural cancer treatment
3) Alternative Cancer Treatments
4) Cancer support groups
5) Cancer survivors
6) Colon cancer support
7) Cancer survivorship
8) Lung cancer support groups
9) Fighting cancer
10) Brain tumor support group
11) Lung cancer support group
12) Breast cancer support groups
13) Cancer groups
14) Thyroid support group
15) Lung cancer support
16) Ovarian cancer support
17) Ovarian cancer support groups
18) Support groups for cancer
19) Online cancer support group
20) Cancer patient support group
21) Cancer patient support
22) Clinical trials cancer
23) Health behavior and health education
24) Thyroid cancer support group
25) Brain cancer support group
26) Leukemia support group
27) Lymphoma support group
28) Skin cancer support
29) Natural treatments for cancer
30) Online cancer support
31) Bladder cancer support groups
32) Support groups for breast cancer
33) Melanoma support group
34) Kidney cancer support
35) Support groups for cancer patients
36) Testicular cancer support
37) Uterine cancer support
38) Kidney cancer support groups
39) Stomach cancer support
40) Support groups for lung cancer
41) Cancer support groups online
42) Cancer patients support
43) Support group for cancer
44) Cancer survivor support groups
45) Cancer patient support groups
46) Cancer support program
47) Cancer help program
48) Cancer patients support group
49) Cancer support family
50) Lung cancer patient support
51) Alternative treatments for cancer
52) Cancer patient

Figure 12. Keywords list used in Google ad

Finally, the Google campaign allows organizations to measure and track how the campaign is performing. It reports back data and statistics on the organizations advertising performance. It measures how the ads are running, if gains or profits are being generated, if the organization is meeting its goals and the organizations' overall quality score.

Direct Physician and Nurses Referrals

Study staff met with physicians and nursing staff at Loma Linda Medical Center, Family Medical Group to explain the rational for, and the foundational basis of the study, the eligibility requirements and the potential benefits. In addition, tear-off flyers were placed in all exam rooms for interested patients.

Intervention

The intervention is conducted on the Health-Space.net social networking website. Online support group services are available to individuals during all hours of the day, which eliminates the need for a group meeting location. It also eliminated the need for participants to travel from their home to the treatment facility that is providing the intervention services. Web-based social support group users have better flexibility in accessing services outside of the usual clinic hours (Finn, 1995) and allows participants living in rural areas the opportunity to participate in support services due to living far away from the treatment facility, due to lack of transportation (Sullivan et al., 1993). Rural communities are underserved medically (Herman, et al., 1996), are socially isolated which may likely lead to poor coping skills (Rowland, 1994), and the location of this intervention could potentially aid those participants with these special needs. In addition, all participants will be able to access Health-Space.net from any location that provides computer and Internet access.

Our intervention is aimed to provide an empirically supported and manualized 12-week treatment program. This 12-week intervention program is intended to aid in the improvement of participants' coping skills. The program is set up in such a way that the series of modules are introduced sequentially on a weekly basis. The coping-skills intervention modules are delivered by facilitators who have previously been trained. Additionally, the modules are located on aesthetically appealing image-rich, interactive web pages (see Figures 13-15). The relevant topics that are introduced include: (a) introduction to the NuCare Coping Workbook, (b) introduction to coping and mindfulness, (c) social support, (d) self and body image, (e) healthy lifestyle choices, (f) self-efficacy, (g) relationships (i.e., communication with partners and healthcare professionals), (h) ways of thinking, (i) self-talk, (j) relaxation and imagery (i.e., developing relaxation skills), (k) identifying and disclosing thoughts and feelings, (l) goal setting, and (m) benefit-finding (see Figure 9). These specified intervention modules are derived from the NuCare program (Gundgaard, Nielsen, Olsen, & Sorensen, 2002). However, these intervention materials have been tailored to fit into a HTML format. The website interventions include both audio and visual components to highlight information and make the guidance NuCare workbook a bit more interactive. Additionally, there are quizzes, exercises, and a section to share thoughts with facilitators and/or other group members. Facilitators are also able to interact with the participants during the module overview and stimulate discussions. This feature is meant to encourage social interaction, greater involvement, and better understanding of the guidance modules.

In addition to the NuCare intervention modules, the website is fundamentally structured in a way to offer ancillary treatment elements to increase magnitude of effects of the interventions. These elements include the ability for participants to self-monitor level so distress and mood, write and read blogs, engage in discussion board postings, set realistic goals and expectations with the help of facilitators and other members who are also participating in the OCSG, give and receive social support, send and receive emails (private emails on the website to and from facilitators and other group members), and use blogs and discussion board as a channel for writing/journaling (expression of thoughts and feelings). The website also has a live chat room feature, where facilitators and groups members are able to sign on and chat live. This feature is offered to all OCSG members on a weekly basis.

How do you cope?

-People use a variety of coping methods

-There are no right or wrong ways to deal with cancer, but some coping methods may be more effective.

-General Theoretical Models: behavioral, cognitive, and emotion focused.

Figure 13. Sample of video interactive module

What makes a healty lifestyle?

-Exercise
-Nutrition
-Laughter
-Handling Fatigue
-Hope
-Spirituality
-Forgiveness
-Self Trust

…and so on

Exercise

Take our physical activity quiz and get personalized recommendations

Lifestyle means exercise! Everyone needs to get active. In fact, many of the changes that occur in our bodies as we get older may not be due to aging but to a lack of physical activity. A more active lifestyle has been proven to reduce the risk of many diseases as well as reduce the symptoms of chronic conditions.

Figure 14. Tailored physical activity module

Figure 15. Nucare workbook**.**

Intervention Framework for Health-Space.net

The intervention framework is built on a Linux server implementing Apache, Perl, and mySQL. We have strengthened an early Perl CGI program used to evaluate a previous version of the intervention (Owen et al., 2005). Our program (health-space.pl, 521kb, 9133 lines of code) manages user security, survey administration, recruitment tracking, storage and retrieval of user-specific data, tailoring page content to individuals, linguistic analysis, and user interactions with the intervention website. The website offers private access to users, a fairly small private group of up to 20 participants and 2-3 trained professional facilitators. The website was designed using principles associated with “web 2.0”: social participation, usability, open access, users adding content, & aesthetic appeal. Components of the Perl-based framework have successfully been used in a series of prior studies (Owen et al., 2004; Owen et al., 2005). The intervention framework for helth-space.net, including, recruitment tracking system, intervention materials, social-networking CGI system, online survey administration, questionnaire scoring, mySQL database structure, and study flow tracking has already been developed and is in working order.

Facilitators

Interventions are facilitated by: Dr. Jason Owen (Licensed Clinical Psychologist, Loma Linda University), Dr. Erin Bantum (University of Hawai’i), Laura Testerman (5th year clinical psychology doctoral student), Natalie Kaiser (6th year clinical psychology doctoral student), and Laura Boxley (6th year clinical psychology doctoral student). Each intervention group will have facilitators and will be actively supervised by Dr. Jason Owen. Facilitator responsibilities include, encouraging participation through promoting daily discussion specific to the weekly intervention modules, leading weakly discussions in the live chat room (Thursdays at noon), providing tailored feedback to participants via discussion board and/or email. Weekly supervision/meetings will be scheduled for the facilitators to meet and discuss interventions from previous week. If any issues are identified, facilitators will plan accordingly to make adjustments.

Weekly review of intervention progress will be discussed as well. Each participant progress note (including diagnoses, treatment, participants needs etc.) will be available to all facilitators to keep an active web-based file. In addition, facilitators will be available for website technical support via email and by phone during regular business hours for all active participants. The Health-Space.net website and all computer program language has been developed and written by Dr. Jason Owen, respectively. This makes it much easier to meet the immediate needs of participants if they come across technical problems with website features. In addition, we are able to provide website support more promptly since the website has been developed in-house and has not been outsourced to outside website developers.

Social Interactive Features of Health-Space.net

Each participant will have the opportunity to create a personal profile page that they can share with other group members. This page will include the participants screen name, cancer story, cancer type, city where they are from, photos, blogs, private personal email, polls, and news from facilitators. The page can be edited at any time and the participant can choose what information to share and what to keep private. The website also has a discussion board that is open to all active group members. The interactive discussion board page allows members and facilitators to discuss topics of interest, post updates and post thought provoking questions that can be discussed among all members and facilitators. In addition, all messages that are posted on the discussion board have information about the members' level of distress and mood. This self-monitoring feature also helps other member better understand the individuals mood and level of distress at the time the message was posted, and the context of the message.

Furthermore, all active members have the chance to interact live in a chat room. The chat room provides 24-hour access to all members of the OCSG. Participants are able to enter and leave the chat room at any given time. In addition, facilitators will be available on a weekly basis to communicate with group members. Another feature of the website is the private email feature that can be accessed directly from each participants' profile page. This feature will be available for all members and facilitators to interact in a more private setting. As members begin to create social bonds with other active members, they will receive visual feedback about the strengths of each social bond. This visual feedback provides information based on the frequency of the interpersonal contact with the members and helps individuals reach out to other members that may be less engaged.

Measures

Potential Participant Characteristics

Data were collected for several participant segmentation variables (i.e., potential participant characteristics). Basic demographic and cancer-related data provided by the cancer-registry; therefore, this information was obtained for potential participants identified through the cancer-registry regardless of enrollment status. In contrast, for potential participants targeted via population-level strategies, this information was available only for those who completed the baseline questionnaire.

Demographic Information

Demographic data available from the cancer-registry database were age (in years), gender (male or female), ethnicity (Caucasian, Hispanic, Asian/Pacific Islander, Black, or other ethnicity, and residential address (street address, city, state, and ZIP Code).

Socioeconomic Status

Area-based estimate of income was estimated using geocoding based upon residential address (see Stopponi et al., 2009).

Rural-Urban Commuting Area Code

The Rural-Urban Commuting Area Code (RUCA) classification system is a frequently used taxonomy of rurality used in health research. Developed by the University of Washington Rural Health Research Center, rurality metric differentiates ZIP codes based upon population and commuting information. Rurality version 2.0 is based upon 2006 ZIP Code data and 2000 commuting pattern information. The 10 primary rurality codes range from one (i.e., metropolitan area core) to ten (i.e., isolated small rural area).

Cancer-Related Factors

Disease-related data available from the cancer-registry database were cancer type (breast, colorectal, female reproductive, hematologic, lung, melanoma, prostate, urinary, multiple, other, or not specified), and age at diagnosis (in years). Data of estimated 5-year survival rate associated with each cancer type was obtained from the Surveillance and Epidemiological End Results website.

Additional Demographic Information

In addition to the aforementioned participant characteristic data, for those who completed the demographic questionnaire at time 1, data were collected regarding education level, household income level, marital status (married, single, divorced/separated, or widowed), employment status (employed, unemployed, or retired), previous use of a support group (yes or no), previous use of an online support group (yes or no), received radiation treatment (yes or no), received chemotherapy treatment (yes or no), and received surgery (yes or no), frequency of internet use, type of internet usage, level of comfort with using a website, and physical limitations.

Recruitment Strategies and Channels

Recruitment efforts for this study will be evaluated in terms of general strategy type as well as at the level of the specific recruitment channels targeted.

General Recruitment Strategy

This refers to individual-level recruitment strategies (i.e., registry-based recruitment) and population-level strategies (e.g., internet advertising, print media, etc.).

Recruitment Channel

Specific recruitment channel types considered include general registry-based recruitment (i.e., registry-based participants enrolled via phone contact), web-based registry recruitment (i.e., registry-based participants who self-enrolled via the study website), print media, cancer websites, cure website, Facebook, and general internet sites.

Distress

The level of distress reported by potential participants on a scale of one to ten, with higher scores indicating more severe distress. A rating of four or higher is considered evidence of clinically significant distress.

Enrollment Process

Aspects of the enrollment will be considered in terms of rate of successful enrollment, completion of the different stages of recruitment, and reasons why potential participants declined participation.

Successful Enrollment

A participant who meets eligibility criteria, registers, consents and completes time 1 questionnaire will be considered successfully enrolled in the study.

Recruitment Stage

The furthest stage of registration and/or enrollment through which a participant progressed, namely determined eligible, completed registration, consented to participation, and fully enrolled (i.e., completed time 1 questionnaire).

Reason Declined Participation

If participation is declined during individual-level recruitment, reason for refusal will be solicited for purposes of identification of barriers to be addressed in future recruitment efforts. Content analysis was performed on reasons stated by individuals for declining participation. Specifically, responses were reviewed by two advanced graduate students to identify themes and patterns, and develop a coding system to best describe the data. Five broad categories for reasons for declining participation were identified: (a) health factors (e.g., poor health, illness-related functional limitation), (b) personal factors (e.g., feeling overwhelmed, lack of time), (c) perceived lack of need (e.g., excellent heath and lack of distress, adequate existing support), (d) general lack of interest, and (e) other reasons (e.g., concerns about privacy, dislike spending time on computer, already part of another OSG).

Data Analysis

Analyses were performed using SPSS 16.0 for Windows (SPSS Inc., 2007). Prior to analysis, the data were inspected with respect to the assumptions of the analyses. An evaluation of descriptive statistics and histograms was performed to assess univariate normality and linearity. Multivariate linearity and normality was assessed through an examination of the bivariate scatterplots of the variables. An examination of the standardized residuals was used to detect univariate outliers and Mahalanobis' and Cooks Distance was calculated to screen for multivariate outliers but no extreme cases were identified. To evaluate multicollinearity among the independent variables, tolerance values were examined but none were small enough to indicate serious problems. For the assumption of homogeneity of variance was assessed using Levene's test of equality of error variances for all univariate tests. Two-tailed tests of significance with an alpha of 0.05 were used for all analyses. Follow-up tests such as the Dunn's Bunferroni was used for multiple comparisons. This test also has strict control for type I error.

Missing Data

Missing data analysis on individual-level recruitment demonstrated varying amounts of evaluable data for the 2521 study participants across the predictors of interest: age (valid *n* = 2049, missing *n* = 472), gender (valid *n* = 2049, missing 472), ethnicity (valid *n* = 2040, missing *n* = 481), SEER 5-year survival rate (valid *n* = 2045, missing *n* = 476), rurality (valid *n* = 1943, missing *n* = 578), income (valid *n* = 1891, missing *n* = 630), and distress (valid *n* = 423, missing *n* = 2098). These predictors had missing values ranging from 19% to 83% of the entire sample size**.** Since distress ratings were not always obtained due to not making contact with potential participants (e.g., participants who were deceased or due to wrong phone number), participant not meeting eligibility criteria due to other reasons (e.g., does not speak English or have no computer and/or internet), or due to declining enrollment, this variable showed the highest number of missing values.

Missing data analysis was also conducted on population-level recruitment. Results demonstrate that from a total of 128 participants, 18 participants had missing data on age, gender and ethnicity. Thirteen participants had missing data on income and rurality, a total of 20 participants have missing data on the SEER 5-year survival rate and only four missing values were detected on the distress variable.

Expectation-Maximization (EM) algorithm through missing value analysis was used to detect randomly missing data, findings demonstrate statistical significant deviation from randomness using Little's MCAR test, $\chi^2(43) = 243.13$, $p < .001$. The EM procedure assumes that the missing cases/information is missing at random and does not communicate new information. Since the data is not missing at random and there is a pattern of missing data, no EM imputation was applied to the dataset. With the limited amount of variables available, all variables were kept for the analysis.

Sample Characteristics

Descriptive statistics will be used to assess the general characteristics of the sample. Specifically, frequencies will be used to characterize the recruitment flow processes. In addition, *t* tests and chi-square analyses were used to compare characteristics of enrolled participants from recruited via registry versus other recruitment sources. It is important to note that only potential participants who reported clinically significant levels of distress (i.e., had a score of 4 and above on the distress scale) and met other eligibility criteria where included in this analysis.

Hypothesis 1a

Multivariate logistic regression was used to evaluate the effects of potential participant segmentation variables on self-reported level of distress in potential participants from individual-level strategies. Particularly, univariate logistic regression analysis was used to identify significant predictors of distress. A total of six univariate regression models were used to identify significant predictors of distress in potential participants. Predictor variables assessed include age, ethnicity (White, Hispanic, Asian/Pacific Islander, Black, Other ethnicity), gender (male or female), income, rurality (measure of rurality), and SEER 5-year survival rate. To simplify interpretation of significant univariate effects, participants who reported clinically significant distress (i.e., distress score of 4 or higher) were compared to those who did not demonstrate clinically significant distress via odds ratios generated using logistic regression. Significant univariate predictors were then simultaneously evaluated in a multivariate logistic regression model.

Hypothesis 1b

A multivariate logistic regression was used to evaluate the effects of participant characteristics on enrollment. Specifically, univariate logistic regression was used to generate odds ratios for enrolling in the study versus failing to enroll. Note: only participants who met eligibility criteria (i.e. score of 4 or greater on distress, reported to have internet and computer, as well as, those who speak English) were included in this analysis. The outcome variable was defined as those who were eligible and enrolled into the study and those who were eligible but did not enroll into the study. Enrollment was strictly contingent on participant completing time 1 questionnaire. A total of seven univariate regression models were used to identify significant predictors of distress in potential participants. Predictor variables assessed include age, ethnicity (White, Hispanic, Asian/Pacific Islander, Black, Other ethnicity), gender (male or female), income, rurality (measure of rurality), SEER 5-year survival rate and distress. Significant univariate predictors were then simultaneously evaluated in a multivariate logistic regression model.

Hypothesis 1c

A mediation model was used to assess if distress mediates the relationship between potential participant segmentation variables and enrollment. According to Baron and Kenny (1986), four steps are necessary for testing meditational hypothesis. First, the initial variable (potential participant segmentation variables, including, age, ethnicity, gender, income, rurality and SEER 5-year survival rate) must be associated with the outcome (enrollment); second, the initial variable (same potential participant segmentation variables used in above analysis) must be associated with the proposed mediator (distress); third, the proposed mediator (distress) must be associated with the outcome (enrollment); and fourth, to establish that proposed mediator completely mediates the relationship between the initial variable and the outcome, the effect of the initial variable (potential participant segmentation variables) on the outcome (enrollment) after controlling for the proposed mediator (distress) should be zero.

Hypothesis 2

In order to assess the effects of congruence between the identified problem (i.e. distress) of the target audience and the perceived benefit associated with participation in the web-based social support intervention on recruitment effectiveness, a sequential multinomial logistic regression analysis was performed to predict membership in one of four categories of recruitment stage (eligible, registered, consented, fully enrolled), first on the basis of six potential participant segmentation predictors and then after addition of a self-perceived psychological factor (i.e., distress). The predictors assessed include age, ethnicity (Caucasian or non-Caucasian), gender (male or female), rurality (measure of rurality), SEER 5-year survival rate, and distress (high, medium, low). Frequency analysis was conducted to see distribution of values on the variable distress. Given that only distress cut-off values of four and above were used to include eligible participants, analysis of normality was assessed. The distress variable was showed to be skewed based on converting the values of both the skewness and kurtosis to z-scores by dividing the value of skewness (S) and kurtosis (K) by its own standard error (Kroenke, Spitzer, Williams, Monahan, & Lowe, 2007). The following formulas are used to calculate the Z-scores for skewness and kurtosis:

$Z_{\text{skewness}} = (S-0)/\ SE_{\text{skewness}}$ $(.302-0)/.125 = 2.42$

$Z_{\text{Kurtosis}} = (K-0)/\ SE_{\text{kurtosis.}}$ $(-.939-0)/.250 = 3.76$

Absolute value greater than 1.96, 2.58, and 3.29 are significant at $p < .05$, $p < .01$ and $p < .001$, respectively. Fisher skewness coefficient exceeded 1.96 for skewness and 3.29 for kurtosis, indicating positive skew significant at $p < .05$. To meet assumptions of normal distribution, the variable distress was trichotomized with cutoffs that corresponded to the 33rd and 66th percentiles. There is a possibility in losing important information when a continuous variable is categorized. These can include loss of power to detect significance, and this may even lead to biased estimates (Holli, Laippala, Ojala, & Pitkanen, 1999). Since positive skewness was observed in the variable distress, and in order to meet assumptions of normal distribution, this variable was trichotomoized.

The ability of the set of predictors to distinguish between potential participants who were eligible, participants who registered, participants who consented to treatment, and participants who fully enrolled was evaluated through examination of the significance of the model χ^2. The ability of each predictor to contribute to the model was established using the Wald statistic. In order for the model to provide an acceptable fit to the data, the Goodness-of-Fit statistics that show non-significant p-values for the Deviance criterion and Pearson criterion is considered a good fit. Additionally, because an odds ratio represents the change in odds for an increase of one unit in the predictor, it is necessary to take into account the scale and range of the variable in order to accurately interpret the magnitude of the change (Hosmer & Lemeshow, 2000) recommend that the change in units reported for a predictor be that which is most meaningful in magnitude. For example, a change of one dollar in income is too small to be meaningfully interpretable. The unit of income was rescaled to units of 1000 dollars for purposes that is more amenable to interpretation.

Hypothesis 3a

A discriminate function analysis was conducted to determine the linear combination of reasons participants declined enrollment in the web-based psychosocial intervention that best separates or discriminates the groups. This analysis was performed using six predictors of membership in five groups. Predictors were age, sex, income, ethnicity, rurality, and SEER-5 year survival rate. The five groups of different reasons participants declined enrollment were related to *health factors* (i.e. poor health, illness-related functional limitation), *personal factors* (feeling overwhelmed, lack of time), *perceived lack of need* (i.e. excellent heath and lack of distress, adequate existing support), *general lack of interest*, and any *other* (i.e. concerns about privacy, dislike spending time on computer, already part of another OSG) reason for decline. The Box's test of the assumption of equality of covariance matrices tests the null hypothesis that the variance-covariance matrices are the same in all three groups. The Box's M results show a significant value $p < .001$, which indicates that the covariance matrices are significantly different and the homogeneity assumption is violated. A one-way analysis of variance was conducted with using the Bonferroni-correction procedure for multiple comparisons to determine between which groups the function significantly discriminated.

Hypothesis 3b

A univariate analysis of variance was tested to investigate whether level of distress varied significantly across the different reasons participants stated to decline enrollment in the web-based psychosocial intervention.

Hypothesis 4a

Chi-square analysis was used to assess mean differences between participants' enrollment based upon recruitment via various recruitment channels. Specifically, recruitment channels will be compared in terms of number of participants who are eligible and enroll in the study versus number participants who are eligible and do not enroll.

Hypothesis 4b

A chi-square analysis was also used to compare the yield of a representative sample of the different communication channels utilized for recruitment of cancer survivors to a web-based psychosocial support intervention. Specifically, yield of representative and/or diverse sample is measured by comparing individual-level strategies and population-level strategies to the representative of the cancer survivors currently living in the United States using the SEER cancer statistics.

Hypothesis 5

A discriminate function analysis was conducted to determine the linear combination of participants accessible via various recruitment communication channels that best separates or discriminates the groups. This analysis was performed using eight predictors of membership in seven groups. Predictors were age, gender, income, ethnicity, rurality, 5 year-survival rate, time since diagnosis and distress. The seven groups of various recruitment communication channels were cancer websites, the Cure website, Facebook, Internet, print media, and Loma Linda registry (sign-up either via web or by phone). The participants were assigned to one of the seven different communication channels depending on what the participants indicated to be the medium in which they found out about health-space.net (cancer-related website, Cure website, Facebook, general Internet sites, print media, registry either by phone contact or via web, in which participants found out about the study through receiving mail and directly accessed the website themselves to be screened, bypassing phone contact with study coordinators). The Box's M results also show a significant value $p<0.001$, which indicates that the covariance matrices are significantly different and the homogeneity assumption is violated. A one-way analysis of variance was conducted with using the Bonferroni-correction procedure for multiple comparisons to determine between which groups the function significantly discriminated.

For all discriminant function analyses, any correlation greater .33 (10% of variance) was considered eligible for interpretation (Tabachnick & Fidell, 2007). Any predictor with a loading of .33 or more was considered to be important in defining the discriminant dimension.

CHAPTER THREE

RESULTS

Sample Characteristics

The sample of cancer survivors for the combined years 2008 to March 2011 consisted of a total of 2649 potential recruits. Of these potential recruits a total of 2521 (95.2%) were potential registry recruits and a total of 128 (4.8%) were other recruits, including web, print/media and friend referral. From the potential registry recruits a total of 995 (39.5%) were able to be contacted, and the remaining 1526 were either reported to be deceased, or were listed under a wrong number. Of those who were contacted a total of 257 (25.8%) met eligibility criteria (spoke English, had internet/computer and met cut-off score of 4 or above for the distress rating). Of the remaining 738 participants, a total of 448 (45.0%) did not meet eligibility criteria, and the remaining 290 (29.2%) potential participants declined participation. Of the 128 potential participants who were reached via communication channels other than the registry, a total of 127 (99.2%) met eligibility criteria, and a total of 97 (76.4%) fully enrolled into the web-based psychosocial intervention. Additionally, a total of 100 (38.9%) participants who met eligibility criteria from the registry fully enrolled into the web-based psychosocial intervention (see Figure 16).

Characteristics of the potential participants recruited from the two different recruitment sources are presented in Table 3. Most potential participants were female (67.2%), however there were more males (52.6%) than females (47.4%) in the registry, and more females (87.4%) than males (12.6%) in the other recruitment sources. Potential

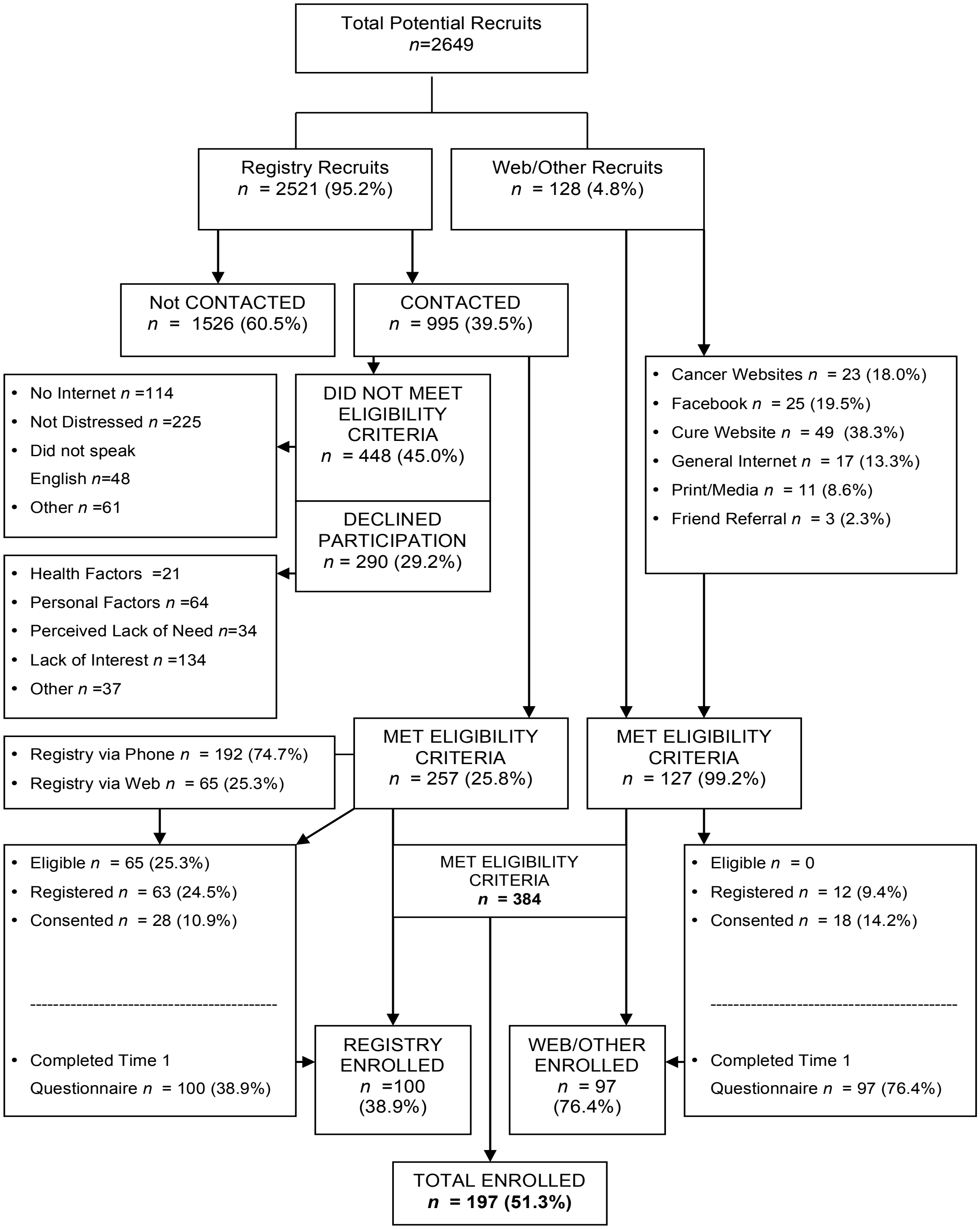


Figure 16. Recruitment Flow Chart

participants were more likely to be Caucasian (87%) and married (67.7%). As compared to the representative of the cancer survivors currently living in the United States, there may have been oversampling of breast, female reproductive and prostate cancer (29.9% in our sample vs. 14.4% in SEER; 9.1% in our sample vs. 5.6% in SEER; 19.3% in our sample vs. 15% in SEER, respectively, Table 8), and under-sampling of lung, urinary and colorectal cancer (2.1% in our sample vs. 13.4% in SEER; 1.1% in our sample vs. 7.9% in SEER; 5.9% in our sample vs. 10.2% in SEER, respectively, Table 8). Additionally, as compared to the estimates in the SEER data, the sample in this study seems to have an oversampling of females (67.2% in our sample vs. 48.5% in SEER) and under-sampling of African-Americans (3.6% in our sample vs. 8.6% in SEER) and Hispanics (5.7% in our sample vs. 8.3% in SEER**).** Average time since diagnosis for cancer survivors in our sample was 4.2 years (*SD* = 4.9, range 0.5 to 35.1 years).

Aim 1 (Participant)

Hypothesis 1a

Multivariate logistic regression was used to evaluate the effects of potential participant segmentation variables on self-reported level of distress. Specifically, univariate logistic regression was used to identify significant predictors of distress. Significant univariate predictors were then simultaneously evaluated in a multivariate logistic regression model.

Hypothesis 1a was partially supported. The results of the univariate analyses showed four of the predictor variables to be significantly associated with participant distress level. Potential participants who reported distress, when compared with those who did not, were generally younger (M_{distress} = 58.13, *SD* = 12.28; $M_{\text{no distress}}$ = 64.21, *SD* = 10.09) and when participant age increased by one year, the odds that clinically significant distress was endorsed decreased by a factor of 0.95 (OR = 0.95, $p < .001$, 95% CI = 0.94-0.96). Sex also showed univariate significance, and the odds of reporting significant distress were over twice as high for women (65%) as men (47%, OR = 2.14, $p = .001$, 95% CI= 1.34-3.39). Further, endorsement of clinically significant distress was associated with lower SEER score ($M_{\text{distress}} = 81.17$, $SD = 19.31$; $M_{\text{no distress}} = 89.54$, $SD = 16.17$), and a participant was more likely to endorse significant distress for each unit decrease in SEER (OR = 0.98, $p = .001$, 95% CI = 0.97-0.99). Rurality score was also negatively associated with distress. Potential participant's who reported distress, when compared with those who did not, generally had a lower rurality score ($M_{\text{distress}} = 1.39$, $SD = 1.23$; $M_{\text{no distress}} = 1.85$, $SD = 1.95$) and with a one unit increase in rurality, the odds that significant distress was endorsed decreased by a factor of 0.81 (OR = 0.81, $p = .002$, 95% CI= 0.71-0.93). In contrast, the potential participant segmentation variables of ethnicity ($p = .266$) and median income of zip code ($p = .252$) did not have significant univariate effects as predictors of distress.

Table 3

Demographic Characteristics of Enrolled Participants by Recruitment Source

	Registry (*n* = 100)	Other (*n* = 97)	Total (*N* = 197)
	n (%)	*n* (%)	*N* (%)
Female***	46 (47.4)	83 (87.4)	129 (67.2)
Marital status			
Married	69 (71.1)	61 (64.2)	130 (67.7)
Single	11 (11.3)	15 (15.8)	26 (13.5)
Divorced/separated	12 (12.4)	15 (15.8)	27 (14.1)
Widowed	5 (5.2)	4 (4.2)	9 (4.7)
Ethnicity			
White	81 (83.5)	86 (90.5)	167 (87.0)
Hispanic	9 (9.3)	2 (2.1)	11 (5.7)
Asian/Pacific Islander	2 (2.1)	0 (0.0)	2 (1.0)
Black	4 (4.1)	3 (3.2)	7 (3.6)
Other ethnicity	1 (1.1)	4 (4.2)	5 (2.6)
Employment status			
Employed	48 (49.5)	57 (60.0)	105 (54.7)
Unemployed	22 (22.7)	24 (25.3)	46 (24.0)
Retired	27 (27.8)	14 (14.7)	41 (21.4)
Ever used support group**	24 (24.7)	44 (46.3)	68 (35.4)
Ever used online support group***	13 (13.4)	38 (40.0)	51 (26.6)
Cancer type***			
Breast	9 (9.6)	47 (50.5)	56 (29.9)
Colorectal	5 (5.3)	6 (6.5)	11 (5.9)
Female Reproductive	9 (9.6)	8 (8.6)	17 (9.1)
Hematologic	5 (5.3)	5 (5.4)	10 (5.3)
Lung	3 (3.2)	1 (1.1)	4 (2.11)
Melanoma	5 (5.3)	1 (1.1)	6 (3.2)
Prostate	31 (33.0)	5 (5.4)	36 (19.3)
Urinary	1 (1.1)	1 (1.1)	2 (1.1)
Multiple	1 (1.1)	1 (1.1)	2 (1.1)
Other	25 (26.6)	18 (19.4)	43 (23.0)
Not specified	6 (n.a)	4 (n.a)	10 (n.a)
Had radiation therapy	62 (63.9)	60 (63.2)	122 (63.5)
Had chemotherapy***	31 (32.0)	63 (66.3)	94 (49.0)
Had surgery***	63 (64.9)	88 (92.6)	151 (78.6)
	M (*SD*)	*M* (*SD*)	*M* (*SD*)
Age***	58.1 (11.7)	49.8 (9.8)	54 (11.6)
Education (years)	15.0 (3.0)	15.7 (2.5)	15.4 (2.8)
SEER 5-year survival rate (%)	78.1 (20.5)	78.4 (15.6)	78.3 (18.1)
Time since diagnosis (years)***	2.7 (4.2)	5.7 (5.0)	4.2 (4.9)
Distress**	5.8 (2.7)	6.9 (1.6)	6.3 (2.3)

$^*p < .05$; $^{**}\ p < .01$; $^{***}p < .001$

The model in which distress was predicted from age, sex, SEER, and rurality was shown to be statistically significant, $\chi^2(4, N = 301) = 38.52, p < .001$, Nagelkerke $R^2 = .161$. In the multivariate logistic regression model, age remained significant as an individual predictor. Specifically, the results indicated that likelihood of participant report of clinically significant distress was associated with younger age; a participant is more likely to endorse significant distress for each year decrease in age (OR = 0.96, $p = .001$, 95% CI = 0.94-0.98). The remaining predictors did not retain significance in the multivariate model, with rurality (OR = 0.85, $p = .054$, 95% CI = 0.73-1.00), SEER (OR = 0.99, $p = .059$, 95% CI = 0.97-1.00) and sex (OR = 1.68, $p = .097$, 95% CI = 0.91-3.08) remaining only marginally significant.

Hypothesis 1b

A multivariate logistic regression was used to evaluate the effects of participant characteristics on enrollment. Specifically, univariate logistic regression was used to generate odds ratios for enrolling in the study versus failing to enroll. Note that only participants who met eligibility criteria (i.e. score of 4 or greater on distress, have internet, and speak English) were included in this analysis.

Hypothesis 1b was not supported as none of the predictor variables (i.e., age, gender, income, RCUA score, SEER 5-year survival rate and distress) were shown to be significantly associated with enrollment in the web-based psychosocial support intervention. The following is a summary of the results obtained from the six unadjusted univariate analyses: age (OR = 0.98, $p = .118$, 95% CI = 0.96-1.01), sex (OR = 1.01, $p = .963$, 95% CI= 0.55-1.89), ethnicity (OR= 1.27, $p = .567$, 95% CI= 0.56-2.89), income

(OR = 1.008, *p* = .442, 95% CI = 0.987-1.030), rurality (OR = 0.86, *p* = .247, 95% CI = 0.66-1.12,), SEER 5-year survival rate (OR = .99, *p* = .319, 95% CI = 0.98-1.01) and distress (OR = 1.10, *p* = .243, 95% CI = 0.94-1.29).

Hypothesis 1c

Since potential participant segmentation variables, including distress, failed to predict enrollment, Hypothesis 1c proposing that distress would mediate the relationship between web-based support group enrollment and potential participant segmentation variables was also refuted. According to Baron and Kenny (1986), four steps are necessary for testing meditational hypothesis. First, the potential participant segmentation variables must be associated with the enrollment. In *hypothesis 1b* non-significant association between the potential participant segmentation variables and enrollment were detected; second, potential participant segmentation variables must be associated with the proposed mediator distress. In Hypothesis 1a, the results demonstrated that distress was predicted from age, sex, SEER, and rurality. In the multivariate logistic regression model, age remained significant as an individual predictor; third, the proposed mediator distress must be associated with the enrollment, in Hypothesis 1b results failed to demonstrate significant association between distress and enrollment; and fourth, to establish that proposed mediator completely mediates the relationship between the initial variable and the outcome, the effect of the potential participant segmentation variables on the enrollment after controlling for the proposed mediator distress should be zero. In the present study, failure to meet the criteria specified in step 1 (i.e., non-significant associations between the potential participant segmentation variables and enrollment) as well as step 3 (a non-significant association between distress and enrollment) precluded consideration of the hypothesized mediation model.

Aim 2 (Product)

Hypothesis 2

A sequential multinomial logistic regression analysis was performed to predict membership in one of four categories of recruitment stage (eligible, registered, consented, fully enrolled), first on the basis of six potential participant segmentation predictors and then after addition of a self-perceived psychological factor (i.e., distress). The predictors assessed include age, ethnicity (Caucasian or non-Caucasian), gender (male or female), rurality, SEER 5-year survival rate and distress (high, medium, low).

Data from 290 potential participants recruited either through individual level recruitment or population level recruitment were available for analysis. There was a good model fit, measured by Pearson and likelihood-ratio chi-square statistics for each model (discrimination among groups) on the basis of the six potential participant segmentation predictors alone $\chi^2(840, N = 290) = 832.52$, $p = .566$, Nagelkerke $R^2 = .146$, using a Pearson criterion. After addition of reported distress, $\chi^2(843, N = 290) = 840.98$, $p = .513$, Nagelkerke $R^2 = .189$. Comparison of log-likelihood ratios (See Table 4) for models including potential participant segmentation predictors, with and without distress showed statistically significant improvement with the addition of distress, $\chi^2(6, N = 290) = 13.20$, $p < .05$.

Overall correct classification on the basis of potential participant segmentation variable alone is 56% overall, with 96% for potential participants who fully enrolled into the study (the largest group), 11% who were eligible but only registered, but no correct classifications for eligible potential participant's and those who were eligible but only consented. No improvement in overall correct classification was noted with the addition of distress. However, distress reflected success rates of 2% and 6% for those who were in the eligible group and those who were eligible and only consented, respectively. Clearly, cases seem to be over-classified into those who fully enrolled (the largest group).

Hypothesis 2 was partially supported. Table 4 shows the contribution of all predictors, including, potential participant segmentation and distress variables to the model by comparing the models with and without each of the predictors. Significant main effects were noted with income, gender and distress, and to a lesser extent ethnicity, which was marginally significant. Income had a significant main effect on recruitment stage, how far a potential participant would be among the different stages of recruitment, $\chi^2(3, N = 290) = 8.18, p < .05$, as did gender $\chi^2(3, N = 290) = 13.01, p < .01$, distress $\chi^2(6, N = 290) = 13.20, p < .05$, and to a lesser extent, ethnicity $\chi^2(3, N = 290) = 6.83, p = .078$.

Table 4

Multinomial Logistic Regression Analysis of Recruitment Stage as a Function of Potential Participant Segmentation Variables and Distress

Variable	χ^2 to Remove	*df*	Model χ^2
Participant Segmentation Variables			
Age	2.468	3	
Gender	13.014**	3	
Ethnicity	6.828	3	
Income[a]	8.180*	3	
SEER 5-Year Survival rate	1.999	3	
Rurality	1.427	3	
All Participant Segmentation Variables			40.851
Perceived Psychological Factor			
Distress	13.201*	6	
All Variables			54.053

Note. Gender is coded 1 = male and 2 = female; Ethnicity is coded 1 = Non-Hispanic Whites and 2 = Other Ethnicity.
[a] Measured in thousands of dollars.
$^*p < .05$; $^{**}p < .01$.

Table 5 shows the individual parameter estimates. Potential participants income significantly predicted whether they would only register or fully enroll in the study, $b = -0.039$, Wald $\chi^2(1) = 6.74$, $p < .01$. As income increases by a unit of $1000, the odds of preferring registration to full enrollment would be expected to decreased by a factor of 0.95, given the other predictors in the model are held constant (OR = 0.95, $p < .01$, 95% CI = 0.93-0.99). In short, the higher the income the less likely a participant is to only register than to fully enroll in the study. Full enrollment into the study is higher for participants who report higher income. Potential participants gender and ethnicity also significantly predicted whether a participant would only register or fully enroll into the study, *b* = 1.359, Wald $\chi^2(1) = 11.38$, $p < .001$ and *b* = 1.023, Wald $\chi^2(1) = 4.87$, $p < .05$, respectively. The odds of only registering compared to fully enrolling was almost four times more likely for women than in men (OR = 3.89, $p < .001$, 95% CI = 1.77-8.57), and three times more likely for other Ethnicity than for Non-Hispanic Whites (OR = 2.78, $p < .05$, 95% CI = 1.12-6.90). Furthermore, potential participants level of distress was only marginally predictive of whether a participant would only register or fully enroll into the study, *b* = 0.851, Wald $\chi^2(1) = 3.25$, $p = .072$. The odds of only registering compared to fully enrolling into the study was almost two times more likely for participants who endorsed medium level of distress than for participants who endorsed the highest level of distress (OR = 2.34, $p = .072$, 95% CI = 0.93-5.91).

And finally, potential participants level of distress was significantly predictive of whether a participant would only consent or fully enroll into the study, *b* = 1.37, Wald $\chi^2(1) = 6.92$, $p = .0094$. The odds of only consenting compared to fully enrolling into the study was almost four times more likely for participants who endorsed medium level of distress than for participants who endorsed the highest level of distress (OR = 3.93, $p = .0094$, 95% CI = 1.42-10.91). Furthermore, ethnicity was only marginally predictive of whether a participant would only consent or fully enroll into the study, $p = .062$. The odds of only consenting compared to fully enrolling was three times more likely for other Ethnicity than for Non-Hispanic Whites (OR = 2.50, $p = 0.062$, 95% CI = 0.95-6.60).

Table 5

Multinomial Logistic Regression Analysis Predicting Recruitment Stage: Individual Parameters

	Eligible vs. Enrolled		Registered vs. Enrolled		Consented vs. Enrolled	
Variable	*B*	OR (95% CI)	*B*	OR (95% CI)	*B*	OR (95% CI)
Age	0.018	1.02 (0.99, 1.05)	0.009	1.01 (0.98, 1.04)	0.021	1.02 (0.99, 1.06)
Gender						
Male (ref)	—	1.00	—	1.00	—	1.00
Female	0.475	1.61 (0.74, 3.50)	1.359***	3.89 (1.77, 8.57)	-0.085	0.92 (0.38, 2.24)
Ethnicity						
Non-Hispanic Whites (ref)	—	1.00	—	1.00	—	1.00
Other Ethnicity	0.694	2.00 (0.81, 4.97)	1.023*	2.78 (1.12, 6.90)	0.917†	2.50 (0.95, 6.60)
Income[a]	-	0.98 (0.96, 1.01)	-0.039**	0.96 (0.93, 0.99)	-0.012	0.99 (0.96, 1.02)
Rurality	-	0.83 (0.59, 1.17)	-0.062	0.94 (0.70, 1.26)	-0.097	0.91 (0.63, 1.31)
SEER Survival	0.015	1.02 (0.99, 1.04)	0.006	1.01 (0.99, 1.03)	0.004	1.00 (0.98, 1.03)
Distress						
Low	0.385	1.47 (0.66, 3.27)	0.709	2.03 (0.81, 5.08)	0.555	1.74 (0.57, 5.35)
Medium	-	0.90 (0.36, 2.22)	0.851‡	2.34 (0.93, 5.91)	1.369**	3.93 (1.42, 10.91)
High (ref)	—	1.00	—	1.00	—	1.00

Note. 95% CI = 95% confidence interval for the odds ratio. Variables with significant regression coefficients and odds ratios greater than 1.00 indicate that as independent variables increased one unit, the odds of being in the eligible, consented, or registered category increased. Variables with significant regression coefficients and odds ratios less than 1.00 indicate that per one unit change in the independent variable, the odds of being in the eligible, consented, or registered category decreased.

[a] Measured in thousands of dollars.

*$p < .05$; ** $p < .01$; ***$p < .001$; †$p = .064$; ‡$p = .072$.

Aim 3 (Price)

In order to identify the perceived costs and the sociodemographic correlates associated with enrollment in the web-based psychosocial intervention, particularly among potential participants with significant self-reported distress, a discriminant analysis was conducted. A total of 290 participants provided information regarding the reason for declining enrollment in the web-based psychosocial intervention. However, only 197 total participants had data on the variables of interest. Of these 197, a total of 99 (50.3%) participants stated that their reason for declining was due to having no interest, 36 (18.3%) stated their reason to be due to personal factors, 25 (12.7%) stated their reason to be due to perceived lack of need, 24 (12.2%) stated their reason to be due to any other factor, 13 (6.6%) stated reasons related to health factors. Of these participants only a total of 29 (14.7%) provided a rating for self-reported distress.

Hypothesis 3a

It was hypothesized that among those who declined participation in individual-level recruitment, potential participant segmentation variables will be associated with the stated reason participation declined. In particular, the following reasons for refusal of participation will be associated with the specified potential participant segmentation variables: *Health factors* (i.e. poor health, illness-related functional limitation) will be associated with older age, being female, residence in census areas of lower income levels, and lower average SEER 5-year survival rate associated with cancer type; *Personal factors* (feeling overwhelmed, lack of time) will be associated with younger age, being female and lower average SEER 5-year survival rate associated with cancer type;

Perceived lack of need (i.e. excellent heath and lack of distress) will be associated with being male, residence in census areas of lower income levels, higher average SEER 5-year survival rate associated with cancer type, and being a minority; *General lack of interest* will be associated with younger age, lower average SEER 5-year survival rate and lower income.

A discriminate function analysis was conducted to determine the linear combination of reasons participants declined enrollment in the web-based psychosocial intervention that best separates or discriminates the groups. This analysis was performed using six predictors of membership in five groups. Predictors were age, sex, income, ethnicity, rurality, and SEER-5 year survival rate. The five groups of different reasons participants declined enrollment were related to health factors, personal factors, perceived lack of need, general lack of interest, and any other reason for decline. The Box's test of the assumption of equality of covariance matrices tests the null hypothesis that the variance-covariance matrices are the same in all three groups. The Box's M results show a significant value $p < .001$, which indicates that the covariance matrices are significantly different and the homogeneity assumption is violated.

Four discriminant functions were calculated and only function 1 was significant according to the chi-square analyses $\chi^2(24, N = 197) = 44.37, p = .007$ in discriminating between the different reasons participants declined enrollment (reasons due to health factors, personal factors, perceived lack of need, general lack of interest, and any other reason for decline). The remaining functions, including function 2, 3 and 4 where not significant ($ps > .05$). The four discriminate functions accounted for 59.8%, 32.3%, 4.7%

and 3.2% of the between-group variability, respectively. Thus, together they accounted for 100% of the between-group variance.

Hypothesis 3a was partially supported. As shown in Figure 17 and as evident from reviewing the canonical discriminant function evaluated at group means (see Table 6), the first function maximally discriminated participants who indicated reasons for decline due to health factors from the other groups, including, personal factors, perceived lack of need, general lack of interest, and any other reason for decline.

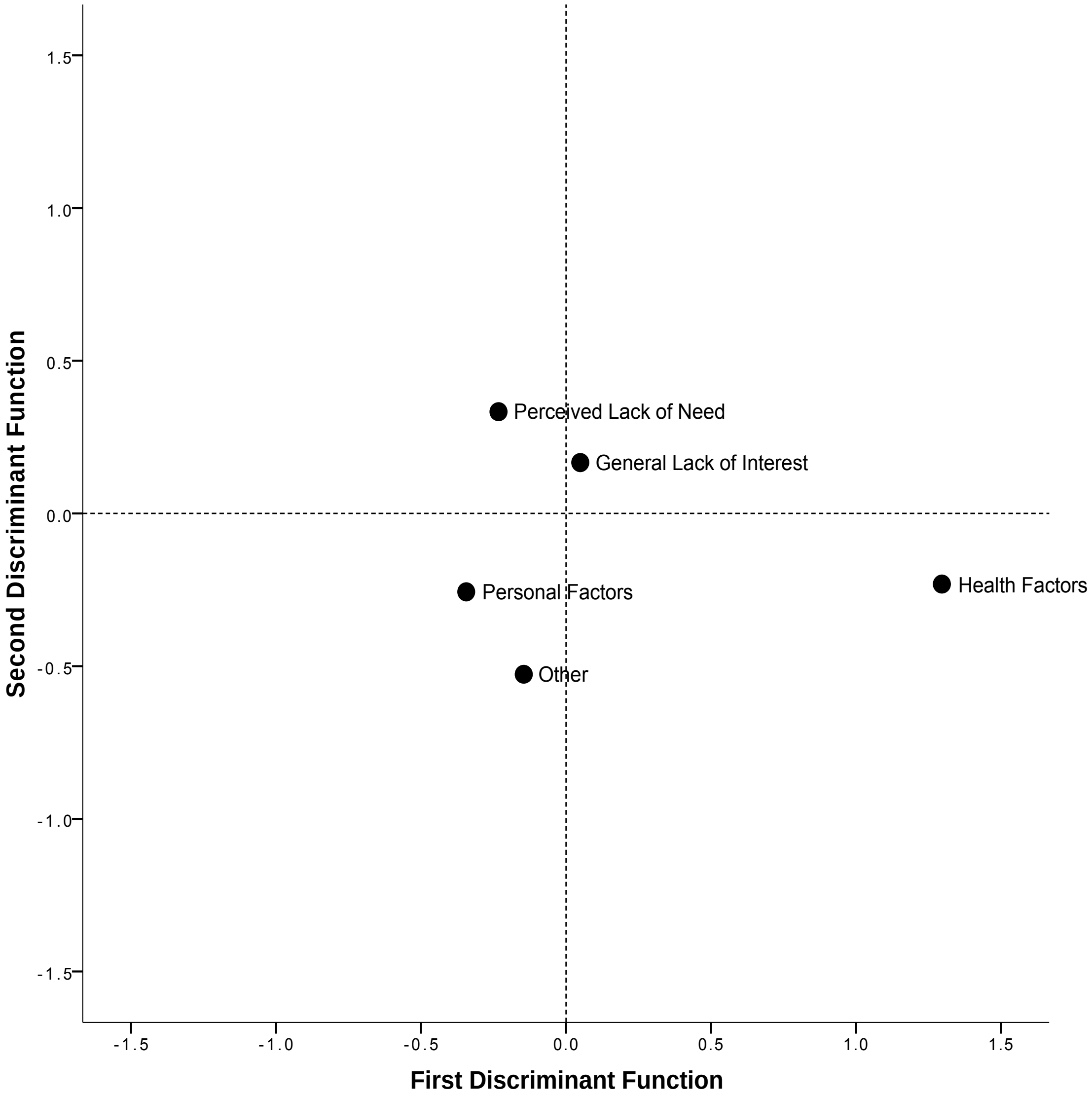


Figure 17. Plots of five group centroids on discriminant functions of age, income and SEER-5 year survival rate (first discriminant function), and gender and rurality (second discriminant function)

Table 6

Group Means on the Discriminant Functions and the Predictor Variables (Age, Income, SEER, Rurality, Gender & Ethnicity)

	Reason for Decline				
Predictor Variable	Health Factors	Personal Factors	Perceived lack of need	General lack of interest	Other
Discriminant function 1	1.30	$-.34_{a}$	$-.23_{ab}$	$.05_{b}$	$-.15_{ab}$
Age	72.77	61.83_{a}	65.00_{ab}	64.67_{b}	62.13_{ab}
Income	39001.31	47950.22_{a}	46491.80_{ab}	47735.19_{b}	46803.13_{ab}
SEER	66.31	87.87_{a}	92.13_{ab}	84.03_{b}	83.87_{ab}
Rurality	1.31_{a}	1.43_{a}	2.08_{a}	1.80_{a}	1.42_{a}
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Gender					
Male	10 (47.6)	35 (55.6)	27 (79.4)	93 (69.9)	18 (52.9)
Female	11 (52.4)	28 (44.4)	7 (20.6)	39 (29.3)	16 (47.1)
Ethnicity					
Non-Hispanic Whites	17 (81.0)	56 (90.3)	31 (91.2)	108 (81.8)	27 (79.4)
Other	4 (19.0)	6 (9.7)	3 (8.8)	24 (18.2)	7 (20.6)

Note. Means in a row sharing common subscripts do not differ significantly from one another ($p > .05$).

One-way analysis of variance with the Bonferroni-correction procedure was used to determine between which groups the function significantly discriminated. Univariate analysis demonstrated that the scores of the first discriminant function differed significantly between participants' reasons for decline groups, $F(4, 196) = 7.06$, $p < .001$, and pairwise comparisons revealed that the discriminant scores of those participants who stated that the reason for declining to enroll into the web-based psychosocial intervention was due to health factors differ significantly from those participants who stated their reasons for decline was due to be personal factors, perceived lack of need, general lack of interest, and other, (*ps* <.001). Pairwise comparisons also showed significant differences between the discriminant scores of participants who indicated that their reason for decline was due to personal factors and those participants who stated their reason to be due to a general lack of interest (*p* = .045).

The structure matrix of correlations between the independent variables and the functions showed that three variable have loadings in excess of .33 on the first function (see Table 7). The variable of SEER-5 year survival rate (-.692) had the strongest relationship with this function, followed by participants' age (.555) and income (-.335). Participants who stated that health factors where the reason for declining to enroll in to the web-based psychosocial intervention were older (*M* = 72.77, *SD* = 13.28) than participants who declined due to personal reasons (*M* = -61.83, *SD* = 9.42), perceived lack of need (*M* = 65.00, *SD* = 9.90), general lack of interest (*M* = 64.67, *SD* = 11.82), and those who stated other as a reason for declining participation (*M* = 62.13, *SD* = 12.71). It was also shown that participants who stated that health factors where the reason for declining to enroll in to the web-based psychosocial intervention also had lower income, (*M* = 39,001.31, *SD* = 13,656.68) than participants who declined due to personal reasons (*M* = 47,950.22, *SD* = 12,471.88), perceived lack of need (*M* = 46,491.80, *SD* = 18,332.07), general lack of interest (*M* = 47,735.19, *SD* = 16,822.31), and those who stated other as the reason for declining participation (*M* = 46,803.13, *SD* = 12,562.73).

Additionally, results demonstrated that participants who stated that health factors where the reason for declining to enroll in to the web-based psychosocial intervention also had a diagnosis of cancer with significantly lower SEER 5-year survival rate,

Table 7

Results of Discriminant Function Analysis (F1: Age, Income & SEER)

	Correlations with Discriminant Functions				Univariate $F(4, 192)$	Pooled Within-Group Correlations among Predictors				
Predictor	1	2	3	4		Age	Gender	Income	Ethnicity	SEER
Age	.56	.21	-.43	.29	2.48	□				
Gender	.10	-.67	.64	.34	2.05	-.34	□			
Income	-.34	.11	.50	-.39	.94	-.05	-.01	□		
Ethnicity	.18	.32	.57	.02	.80	-.29	.24	-.03	□	
SEER	-.69	.29	-.38	.41	3.83	.14	-.39	.10	-.21	□
Rurality	-.09	.48	.09	.49	1.02	.01	-.10	-.20	-.16	.16
Canonical R	.36	.27	.11	.09						
Eigenvalue	.15	.08	.01	.01						

Note. Gender is coded 1 = male and 2 = female; Ethnicity is coded 1 = Non-Hispanic White and 2 = Other Ethnicity.

(*M* = 66.31, *SD* = 26.53) than participants who declined due to personal reasons (*M* = 87.87, *SD* = 18.22), perceived lack of need (*M* = 92.13, *SD* = 18.63), general lack of interest (*M* = 84.03, *SD* = 21.34), and those who stated other reasons (*M* = 83.87, *SD* = 14.26). Furthermore, those participants who stated that their reason for declining enrollment in to the web-based psychosocial intervention was due to personal factors were younger (*M* = 61.83, *SD* = 9.42), had higher income (*M* = 47,950.22, *SD* = 12,471.88), and had higher SEER 5-year survival rates (*M* = 87.87, *SD* = 18.22) than participants who declined enrollment due to general lack of interest (*M* = 64.67, *SD* = 11.82; *M* = 47,735.19, *SD* = 16,822.31; *M* = 84.03, *SD* = 21.34, respectively).

As discussed earlier, participants who stated that health factors where the reason for declining to enroll in to the web-based psychosocial intervention were of older age, had lower income and were more likely to have a diagnosis of cancer with lower SEER 5-year survival rate as compared to those participants who reported all other reasons for declining to enroll, including perceived lack of need, general lack of interest, personal factors, and other. Participants who stated that the reason for declining enrollment into the web-based psychosocial intervention was due to personal factors were younger, had higher income, and had lower SEER 5-year survival rates than those participants who stated that their reason for declining enrollment was due to their general lack of interest.

Hypothesis 3b

Additionally, it was hypothesized that in individual-level recruitment, self-reported distress will be associated with the stated reason participation was declined, with greater distress associated with reasons related to *health factors* (i.e. poor health, illness-related functional limitation) and *personal factors* (feeling overwhelmed, lack of time). A univariate analysis of variance was tested to investigate whether level of distress varied significantly across the different reasons participants stated to decline enrollment in the web-based psychosocial intervention. Hypothesis 3b was refuted as results demonstrated that participants who provided reasons for declining participation did not significantly differ on their average distress score F (3, 29) = 0.61, *p* = .62.

Aim 4 (Place)

Hypothesis 4a

To evaluate the effectiveness, including yield of a representative and/or diverse sample, of the communication channels utilized for recruitment of cancer survivors to a web-based psychosocial support intervention, a bivariate analysis was used. Specifically, chi-square analysis was used to assess mean differences between participants' enrollment based upon recruitment via various communication channels. From a total of 1123 potential participants, 995 (88.6%) were contacted via individual-level strategies (e.g., registry), and 128 (11.4%) from population-level strategies.

Contrary to the hypothesis that individual-level strategies would be more effective as compared with population-level strategies, the results demonstrated that population-level strategies were significantly more effective than individual-level strategies $\chi^2(1, N = 1123) = 338.75, p < .001$. Only 10.1% ($n = 100$) of potential participants contacted via the registry fully enrolled in the study (completed time 1 questionnaire). In contrast, 75.8% ($n = 97$) of potential population-level recruits fully enrolled in the study.

Hypothesis 4b

A chi-square analysis was also used to compare the yield of a representative sample of the different communication channels utilized for recruitment of cancer survivors to a web-based psychosocial support intervention. Only participants who met eligibility criteria who enrolled in the study were used in this analysis. As compared to the representative of the cancer survivors currently living in the United States, there seems to be a discrepancy between the yield of a representative and/or diverse sample, of the different communication channels utilized for recruitment of cancer patients to a web-based psychosocial support intervention (see Table 8). In the population-level recruitment strategies there may have been under-sampling of males (12.6% in population-level sample vs. 51.5% in SEER), African-Americans (3.2% in population-level sample vs. 8.6% in SEER), and Hispanics (2.1% in population-level sample vs. 8.3% in SEER), and

Table 8.

Representativeness of Recruits Compared to Cancer Survivors Currently Living in the United States

	Total	Registry	Other	SEER
Median age (years)	54	58.1	49.8	66
Gender				
Male	32.8%	52.6%	12.6%	51.5%
Female	67.2%	47.4%	87.4%	48.5%
Ethnicity				
Caucasian	87.0%	83.5%	90.5%	77.2%
African-American	3.6%	4.1%	3.2%	8.6%
Asian/Pacific Islander	1.0%	2.1%	0.0%	2.8%
Hispanic	5.7%	9.3%	2.1%	8.3%
Other ethnicity	2.6%	1.1%	4.2%	5.9%
Cancer Type				
Breast	29.9%	9.6%	50.5%	14.4%
Colorectal	5.9%	5.3%	6.5%	10.2%
Female reproductive	9.1%	9.6%	8.6%	5.6%
Hematologic	5.3%	5.3%	5.4%	8.8%
Lung	2.1%	3.2%	1.1%	13.4%
Melanoma	3.2%	5.3%	1.1%	4.5%
Prostate	19.3%	33.0%	5.4%	15.0%
Urinary	1.1%	1.1%	1.1%	7.9%

oversampling of Caucasians (90.5% in population-level sample vs. 77.2% in SEER). Additionally, as compared to the estimates in the SEER data, the population level recruitment strategies may have also been oversampling breast cancer (50.5% in our sample vs. 14.4% in SEER), and under-sampling of lung (1.1% in our sample vs. 13.4%

in SEER), prostate (5.4% in our sample vs. 15.0% in SEER) and urinary cancer (1.1% in our sample vs. 7.9% in SEER). Furthermore, in the individual-level recruitment strategies there may have been under-sampling of African-Americans (4.1% in population-level sample vs. 8.6% in SEER), lung (3.2% in our sample vs. 13.4% in SEER), and urinary cancer (1.1% in our sample vs. 7.9% in SEER), and oversampling of female reproductive (9.6% in our sample vs. 5.6% in SEER) and prostate cancer (33% in our sample vs. 15% in SEER).

The results clearly demonstrated that population-level strategies were significantly more effective than individual-level strategies. However, despite its effectiveness, this particular strategy did not yield a good representative sample of cancer survivors currently living in the United States. Even though Individual level recruitment strategies seem to be significantly less effective, its potential to recruit a better representative sample of cancer survivors currently living in the United States is higher.

Aim 5 (Promotion)

Hypothesis 5

In order to assess sociodemographic characteristics of participants accessible via various communication channels as well as characteristics of those with significant self-reported distress to inform more targeted promotional strategies, a discriminant analysis was conducted. It was hypothesized that participant segmentation variables will be differentially associated with the recruitment communication channels. In particular, and as compared with average sociodemographic characteristics of cancer survivors, we hypothesized that the following participant segmentation variables will be associated with the various recruitment communication channels: *Registry-based recruitment* (older age, lower average SEER 5-year survival rate associated with cancer type, more recent time since diagnosis and greater distress); *Web-based Registry recruitment* (younger age, residence in census areas of higher educational and income levels); *Print Media* (older age, residence in census areas of lower income levels); *Cancer Websites* (younger age, greater distress, more recent time since diagnosis and lower average SEER 5-year survival rate); *Cure Website* (younger age, greater distress, lower average SEER 5-year survival rate, residence in census areas of higher income levels, and more likely to be female); *Facebook* (younger age, lower distress, residence in census areas of higher income levels); *General Internet Sites* (older age, lower distress, more likely to be male, lower average SEER 5-year survival rate).

From the total of 384 participants who were eligible, a total of 314 participants provided information regarding how they heard about the web-based psychosocial intervention and the remaining 70 participants were phone recruits from the Loma Linda Registry. However, only 197 of those participants had full data on the variables of interest in this analysis. From these 197 participants, a total of 16 (8.1%) stated that they heard about the study from a cancer website (e.g. yahoo group, cancer blog site, cancer alliance site, etc.), 20 (10.2%) participants reported that they found out about the study from Facebook, 42 (21.3%) reported to have found out about the study through the Cure website, 8 (4.1%) reported to have seen an ad on the internet (Craig’s list, Google search, etc.), 7 (3.6%) participants reported to have found out about the study through print media (e.g. flyers at LLUMC, physician, Redlands daily facts, etc.), and a total of 102 participants were from the Loma Linda Registry. Of these participants, 47 (23.9%) noted that they received a letter from Loma Linda University (or from Dr. Jason Owen) inviting them to participate. These participants also accessed the website directly to undergo the screening process. The remaining 55 (27.9%) participants were contacted by phone by a study coordinator for the screening process.

A discriminate function analysis was conducted to determine the linear combination of participants accessible via various recruitment communication channels that best separates or discriminates the groups. This analysis was performed using eight predictors of membership in seven groups. Predictors were age, gender, income, ethnicity, rurality, 5 year-survival rate, time since diagnosis and distress. The seven groups of various recruitment communication channels were cancer websites, the Cure website, Facebook, Internet, print media, and Loma Linda registry (sign-up either via web or by phone).

Hypothesis 5 was partially supported. Six discriminant functions were calculated and both function 1 and function 2 were significant according to the chi-square analyses $\chi^2(48, N = 197) = 194.64, p < .001$ and $\chi^2(35, N = 197) = 66.23, p < .01$, respectively, in discriminating between the various recruitment communication channels. The two discriminant functions accounted for about 70.3% and 39.1% of the total relationship between all the predictors of interest and the various recruitment communication channels of interests (groups). The two discriminate functions account for 72.3% and 13.3%, respectively, of the between-group variability. The remaining functions, including function 3, 4, 5 and 6 where not significant (*ps* > .05).

Function 1

As shown in Figure 18 and as evident from reviewing the canonical discriminant function evaluated at group means (see Table 9), the first function maximally discriminated participants accessible via registry (accessible by phone) from participants accessible via cancer-related websites, the Cure website, Facebook, other Internet sites, print media, and registry-based web enrollees. A one-way analysis of variance was conducted with using the Bonferroni-correction procedure to determine between which groups the function significantly discriminated. Univariate analysis demonstrated that the scores of the first discriminant function differed significantly between group of participants accessible via various communication channels, $F(6, 196) = 30.92$, $p < .001$, and pairwise comparisons revealed that the discriminant scores of those participants who were accessible via registry by phone differ significantly from those participants who were accessible through various cancer-related websites, Facebook, the Cure website, the general Internet sites, and print media (*ps* <.001), as well as, registry-based web enrollees ($p = .001$). Pairwise comparisons also showed significant between the discriminant scores of registry-based web enrollees differ significantly from those participants who were accessible through Facebook and the Cure website (*ps* <.001), and various cancer-related websites ($p = .007$). Additionally, results demonstrated significant differences between the discriminant scores of participants accessible via Facebook and those participants accessible through general Internet sites ($p = .024$).

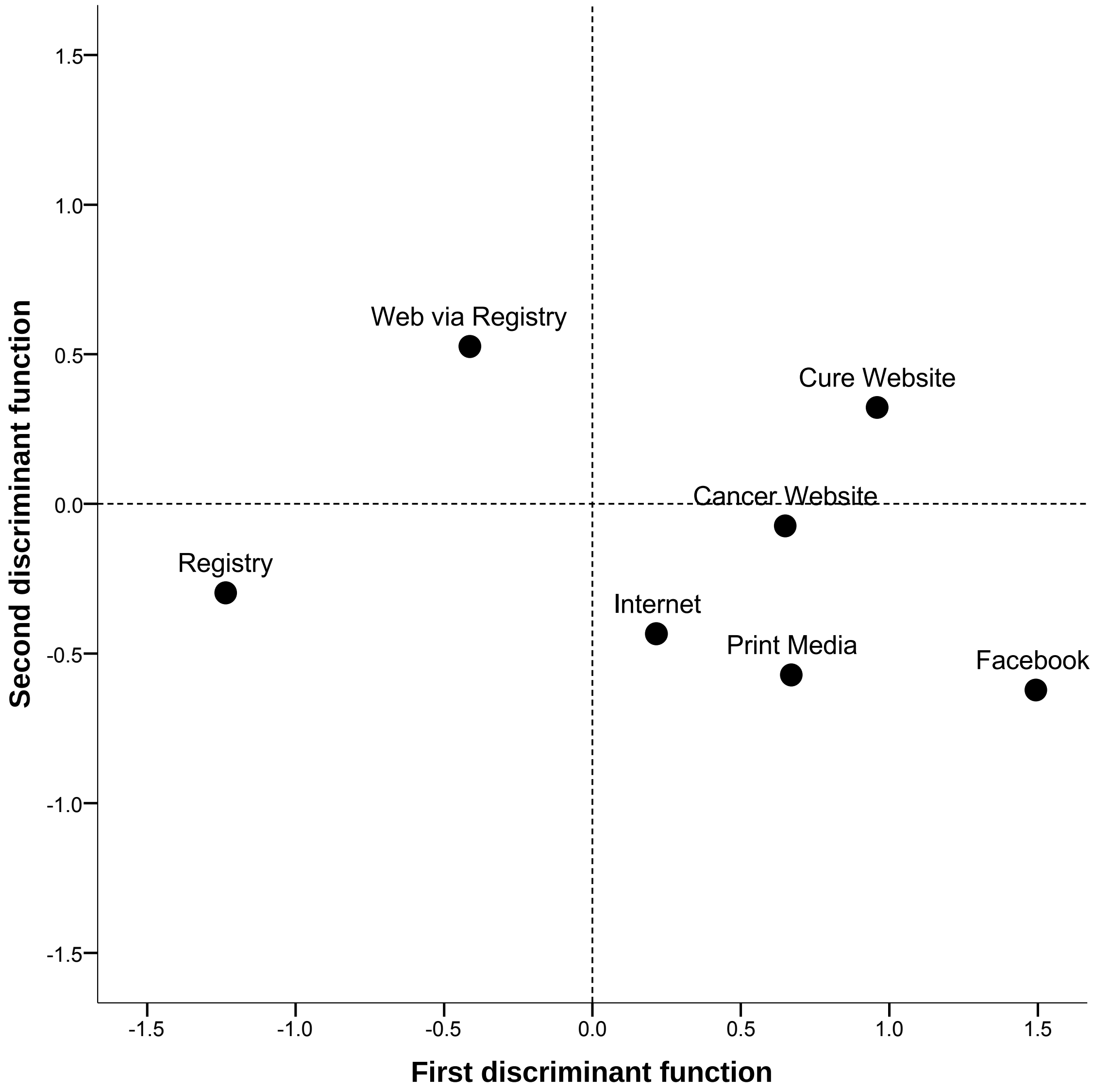


Figure 18. Plots of seven group centroids on discriminant functions of age and gender (first discriminant function), and distress and income (second discriminant function)

The structure matrix of correlations between the independent variables and the functions showed that two variable have loadings in excess of .33 on the first function without cross loading on the second function (see Table 10). The variable of gender (.547) had the strongest relationship with the first function, followed by participants' age (-.414). Participant's accessible from the registry were older (*M* = 59.04, *SD* = 12.03) than participants accessible from Facebook (*M* = 44.55, *SD* = 7.19) and the Cure website (*M* = 51.31, *SD* = 7.38). Results also demonstrate that participants accessible from the registry were more likely to be male than female (61.8% male vs. 38.2% female) as compared to those participants accessible from various cancer-related websites (12.5% male vs. 87.5% female), Facebook (10.0% male vs. 90.0% female), the Cure website (4.8% male vs. 95.2% female), general Internet sites (20.0% male vs. 80.0% female), print media (28.6% male vs. 71.4% female), and registry-based web enrollees (42.6% male vs. 57.4% female).

Additionally, registry-based web enrollees were also older (*M* = 58.23, *SD* = 12.63) than participants accessible from Facebook (*M* = 44.55, *SD* = 7.19), and more likely to be male than female (42.6% male vs. 57.4% female) as compared to those participants accessible from various cancer-related websites (12.5% male vs. 87.5% female), Facebook (10.0% male vs. 90.0% female) and the Cure website (4.8% male vs. 95.2% female). Furthermore, those participants accessible from Facebook were more likely to be female than male (10.0% male vs. 90.0% female), than participants accessible from general Internet sites (20% male vs. 80% female, respectively).

Table 9

Group Means on the Discriminant Functions and the Predictor Variables (Age, Income, SEER, Rurality, Distress, Time Since Diagnosis, Gender & Ethnicity)

	Recruitment Communication Channels						
Predictor Variable	Registry Phone	Registry Web	Facebook	Cancer Websites	Cure Website	General Internet	Print Media
Discriminant function 1	-1.24	-0.41_{a}	1.49_{b}	0.65_{bc}	0.96_{bc}	0.22_{ac}	0.67_{abc}
Discriminant function 2	-0.30_{ab}	0.53_{c}	-0.62_{a}	-0.07_{abc}	0.32_{bc}	-0.43_{abc}	-0.57_{abc}
Age	59.04_{a}	58.23_{ab}	44.55_{c}	51.56_{abc}	51.31_{bc}	51.40_{abc}	53.57_{abc}
Income	45484.15_{a}	43897.60_{a}	63860.35_{b}	47431.13_{a}	46803.13_{ab}	45982.00_{a}	51835.00_{a}
SEER	75.90	81.30	81.79	73.34	69.55	67.58	81.63
Rurality	1.50	1.44	1.58	1.83	1.62	2.61	1.29
Distress	5.02_{a}	6.68_{b}	6.55_{ab}	6.63_{ab}	7.26_{b}	7.00_{ab}	6.29_{ab}
Time since diagnosis	2.38_{a}	3.55_{ab}	5.50_{abc}	7.66_{bc}	5.10_{abc}	5.43_{abc}	9.63_{c}
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
Gender							
Male	34 (61.8)	20 (42.6)$_{a}$	2 (10.0)$_{b}$	2 (12.5)$_{b}$	2 (4.8)$_{b}$	2 (20.0)$_{ab}$	2 (28.6)$_{ab}$
Female	21 (38.2)$_{ab}$	27 (57.4)$_{ab}$	18 (90.0)$_{a}$	14 (87.5)$_{ab}$	40 (95.2)$_{ab}$	8 (80.0)$_{b}$	5 (71.4)$_{ab}$
Ethnicity							
Non-Hispanic Whites	44 (80.0)	42 (89.4)	190 (95.0)	15 (93.8)	41 (97.6)	8 (80.0)	5 (71.4)
Other Ethnicity	11 (20.0)	5 (10.6)	1 (5.0)	1 (6.2)	1 (2.4)	2 (20.0)	2 (28.6)

Note. Means in a row sharing common subscripts do not differ significantly from one another ($p > .05$).

Function 2

The second function separates participants accessible via Facebook from participants accessible via registry (phone and web), cancer-related websites, the Cure website, other Internet sites, and print media. Univariate analysis showed that the scores of the second discriminant function significantly differ between participants from various communication channels, *F*(6, 196) = 5.71, *p* < .001. Pairwise comparisons demonstrated that the discriminant scores of participants accessible via Facebook differ from registry-based web enrollees (*p* < .001) and Cure website (*p* = .013). Results also showed that the discriminant scores of participants accessible via the registry by phone differ from registry-based web enrollees (*p* = .001), and to a lesser extent participants accessible through the Cure website (*p* = .060).

Two of the predictors, distress and income, had a loading in excess of .33 on the second discriminant function (see Table 10), which separates participants accessible via Facebook from those participants accessible from other communication channels, such as the participants accessible via the Cure website and the registry-based web enrollees. The variable distress had the strongest relationship with this function (.52), followed by income (-.39). Both of these predictors were considered important in defining the discriminant dimension. Participants accessible via Facebook exhibited less average distress, as indicated by lower average scores on the measure of distress (*M* = 6.55, *SD* = 1.70) than registry-based web enrollees (*M* = 6.68, *SD* = 1.76) or the Cure website (*M* = 7.26, *SD* = 1.58), who had the highest average distress score. In addition, participant accessible via Facebook had significantly higher income (*M* = 63,860.35, *SD* = 14,815.01), than registry-based web enrollees (*M* = 43,897.69, *SD* = 13,610.26) or the

Cure website (*M* = 52,845.43, *SD* = 16,488.10). Results also showed that compared to participants accessible through the registry by phone had lower average distress scores (*M* = 5.02, *SD* = 2.84) and higher income (*M* = 45,484.15, *SD* = 12,370.48) as compared to participants accessible through the registry through the web (*M* = 6.68, *SD* = 1.76; *M* = 43,897.69, *SD* = 13,610.26, respectively), and to a lesser extent lower average distress score and income as compared to participants accessible via the Cure website (*M* = 7.26, *SD* = 1.58; *M* = 52,845.43, *SD* = 16,488.10, respectively).

Table 10

Results of Discriminant Function Analysis (F1: Age & Gender; F2: Distress & Income)

Predictor	Correlations of Predictor Variables with Discriminant Functions						Univariate *F* (6, 190)	Pooled Within-Group Correlations among Predictors						
	1	2	3	4	5	6		Age	Gender	Income	Ethnicity	SEER	Rurality	Distress
Age	-.41	.32	.11	-.24	.08	.48	6.06	□						
Gender	.55	.16	.19	.30	-.43	.54	9.85	-.17	□					
Income	.34	-.39	-.53	-.01	.15	.31	5.43	.15	-.05	□				
Ethnicity	-.10	-.29	.55	.04	.56	.46	2.10	.10	.06	-.08	□			
SEER	.06	.22	-.40	-.46	.54	-.02	1.52	.14	-.32	.06	-.07	□		
Rurality	.05	-.10	.30	.48	-.002	-.27	0.89	-.01	.05	-.22	-.08	.002	□	
Distress	.34	.52	.26	.22	.49	-.23	5.64	-.04	-.01	-.06	.17	-.04	-.07	□
Time since dx	.31	-.13	.58	-.55	-.25	-.05	4.79	.27	.06	.02	.04	-.14	.09	-.004
Canonical R	.70	.39	.32	.24	.13	.07								
Eigenvalue	.98	.18	.11	.06	.02	.01								

Note. Gender is coded 1 = male and 2 = female; Ethnicity is coded 1 = Non-Hispanic White and 2 = Other Ethnicity.

CHAPTER FOUR

DISCUSSION

Recruitment is fundamental to project success and the production of both clinical and statistical meaningful results. However, researchers have faced challenges in the recruitment of adequate numbers of participants to supportive interventions for cancer patients (Buss et al., 2008). In view of the importance of effective recruitment and the challenges associated with recruitment of cancer patients, it is critical that recruitment efforts are planned and executed in a systematic manner. However, effective recruitment strategies alone are not enough in that these methods cannot compensate for an intervention that was not designed to address participant needs or expectations. A continuous process of research and revision is necessary to not only enhance recruitment but also built better interventions that are of high quality and efficacy.

Social marketing is a promising theoretical framework for understanding, designing and implementing recruitment efforts and interventions. Social marketing theory also provides for a continuous feedback loop in which strategies may be evaluated as precursors to interventions as well as during the interventions to identify major gaps that would lead to refinement of promotional materials and revision of methods to increase participation. The current study proposed to demonstrate the use of the social marketing model, analyzing data that characterized potential participants and providing information for marketing mix decisions. Ultimately, the results of this study contribute to a better understanding of recruitment of cancer patients and serve to inform the identification of more effective and appropriate strategies to guide recruitment and intervention design in future cancer research.

Findings of the Present Study and the Marketing Mix

Participant

The identification of the target audience is intertwined with the identified need or problem and the central focus of interventions to address the problem. In psycho-oncology research and practice, because cancer survivorship is associated with a higher prevalence and severity of mood disturbance than exists in the general population (Kaiser, et al., 2010), interventions such as the web-based psychosocial support at health-space.net have been developed. Because knowledge of the population characteristics most associated with the identified need or problem is necessary for efficient and effective targeted recruitment strategies, predictors of distress among potential participant in this study were evaluated.

Consistent with the first hypothesis, greater distress was associated with younger age, being female, and lower SEER score. These findings replicate the existing literature on distress in cancer survivors and, similar to the current study, others have also documented that distress is associated with younger age (Kaiser, et al., 2010; Kulik, Skorzynska, Rudnicka-Drozak, & Pacian, 2003), being female, having lower educational attainment, being unmarried, and non-White ethnicity (Kaiser, et al., 2010). Contrary to the first hypothesis, lower measure of rurality (i.e., living in more urban areas) was associated with greater distress as compared to potential participants from areas with higher rurality scores. This is inconsistent with the extant, albeit mixed, literature in which rural residence is shown as a risk factor for cancer-related distress in some studies (e.g., Andrykowski & Burris, 2008) but not others (Kulik, et al., 2003). Factors that may be influencing this discrepancy that necessitate consideration include characteristics of the samples, including the percentage of potential participants from rural areas in the current study (less than ten percent of the sample reported residing in rural areas). These results indicate that characteristics of potential participants indeed seem to be linked with the identified need or problem (i.e., high level of distress).

In an attempt to better understand factors that affect enrollment, this study examined potential participants characteristics and their influence on study enrollment. Contrary to hypothesis 1b, findings showed no significant association between participant characteristics and enrollment. Additionally, since participant characteristics and distress failed to predict enrollment, hypothesis 1c, proposing that distress would mediate the relationship between participant characteristics and enrollment was also refuted. It is important to note that only participants who met eligibility criteria were used in this analysis. Therefore, potential participants who may have been interested in the intervention were excluded if they did not endorse a clinically significant level of distress. The restricted range of the distress variable necessitates consideration in interpretation of these non-significant findings, particularly the non-significant association between distress and enrollment.

Product

This study yielded a number of interesting findings with regard to the product being provided and the relationship between the identified problems and the perceived benefit associated with the product (i.e., enrolling in the web-based psychosocial intervention study). The product in this research study, the online psychosocial intervention, was designed to enhance coping skills, lower distress and improve overall quality of life. In an attempt to better understand the effects of congruence between identified problem and the perceived benefit associated with participation in the web-based social support intervention on recruitment effectiveness, the study assessed the association of between participant characteristics, distress and recruitment stage (i.e., how far along in the recruitment process participants progressed).

Consistent with the second hypothesis, high level of distress predicted greater progression through the enrollment process. In particular, the odds of just registering compared to fully enrolling was almost two times more likely for participants who endorsed medium level of distress than for participants who endorsed the highest level of distress. Furthermore, participants with a medium level of distress were almost four times more likely to only consent than fully enroll compared to participants with a high level of distress. The potential participant characteristics of income, gender and ethnicity were also shown to significantly predict whether a participant would only register or fully enroll in the study. Full enrollment into the study was higher for participants who report higher income. Additionally, the odds of only registering compared to fully enrolling was almost four times more likely for women than in men, and three times more likely for ethnic minority groups than for non-Hispanic Whites.

These results clearly demonstrate that enrollment into this psychosocial intervention is higher for potential participants demonstrative of greater distress. Additionally, movement along the recruitment stage continuum in this study appeared contingent on certain potential participant characteristics. This is consistent with existing recruitment literature, including several studies describing difficulty retaining ethnic minorities throughout the recruitment process (Yancey, Ortega, & Kumanyika, 2006). It is also notable that in the present study, when enrollment was considered as a process rather than a dichotomous outcome (i.e., enrolled or not enrolled), distress and various participant characteristics emerged as significant predictors. This examination of enrollment as a process yielded significant insight that was not apparent through less nuanced analyses, such as those performed for hypothesis 1b.

Price

In addition to the benefits associated with participation in an intervention, there are also some costs and a price. Participating in the intervention and making any behavior change has a cost to the participant. Minimizing costs increases the likelihood of successful recruitment and participant retention and successful implementation of the intervention. Managing barriers or costs may be the single most important factor worthy of consideration within the social marketing theory. In an effort to better understand the costs associated with declining enrollment, the study examined perceived costs and sociodemographic correlates, and their associations with declining enrollment.

Consistent with the hypotheses, participants who attributed declining enrollment to health factors were older, had lower income, and had a diagnosis of cancer with significantly lower SEER 5-year survival rate than participants who declined due to personal reasons, perceived lack of need, general lack of interest, and those who gave other reasons for declining participation. Furthermore, participants who endorsed personal factors for declining enrollment were younger, had higher income, and had lower SEER 5-year survival rates than participants who declined enrollment due to general lack of interest. These results are consistent with previous research indicating that identifiable barriers/costs exist that decrease utilization of supportive interventions, such as transportation difficulties, concerns and misunderstanding of what support services have to offer (Kurtz, Kurtz, Given, & Given, 2006; Menegoz et al., 1999). The findings of the present study also indicate that perceived costs of enrollment were associated with certain participant characteristics. This sort of information may prove useful for the specific targeting of potential barriers in future recruitment efforts.

Place

A thorough evaluation of recruitment effectiveness necessities consideration of the communication channels utilized to reach potential participants. For the present study, the communication channels utilized for recruitment of cancer survivors to a web-based psychosocial support intervention were examined, including general effectiveness, yield of a representative and/or diverse sample, and mean differences between participants' enrollment based upon recruitment via various communication channels. Contrary to what was hypothesized, population-level strategies were more effective than individual-level strategies. Although population-level strategies, such as recruitment from Facebook and other websites, were more effective and less resource intensive, the sample yielded from these approaches was not representative of the population of cancer survivors living in the United States. This suggests that it is important for researchers to bear in mind that utilization of a less resource intensive pathway of recruitment may also limit the generalizability of the findings obtained with the sample.

Thus, although individual level recruitment strategies were significantly less effective in the present study, it yielded a sample more representative of the population of cancer survivors. This is consistent with other research showing that recruitment of from a cancer registry limits selection biases and better allows for generalization of findings to the population of cancer survivors living in the United States (Okamoto et al., 1996). The potential for registries to yield a more representative sample need to be balanced against the greater resources required for use of registry and other individual-level recruitment strategies. Another potential drawback to registry-based strategies is privacy concerns expressed by some potential participants contacted via registries. A number of studies report that cancer survivors oftentimes perceive uninvited contact for research studies as an invasion of privacy, and many survivors are not even aware that cancer registries exist (Olfson, Marcus, Druss, Alan Pincus, & Weissman, 2003; Pearson et al., 1999). Additionally, concerns about violating confidentiality have also been raised when using a cancer registry to recruit cancer survivors for studies (Poveda Monge, et al., 2000). Future research would benefit from exploration of additional recruitment channels that have the potential to yield a representative sample similar to registry-based approaches.

Promotion

In addition to general type of communication channel used, the specific marketing techniques designed to promote research studies are fundamentally important in reaching the desired target audience. Strategies used to disseminate information about the intervention that is the focus of the current study included flyers, tear-off flyers and tailored flyers for colleagues (physicians, oncologist and social workers), newspaper advertisements, links on cancer-related web sites, Google ads, television advertisements, targeted mass mailings, magnets, and business cards.

Partially consistent with the fifth hypothesis, potential participants reached through the registry were older than participants accessible from various cancer-related websites, Facebook, the Cure website, general Internet sites, print media, and registry-based web enrollees. Participants reached via the registry were also more likely to be male compared to those accessible from other sources. Moreover, participants accessible through the registry by phone had lower average distress scores and higher income as compared to participants accessible through the registry through the web. Participants reached through Facebook were significantly younger and were more likely to be female. Furthermore, participant accessible via Facebook exhibited less distress, had higher income than registry-based web enrollees or the Cure website, who endorsed the highest average distress score.

Internet based strategies seemed to be the most successful in recruiting potential participant. Those recruited from Facebook were generally younger, wealthier and endorsed lower levels of distress. This suggests a lower need for psychosocial services among these participants than registry-based web enrollees or those reached via the Cure website, who endorsed higher levels of distress. The promotional strategies we used for Facebook was very generic, where administrators of cancer-specific groups provided information about the study and a link to the study website for enrollment. In order to recruit a more representative sample from a source like Facebook, perhaps promotional messages targeted to specific sociodemographic groups (e.g., males and older adults) could be utilized.

Only a small percentage of participants were recruited form print and other media sources. This is consistent with literature showing that media advertisements are generally not successful in increasing recruitment or referral rates (Arean, Alvidrez, Nery, Estes, & Linkins, 2003). The poor yield of media-based recruitment strategies in the present study may be partially related to space limitations inherent to advertisements in newspapers and other print media which precluded targeting potential participants or providing more specific information about consumer fit to the study. The increased cost associated with procurement of the page space necessary to allow for even a moderate degree of advertisement targeting is exorbitant given the budgetary constraints of most research. Issues pertaining to the expense and relatively lower effectiveness of media driven advertisements for recruitment have been previously noted (Nichols, et al., 2004).

Limitations

There are a few limitations in this current study that are important to consider. First, the nature of population-level recruitment strategies limited collection of data regarding a good number of potential participants. Specifically, the demographic information of potential participants who were successfully reached but not recruited from channels other than the Loma Linda Cancer Registry was not nor could realistically be collected. Only the demographic information of potential participants who were interested enough to visit the health-space.net website was obtained. This significantly limited investigators' abilities to gather information of potential participants who were exposed to advertisement materials but not interested in seeking online cancer-related support services.

This raises concern regarding the representativeness of the sample that was not successfully recruited from sources not related to the cancer registry, as well as questions regarding the true effectiveness of recruitment strategies utilized in even reaching a group of individuals representative of cancer survivors currently living in the United States. Additionally, further questions remain regarding why the potential participants reached via population-level strategies declined participation or perhaps even to visit the health-space website to learn more about how they might benefit from the intervention, as well as the factors (e.g. demographic factors, distress) that may influenced the decision to decline participation among those not successfully recruited from population-level strategies.

Another limitation to the study findings was that data regarding potential participant income were estimates derived from geocoding based upon residential address. Because not all potential participants who registered through the website provided their exact address, alternative strategies to approximate potential participants geographic location were employed. Specifically, participant zip codes were entered based upon IP address data collected during website visits, which were then used to generate the area-based estimates of income. It is important to note that mapping residential zip codes based on individual IP addresses is not entirely accurate and could lead to errors and possible systematic bias. Yahoo researchers describe that router locations can vary based on Internet service providers and demographic profiling based on arbitrary web servers (Raebel et al., 2004). Additionally, potential participants may have been in locations distinct from their residence (e.g., their job) when they visited the health-space website. The potential issues may have contributed to errors in generation of IP-derived location (Raebel, et al., 2004).

Implications

The findings of the present study extend the literature regarding recruitment for web-based interventions and offer a number of implications for recruitment and intervention design in research with cancer patients as well as medically ill populations in general. The reliability, validity and clinical applicability of intervention research are important, such that research studies should be generalizable or produce equivocal results when replicated in other clinical settings. An adequate number of participants is necessary to provide enough power for a study yield statistically meaningful results, while a representative sample is essential to yield results that are clinically meaningful and pragmatically effective. Recruitment is the key to ensure the sample for a study is representative of the research population and contains enough participants sufficient for power considerations, and is foundational to program success in general. However, recruitment and effective recruitment strategies remain one of the most challenging and elusive elements of research (Appel, et al., 1999; Blumenthal, et al., 1995; Steinhauser, et al., 2006; Swanson & Ward, 1995).

The use of effective recruitment strategies alone is not enough, in that these recruitment methods cannot simply compensate for an intervention that was not designed to address participant needs or expectations. Thus, researchers would also benefit from guidance to better understand the relationship between the needs of potential participants and intervention design and implementation. A continuous feedback loop of research and revision is necessary to enhance recruitment and to design interventions that are of high quality, efficacious and appealing. Participant attrition throughout the intervention and even in the enrollment process poses a major threat to the success and clinical utility of research since it leads to systematic error or selection bias (McGregor, et al., 2010), reducing statistical power and ultimately limiting the generalizability of study findings

(Ribisl, et al., 1996).

This points to the importance of not only having effective promotion to get non-majority population groups interested in research, but the need to evaluate attrition in stages of enrollment to make sure certain factors in this process are not driving off eligible potential participants. For example, in the current study, participants with lower income were more likely to just register and not follow through to enroll. Additionally, participants who identified as ethnic minorities were almost three times more likely to just register than to fully complete the enrollment processes compared to Non-Hispanic Whites. Given that all of these potential participants were eligible and at least initially perceived potential benefit of the intervention, this attrition through the enrollment process raises questions of what may have contributed to higher levels of registration than enrollment among participants with lower incomes and those from ethnic minority groups that necessitate consideration in future research.

These methods also offer significant potential to inform planning for the recruitment of racial and ethnic minorities and ultimately aid in efforts to reduce health disparities. Because existing, accepted recruitment strategies are also those developed in research with samples characterized by non-minority participants (e.g., non-Hispanic White), well-intentioned researchers oftentimes use similar strategies in recruiting participants across all population groups, irrespective of race, ethnicity and culture. Within this study, retrospective examination of the population-level vs. an individual-level recruitment strategies shed light on factors that may have contributed discrepancy between the target population and the representativeness of the obtained sample. Mounting evidence of the differential effectiveness of recruitment strategies across population groups underscores the essentiality of the development and implementation of strategies that better align with the cultures of minority populations and underserved communities.

To better address the challenges associated with successful recruitment and retention of underserved populations in research, experts recommended that both culture and the communities of ethnic minorities be integrated into models of recruitment (Levkoff & Sanchez, 2003). Studies have demonstrated that underserved populations frequently perceive academic institutions as part of an elite power structure that are not invested in the health and wellbeing of ethnic minority communities (Norredam, Krasnik, & Petersen, 1999). This wariness of academia represents a cost of participation for members of ethnic minority groups and detracts from potential perceived benefit of participation (e.g., product being offered will help to lower distress associated with medical condition). To address this and other challenges, researchers are encouraged to incorporate key community members in the intervention design and recruitment process to promote cross-cultural competence and to better ensure a match between the goals of the research community and the communities of ethnic minority groups (Levkoff & Sanchez, 2003).

In view of the importance of effective recruitment and the challenges associated with recruitment of cancer patients, it is critical that recruitment efforts are planned and carried out in a systematic and organized manner. Use of a plan for recruitment in place from the outset of research can guide recruitment efforts and also provide a framework in which to quantify and evaluate such efforts. Strategies of recruitment are often executed without a comprehensive plan. Our field could benefit from systematically collecting and organizing information regarding researchers' experiences in the design and implementation of recruitment efforts to elucidate the strategies can yield more effective recruitment. However, data describing or testing recruitment strategies are limited and oftentimes study investigators do not report recruitment experiences carefully (Hunninghake, et al., 1987).

It is understandable though that oftentimes collecting data that describes or testing the processes of recruitment goes unconsidered in research studies. Information of the *what* and *why* of recruitment and its importance is prevalent but generally seems unaccompanied by knowledge about the *how*. Psychologists do not, nor should be expected to, have expertise in matters of marketing and business. Furthermore, resource and time constraints make it unreasonable for psychologists to independently perform full-scale prospective surveys and analyses for explicit purpose of exploration of information related to intervention recruitment and design. Social marketing offers a promising structure and organized theoretical framework for researchers to utilize for understanding, designing, and implementing recruitment efforts and interventions.

Social marketing theory has the potential to serve as a viable framework to provide researchers specific, structured guidance to collect and report data regarding their recruitment endeavors. Within this study, application of social marketing theory using accessible data that characterized the potential participants provided information for marketing mix decisions that may be utilized to bolster existing recruitment and intervention efforts. Our field will benefit from research that employs retrospective evaluation of recruitment and potential participant data, as well as future research with prospective implementation of a social marketing framework for recruitment and intervention. The importance of providing psychosocial treatment for cancer patients and survivors needs ongoing attention and these sorts of efforts are necessary to provide an increased understanding of factors that contribute to recruitment success or failure. A better understanding of recruitment and new and improved recruitment strategies is essential to the development of interventions that are efficacious and effective for all individuals, particularly those most in need of the help and support we can provide.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., . . . et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *Journal of the National Cancer Institute, 85*(5), 365-376.

Academy for Educational Development (2008). *Social marketing behavior: a practical resource for social change professionals.* Washington, DC: AED.

Albrecht, T. L., Blanchard, C., Ruckdeschel, J. C., Coovert, M., & Strongbow, R. (1999). Strategic physician communication and oncology clinical trials. *Journal of Clincal Oncology, 17*(10), 3324-3332.

Alexa Internet, Inc. (2010). *Top sites: The top 500 sites on the web*. Retrieved from http://www.alexa.com/topsites

American Cancer Society. (2009). *California cancer facts and figures*. Retrieved from http://www.ccrcal.org

Andersen, R. M. (2008). National health surveys and the behavioral model of health services use. *Medical Care, 46*(7), 647-653. doi: 10.1097/MLR.0b013e31817a835d00005650-200807000-00002

Andreasen, A. R. (1995). *Marketing social change: changing behavior to promote health, social development, and the environment.* San Francisco: Jossey-Bass.

Andrykowski, M., & Burris, J. (2008). Abstract CN11-01: Disparities in mental health outcomes between rural and nonrural cancer survivors. *Cancer Prevention Research, 1*(7 Supplement), CN11-01. doi: 10.1158/1940-6207.prev-08-cn11-01

Antoni, M. H., Lutgendorf, S. K., Cole, S. W., Dhabhar, F. S., Sephton, S. E., McDonald, P. G., . . . Sood, A. K. (2006). The influence of bio-behavioural factors on tumour biology: pathways and mechanisms. *Natute Reviews Cancer, 6*(3), 240-248. doi: nrc1820 10.1038/nrc1820

Appel, L. J., Vollmer, W. M., Obarzanek, E., Aicher, K. M., Conlin, P. R., Kennedy, B. M., . . . Reams, P. M. (1999). Recruitment and baseline characteristics of participants in the Dietary Approaches to Stop Hypertension trial. DASH Collaborative Research Group. *Journal of American Dietetic Association, 99*(8 Suppl), S69-75.

Arean, P. A., Alvidrez, J., Nery, R., Estes, C., & Linkins, K. (2003). Recruitment and retention of older minorities in mental health services research. *Gerontologist, 43*(1), 36-44.

Ayres, A., Hoon, P. W., Franzoni, J. B., Matheny, K. B., Cotanch, P. H., & Takayanagi, S. (1994). Influence of mood and adjustment to cancer on compliance with chemotherapy among breast cancer patients. *Journal of Psychosomatic Research, 38*(5), 393-402.

Bandura, A. (1963). Behavior theory and identificatory learning. *American Journal of Orthopsychiatry, 33*, 591-601.

Bandura, A. (1977). Self-efficacy: toward a unifying theory of behavioral change. *Psychological Review, 84*(2), 191-215.

Bandura, A. (1977). *Social learning theory*. Englewood Cliffs, N.J.: Prentice Hall.

Bandura, A. (1986). *Social foundations of thought and action : a social cognitive theory*. Englewood Cliffs, N.J.: Prentice-Hall.

Bandura, A. (1989). Human agency in social cognitive theory. *American Psychologist, 44*(9), 1175-1184.

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior, 31*(2), 143-164. doi: 10.1177/1090198104263660

Baron, R. M., & Kenny, D. A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology, 51*, 1173-1182.

Beaudoin, C. E., & Tao, C. C. (2007). Benefiting from social capital in online support groups: an empirical study of cancer patients. *CyberPsychology & Behavior, 10*(4), 587-590. doi: 10.1089/cpb.2007.9986

Beekman, A. T., Copeland, J. R., & Prince, M. J. (1999). Review of community prevalence of depression in later life. *British Journal of Psychiatry, 174*, 307-311.

Bellg, A. J., Borrelli, B., Resnick, B., Hecht, J., Minicucci, D. S., Ory, M., . . . Czajkowski, S. (2004). Enhancing treatment fidelity in health behavior change studies: best practices and recommendations from the NIH Behavior Change Consortium. *Health Psychology, 23*(5), 443-451. doi: 10.1037/0278-6133.23.5.442004-18051-001

Benson, A. B., 3rd, Pregler, J. P., Bean, J. A., Rademaker, A. W., Eshler, B., & Anderson, K. (1991). Oncologists' reluctance to accrue patients onto clinical trials: an Illinois Cancer Center study. *Journal of Clinical Oncology, 9*(11), 2067-2075.

Berkowitz, E. N. (2006). *Essentials of Health Care Marketing.* Sudbury: Jones and Bartlett Publishers.

Bernstein, S. L. (2006). Frequent emergency department visitors: the end of inappropriateness. *Annals of emergency medicine, 48*(1), 18-20. doi: S0196-0644(06)00489-6 10.1016/j.annemergmed.2006.03.033

Bindman, A. B., Forrest, C. B., Britt, H., Crampton, P., & Majeed, A. (2007). Diagnostic scope of and exposure to primary care physicians in Australia, New Zealand, and the United States: cross sectional analysis of results from three national surveys. *British Medical Journal, 334*(7606), 1261. doi: bmj.39203.658970.55 10.1136/bmj.39203.658970.55

Block, L. E. (1997). Evolution, growth, and status of managed care in the United States. *Public Health Reviews, 25*(3-4), 193-244.

Bloom, J. R. (2002). Surviving and thriving? *Psychooncology, 11*(2), 89-92. doi: 10.1002/pon.606

Blumenthal, D. S., Sung, J., Coates, R., Williams, J., & Liff, J. (1995). Recruitment and retention of subjects for a longitudinal cancer prevention study in an inner-city black community. *Health Services Research, 30*(1 Pt 2), 197-205.

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication, 11*(2), 123-151. doi: 10.1207/s15327027hc1102_2

Bramsen, I., van der Linden, M. H., Eskens, F. J., Bijvank, E. M., van Groeningen, C. J., Kaufman, H. J., & Aaronson, N. K. (2008). Evaluation of a face-to-face psychosocial screening intervention for cancer patients: acceptance and effects on quality of life. *Patient Education & Counseling, 70*(1), 61-68. doi: S0738-3991(07)00350-3 10.1016/j.pec.2007.09.010

Buck, J. A., Teich, J. L., & Miller, K. (2003). Use of mental health and substance abuse services among high-cost Medicaid enrollees. *Administration & Policy in Mental Health, 31*(1), 3-14.

Buss, M. K., DuBenske, L. L., Dinauer, S., Gustafson, D. H., McTavish, F., & Cleary, J. F. (2008). Patient/Caregiver influences for declining participation in supportive oncology trials. *The Journal of Supportive Oncology, 6*(4), 168-174.

California Cancer Registry. (2009). *Cancer incidence/mortality rates in California, 2006.* Retrieved from http://www.cancer-rates.info/ca

Case, D. O., Andrews, J. E., Johnson, J. D., & Allard, S. L. (2005). Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association, 93*(3), 353-362.

Cella, D. F., & Tross, S. (1987). Death anxiety in cancer survival: a preliminary cross-validation study. *Journal of Personality Assessment, 51*(3), 451-461.

Cella, D. F., & Yellen, S. B. (1993). Cancer support groups: the state of the art. *Cancer Practice, 1*(1), 56-61.

Center of Disease Control and Prevention. (2007, December 5). *eHealth marketing: Internet users data brief*. Retrieved from http://www.cdc.gov /healthmarketing/ehm/databriefs/

Chida, Y., Hamer, M., Wardle, J., & Steptoe, A. (2008). Do stress-related psychosocial factors contribute to cancer incidence and survival? *Nature Clinical Practice Oncology, 5*(8), 466-475. doi: ncponc1134 10.1038/ncponc1134

Cluck, G. G., & Cline, R. J. (1986). The circle of others: Self□help groups for the bereaved. *Communication Quarterly, 34*(3), 306-325.

Cockburn, J., Redman, S., & Kricker, A. (1998). Should women take part in clinical trials in breast cancer? Issues and some solutions. *Journal of Clinical Oncology, 16*(1), 354-362.

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). New York: Lawrence Erlbaum.

Cohen, R. A., & Stussman, B. (2010). Health information technology use among men and women aged 18–64: early release of estimates from the National Health Interview Survey, January–June 2009. *National Center for Health Statistics*.

Colleoni, M., Mandala, M., Peruzzotti, G., Robertson, C., Bredart, A., & Goldhirsch, A. (2000). Depression and degree of acceptance of adjuvant cytotoxic drugs. *Lancet, 356*(9238), 1326-1327. doi: S0140-6736(00)02821-X 10.1016/S0140-6736(00)02821-X

ConsumerAffairs.com, Inc. (2009, February 26). *Economic concerns and gas prices keep consumers driving less: Behavioral shift seen as long-term.* Retrieved from http://www.consumeraffairs.com/news04/2009/02/gas_prices333.html

Coward, D. D. (1998). Facilitation of self-transcendence in a breast cancer support group. *Oncology Nursing Forum, 25*(1), 75-84.

Coyne, J. C., Lepore, S. J., & Palmer, S. C. (2006). Efficacy of psychosocial interventions in cancer care: evidence is weaker than it first looks. *Annals of Behavioral Medicine, 32*(2), 104-110. doi: 10.1207/s15324796abm3202_5

Curran, G. M., Sullivan, G., Williams, K., Han, X., Allee, E., & Kotrla, K. J. (2008). The association of psychiatric comorbidity and use of the emergency department among persons with substance use disorders: an observational cohort study. *BMC Emergency Medicine, 8*, 17. doi: 1471-227X-8-17 10.1186/1471-227X-8-17

Czaja, R., Manfredi, C., & Price, J. (2003). The determinants and consequences of information seeking among cancer patients. *Journal of Health Communication, 8*(6), 529-562. doi: G3BRB7BCP3DKM1PD

Danaher, B. G., Hart, L. G., McKay, H. G., & Severson, H. H. (2007). Measuring participant rurality in Web-based interventions. *BMC Public Health, 7*, 228. doi: 1471-2458-7-228 10.1186/1471-2458-7-228

Dancy, B. L., Wilbur, J., Talashek, M., Bonner, G., & Barnes-Boyd, C. (2004). Community-based research: barriers to recruitment of African Americans. *Nursing Outlook, 52*(5), 234-240. doi: S0029655404000995 10.1016/j.outlook.2004.04.012

Das, A. K., Olfson, M., McCurtis, H. L., & Weissman, M. M. (2006). Depression in African Americans: breaking barriers to detection and treatment. *The Journal of Family Practice, 55*(1), 30-39. doi: jfp_0106_5501b

Deimling, G. T., Bowman, K. F., Sterns, S., Wagner, L. J., & Kahana, B. (2006). Cancer-related health worries and psychological distress among older adult, long-term cancer survivors. *Psychooncology, 15*(4), 306-320. doi: 10.1002/pon.955

Demasio, K. A. (2003). The complexity of finding solutions to reducing racial/ethnic disparities in health care outcomes. Commentary on "A community approach to addressing excess breast and cervical cancer mortality among women of African descent in Boston". *Public Health Reports, 118*(4), 348.

Derdiarian, A. (1987). Informational needs of recently diagnosed cancer patients. A theoretical framework. Part I. *Cancer Nursing, 10*(2), 107-115.

DiMatteo, M. R., Lepper, H. S., & Croghan, T. W. (2000). Depression is a risk factor for noncompliance with medical treatment: meta-analysis of the effects of anxiety and depression on patient adherence. *Archives of Internal Medicine, 160*(14), 2101-2107. doi: ioi90679

Dugdale, D. C., Epstein, R., & Pantilat, S. Z. (1999). Time and the patient-physician relationship. *Journal of General Internal Med, 14 Suppl 1*, S34-40.

Dutta-Bergman, M. J. (2004). Health attitudes, health cognitions, and health behaviors among Internet health information seekers: population-based survey. *Journal of Medical Internet Research, 6*(2), e15. doi: v6e15 10.2196/jmir.6.2.e15

Dutta-Bergman, M. J. (2005). Developing a profile of consumer intention to seek out additional information beyond a doctor: the role of communicative and motivation variables. *Health Communication, 17*(1), 1-16. doi: 10.1207/s15327027hc1701_1

Easterling, D. V., & Leventhal, H. (1989). Contribution of concrete cognition to emotion: neutral symptoms as elicitors of worry about cancer. *The Journal of Applied Psychology, 74*(5), 787-796.

Edwards, S. J., Lilford, R. J., Thornton, J., & Hewison, J. (1998). Informed consent for clinical trials: in search of the "best" method. *Social Science & Medicine, 47*(11), 1825-1840. doi: S0277953698002354

Fallowfield, L., Ratcliffe, D., & Souhami, R. (1997). Clinicians' attitudes to clinical trials of cancer therapy. *European Journal of Cancer, 33*(13), 2221-2229. doi: S0959-8049(97)00253-0

Fallowfield, L. J., Jenkins, V., Brennan, C., Sawtell, M., Moynihan, C., & Souhami, R. L. (1998). Attitudes of patients to randomised clinical trials of cancer therapy. *European Journal of Cancer, 34*(10), 1554-1559. doi: S0959804998001932

Fernsler, J. I., & Manchester, L. J. (1997). Evaluation of a computer-based cancer support network. *Cancer Practice, 5*(1), 46-51.

Ferrell, B. R., Grant, M. M., Funk, B., Otis-Green, S., & Garcia, N. (1997). Quality of life in breast cancer survivors as identified by focus groups. *Psychooncology, 6*(1), 13-23. doi: 10.1002/(SICI)1099-1611(199703)6:1<13::AID-PON231>3.0.CO;2-S

Finfgeld, D. L. (2000). Therapeutic groups online: the good, the bad, and the unknown. *Issues in Mental Health Nursing, 21*(3), 241-255.

Finn, J. (1995). Computer-based self-help groups: A new resource to supplement support groups. *Support groups: Current perspectives on theory and practice*, 109-117.

Fogel, J., Albert, S. M., Schnabel, F., Ditkoff, B. A., & Neugut, A. I. (2002). Internet use and social support in women with breast cancer. *Health Psychology, 21*(4), 398-404.

Folkman, S. (1984). Personal control and stress and coping processes: a theoretical analysis. *Journal Personality and Social Psychology, 46*(4), 839-852.

Ford, J. D., Trestman, R. L., Steinberg, K., Tennen, H., & Allen, S. (2004). Prospective association of anxiety, depressive, and addictive disorders with high utilization of primary, specialty and emergency medical care. *Social Science & Medicine, 58*(11), 2145-2148. doi: 10.1016/j.socscimed.2003.08.017S0277953603004349

Ford, J. D., Trestman, R. L., Tennen, H., & Allen, S. (2005). Relationship of anxiety, depression and alcohol use disorders to persistent high utilization and potentially problematic under-utilization of primary medical care. *Social Science & Medicine, 61*(7), 1618-1625. doi: S0277-9536(05)00112-7 10.1016/j.socscimed.2005.03.017

Fox, S. (2003). Wired for health: how Californians compare to the rest of the nation: a case study sponsored by the California HealthCare Foundation. Washington, DC: Pew Internet & American Life Project.

Fox, S., & Jones, S. (2009). The social life of health information. Washington, DC: Pew Internet & American Life Project.

Fredette, S. L. (1995). Breast cancer survivors: concerns and coping. *Cancer Nursing, 18*(1), 35-46.

Fuda, K. K., & Immekus, R. (2006). Frequent users of Massachusetts emergency departments: a statewide analysis. *Annals of Emergency Medicine, 48*(1), 9-16. doi: S0196-0644(06)00317-9 10.1016/j.annemergmed.2006.03.001

Fukui, S., Kugaya, A., Kamiya, M., Koike, M., Okamura, H., Nakanishi, T., . . . Uchitomi, Y. (2001). Participation in psychosocial group intervention among Japanese women with primary breast cancer and its associated factors. *Psychooncology, 10*(5), 419-427. doi: 10.1002/pon.534

Galloway, S. C., & Graydon, J. E. (1996). Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nursing, 19*(2), 112-117.

Ganz, P. A., Kwan, L., Somerfield, M. R., Alberts, D., Garber, J. E., Offit, K., & Lippman, S. M. (2006). The role of prevention in oncology practice: results from a 2004 survey of American Society of Clinical Oncology members. *Journal of Clinical Oncology, 24*(18), 2948-2957. doi: JCO.2006.05.8321 10.1200/JCO.2006.05.8321

Ganz, P. A., Kwan, L., Stanton, A. L., Krupnick, J. L., Rowland, J. H., Meyerowitz, B. E., . . . Belin, T. R. (2004). Quality of life at the end of primary treatment of breast cancer: first results from the moving beyond cancer randomized trial. *Journal of the National Cancer Institute, 96*(5), 376-387.

Gaston-Johansson, F., Fall-Dickson, J. M., Bakos, A. B., & Kennedy, M. J. (1999). Fatigue, pain, and depression in pre-autotransplant breast cancer patients. *Cancer Practice, 7*(5), 240-247.

Gaston-Johansson, F., Ohly, K. V., Fall-Dickson, J. M., Nanda, J. P., & Kennedy, M. J. (1999). Pain, psychological distress, health status, and coping in patients with breast cancer scheduled for autotransplantation. *Oncology Nursing Forum, 26*(8), 1337-1345.

Gattuso, S. M., Litt, M. D., & Fitzgerald, T. E. (1992). Coping with gastrointestinal endoscopy: self-efficacy enhancement and coping style. *Journal of Consulting & Clinical Psychology, 60*(1), 133-139.

Gotay, C. C., & Muraoka, M. Y. (1998). Quality of life in long-term survivors of adult-onset cancers. *Journal of the National Cancer Institute, 90*(9), 656-667.

Grassman, D. (1993). Development of inpatient oncology educational and support programs. *Oncology Nursing Forum, 20*(4), 669-676.

Griffiths, F., Lindenmeyer, A., Powell, J., Lowe, P., & Thorogood, M. (2006). Why are health care interventions delivered over the internet? A systematic review of the published literature. *Journal of Medical Internet Research, 8*(2), e10. doi: v8i2e10 10.2196/jmir.8.2.e10

Gundgaard, J., Nielsen, J. N., Olsen, J., & Sorensen, J. (2002). [Health care costs of cancer patients. Resource utilization by cancer patients]. *Ugeskr Laeger, 164*(22), 2882-2885.

Gustafson, D. H., Bosworth, K., Hawkins, R. P., Boberg, E. W., & Bricker, E. (1992). CHESS: a computer-based system for providing information, referrals, decision support and social support to people facing medical and other health-related crises. *Proceedings Annual Symposium on Computer Application Medical Care*, 161-165.

Gustafson, D. H., Hawkins, R., Pingree, S., McTavish, F., Arora, N. K., Mendenhall, J., . . . Salner, A. (2001). Effect of computer support on younger women with breast cancer. *Journal of General Internal Medicine, 16*(7), 435-445. doi: jgi00332

Gustafson, D. H., Hawkins, R. P., Boberg, E. W., McTavish, F., Owens, B., Wise, M., . . . Pingree, S. (2002). CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. *International Journal of Medical Informatics, 65*(3), 169-177. doi: S1386505602000485

Gustafson, D. H., McTavish, F. M., Stengle, W., Ballard, D., Hawkins, R., Shaw, B. R., . . . Landucci, G. (2005). Use and Impact of eHealth System by Low-income Women With Breast Cancer. *Journal of Health Communication, 10 Suppl 1*, 195-218. doi: M33468736P755224 10.1080/10810730500263257

Gustafson, D. H., Taylor, J. O., Thompson, S., & Chesney, P. (1993). Assessing the needs of breast cancer patients and their families. *Quality Management in Health Care, 2*(1), 6-17.

Gustafson, D. H., Wise, M., McTavish, F., Taylor, J. O., Wolberg, W., Stewart, J., . . . PhD, K. B. (1994). Development and pilot evaluation of a computer-based support system for women with breast cancer. *Journal of Psychosocial Oncology, 11*(4), 69-93.

Haas, L. J., Spendlove, D. C., Silver, M. P., & Holmberg, T. C. (1999). Psychopathology and emotional distress among older high-utilizing health maintenance organization patients. *The Journal of Gerontology. Series A, Biological Sciences Medical Sciences, 54*(11), M577-582.

Hamer, M., Chida, Y., & Molloy, G. J. (2009). Psychological distress and cancer mortality. *Journal of Psychosomatic Research, 66*(3), 255-258. doi: S0022-3999(08)00527-8 10.1016/j.jpsychores.2008.11.002

Hanauer, D. A., Fortin, J., Dibble, E., & Col, N. F. (2003). Use of the Internet for seeking health care information among young adults. *AMIA Annual Symposium Proceedings*, 857. doi: D030002880

Harter, M., Reuter, K., Aschenbrenner, A., Schretzmann, B., Marschner, N., Hasenburg, A., & Weis, J. (2001). Psychiatric disorders and associated factors in cancer: results of an interview study with patients in inpatient, rehabilitation and outpatient treatment. *European Journal of Cancer, 37*(11), 1385-1393. doi: S0959804901001368

Hasin, D. S., Goodwin, R. D., Stinson, F. S., & Grant, B. F. (2005). Epidemiology of major depressive disorder: results from the National Epidemiologic Survey on Alcoholism and Related Conditions. *Archieves of General Psychiatry, 62*(10), 1097-1106. doi: 62/10/1097 10.1001/archpsyc.62.10.1097

Herman, C. J., Lengerich, E. J., & Stoodt, G. (1996). Variation in recommendations for breast and cervical cancer screening among primary care physicians in North Carolina, 1991. *Southern Medicine Journal, 89*(6), 583-590.

Hjerl, K., Andersen, E. W., Keiding, N., Mouridsen, H. T., Mortensen, P. B., & Jorgensen, T. (2003). Depression as a prognostic factor for breast cancer mortality. *Psychosomatics, 44*(1), 24-30.

Holli, K., Laippala, P., Ojala, A., & Pitkanen, M. (1999). Quality control in health care: an experiment in radiotherapy planning for breast cancer patients after mastectomy. *International Journal of Radiation Oncology, Biology, Physics, 44*(4), 827-833.

Holmes, M. D., Chen, W. Y., Feskanich, D., Kroenke, C. H., & Colditz, G. A. (2005). Physical activity and survival after breast cancer diagnosis. *Journal of the American Medical Association, 293*(20), 2479-2486. doi: 293/20/2479 10.1001/jama.293.20.2479

Hosmer, D. W., & Lemeshow, S. (2000). *Applied logistic regression* (Vol. 354): Wiley-Interscience.

Hunninghake, D. B., Darby, C. A., & Probstfield, J. L. (1987). Recruitment experience in clinical trials: literature summary and annotated bibliography. *Control Clinical Trials, 8*(4 Suppl), 6S-30S.

Im, E. O., & Chee, W. (2005). Methodological issues in the recruitment of ethnic minority subjects to research via the Internet: a discussion paper. *International Journal of Nursing Studies, 42*(8), 923-929. doi: S0020-7489(05)00032-5 10.1016/j.ijnurstu.2005.01.002

Im, E. O., Chee, W., Tsai, H. M., Lin, L. C., & Cheng, C. Y. (2005). Internet cancer support groups: a feminist analysis. *Cancer Nursing, 28*(1), 1-7. doi: 00002820-200501000-00001

Institute of Medicine. (2007). *Cancer care for the whole patient: Meeting psychosocial health needs.* Washington, D.C.: National Academies Press.

Jackson, L. A., Ervin, K. S., Gardner, P. D., & Schmitt, N. (2001a). Gender and the Internet: Women communicating and men searching. *Sex Roles, 44*(5-6), 363-379.

Jackson, L. A., Ervin, K. S., Gardner, P. D., & Schmitt, N. (2001b). The racial digital divide: Motivational, affective, and cognitive correlates of Internet use. *Journal of Applied Social Psychology, 31*(10), 2019-2046.

James, N., Daniels, H., Rahman, R., McConkey, C., Derry, J., & Young, A. (2007). A study of information seeking by cancer patients and their carers. *Clinical Oncology (R Coll Radiol), 19*(5), 356-362. doi: S0936-6555(07)00520-1 10.1016/j.clon.2007.02.005

Jemal, A., Siegel, R., Ward, E., Hao, Y., Xu, J., & Thun, M. J. (2009). Cancer statistics, 2009. *CA: A Cancer Journal for Clinicians, 59*(4), 225-249. doi: caac.20006 10.3322/caac.20006

Jenkins, V., & Fallowfield, L. (2000). Reasons for accepting or declining to participate in randomized clinical trials for cancer therapy. *British Journal of Cancer, 82*(11), 1783-1788. doi: S000709200091142X 10.1054/bjoc.2000.1142

Johnson, J. D., & Meischke, H. (1993). A Comprehensive Model of Cancer-Related Information Seeking Applied to Magazines. *Human Communication Research, 19*(3), 343-367.

Jones, G. N., Ames, S. C., Jeffries, S. K., Scarinci, I. C., & Brantley, P. J. (2001). Utilization of medical services and quality of life among low-income patients with generalized anxiety disorder attending primary care clinics. *International Journal of Psychiatry Medicine, 31*(2), 183-198.

Kaiser, N. C., Hartoonian, N., & Owen, J. E. (2010). Toward a cancer-specific model of psychological distress: population data from the 2003-2005 National Health Interview Surveys. *Journal of Cancer Survivorship*. doi: 10.1007/s11764-010-0120-3

Kalsekar, I. D., Madhavan, S. M., Amonkar, M. M., Scott, V., Douglas, S. M., & Makela, E. (2006). The effect of depression on health care utilization and costs in patients with type 2 diabetes. *Managed Care Interface, 19*(3), 39-46.

Kaplan, G. A., & Reynolds, P. (1988). Depression and cancer mortality and morbidity: prospective evidence from the Alameda County study. *Journal of Behavioral Medicine, 11*(1), 1-13.

Karel, M. J. (1997). Aging and depression: vulnerability and stress across adulthood. *Clinical Psychology Review, 17*(8), 847-879. doi: S0272-7358(97)00053-6

Katon, W., Von Korff, M., Lin, E., Lipscomb, P., Russo, J., Wagner, E., & Polk, E. (1990). Distressed high utilizers of medical care. DSM-III-R diagnoses and treatment needs. *General Hospital Psychiatry, 12*(6), 355-362.

Katz, E., Gurevitc.M, & Haas, H. (1973). Use of Mass Media for Important Things. *American Sociological Review, 38*(2), 164-181.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Koretz, D., Merikangas, K. R., . . . Wang, P. S. (2003). The epidemiology of major depressive disorder: results from the National Comorbidity Survey Replication (NCS-R). *The Journal of the American Medical Association, 289*(23), 3095-3105. doi: 10.1001/jama.289.23.3095289/23/3095

Klabunde, C. N., Springer, B. C., Butler, B., White, M. S., & Atkins, J. (1999). Factors influencing enrollment in clinical trials for cancer treatment. *Southern Medical Journal, 92*(12), 1189-1193.

Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P., & Holecek, A. (2003). Online cancer support groups: a review of the research literature. *Computer, Informatics, Nursing, 21*(3), 136-142.

Klemm, P., Reppert, K., & Visich, L. (1998). A nontraditional cancer support group. The Internet. *Computers in Nursing, 16*(1), 31-36.

Knols, R., Aaronson, N. K., Uebelhart, D., Fransen, J., & Aufdemkampe, G. (2005). Physical exercise in cancer patients during and after medical treatment: a systematic review of randomized and controlled clinical trials. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology, 23*(16), 3830-3842. doi: 10.1200/JCO.2005.02.148

Koller, M., Kussman, J., Lorenz, W., Jenkins, M., Voss, M., Arens, E., . . . Rothmund, M. (1996). Symptom reporting in cancer patients: the role of negative affect and experienced social stigma. *Cancer, 77*(5), 983-995. doi: 10.1002/(SICI)1097-0142(19960301)77:5<983::AID-CNCR27>3.0.CO;2-Z

Kotler, P., & Zaltman, G. (1971). Social marketing: an approach to planned social change. *Journal of Marketing, 35*(3), 3-12.

Kroenke, K., Spitzer, R. L., Williams, J. B., Monahan, P. O., & Lowe, B. (2007). Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. *Annals of Internal Medicine, 146*(5), 317-325. doi: 146/5/317

Kulik, T. B., Skorzynska, H., Rudnicka-Drozak, E., & Pacian, A. (2003). Prophylaxis of breast cancer among nurses in health care settings in the city of Lublin. *Ann Univ Mariae Curie Sklodowska [Med], 58*(2), 208-213.

Kurtz, M. E., Kurtz, J. C., Given, C. W., & Given, B. (2006). Effects of a symptom control intervention on utilization of health care services among cancer patients. *Medical Science Monitor, 12*(7), CR319-324. doi: 9168

Lampic, C., Wennberg, A., Schill, J. E., Brodin, O., Glimelius, B., & Sjoden, P. O. (1994). Anxiety and cancer-related worry of cancer patients at routine follow-up visits. *Acta Oncologica, 33*(2), 119-125.

Lancee, W. J., Vachon, M. L., Ghadirian, P., Adair, W., Conway, B., & Dryer, D. (1994). The impact of pain and impaired role performance on distress in persons with cancer. *Canadian Journal of Psychiatry, 39*(10), 617-622.

Landro, L. (2006, December). Social networking comes to health care. *The Wall Street Journal, Health*. Retrieved from http://online.wsj.com/article /SB116717686202159961.html

LaRose, R., Mastro, D., & Eastin, M. S. (2001). Understanding internet usage - A social-cognitive approach to uses and gratifications. *Social Science Computer Review, 19*(4), 395-413.

Latimer, A. E., Katulak, N. A., Mowad, L., & Salovey, P. (2005). Motivating cancer prevention and early detection behaviors using psychologically tailored messages. *Journal of Health Communication, 10 Suppl 1*, 137-155. doi: K582350T662QT1V7 10.1080/10810730500263364

Lauver, D., Connolly-Nelson, K., & Vang, P. (2007). Health-related goals in female cancer survivors after treatment. *Cancer Nursing, 30*(1), 9-15. doi: 00002820-200701000-00002

Lefebvre, R. C., & Flora, J. A. (1988). Social marketing and public health intervention. *Health Education Quarterly, 15*(3), 299-315.

Lefevre, F., Reifler, D., Lee, P., Sbenghe, M., Nwadiaro, N., Verma, S., & Yarnold, P. R. (1999). Screening for undetected mental disorders in high utilizers of primary care services. *Journal of General Internal Medicine, 14*(7), 425-431. doi: jgi7238

Lerman, C., Rimer, B., Blumberg, B., Cristinzio, S., Engstrom, P. F., MacElwee, N., . . . Seay, J. (1990). Effects of coping style and relaxation on cancer chemotherapy side effects and emotional responses. *Cancer Nursing, 13*(5), 308-315.

Leveille, S. G., Huang, A., Tsai, S. B., Weingart, S. N., & Iezzoni, L. I. (2008). Screening for chronic conditions using a patient internet portal: recruitment for an internet-based primary care intervention. *Journal of General Internal Medicine, 23*(4), 472-475. doi: 10.1007/s11606-007-0443-6

Levkoff, S., & Sanchez, H. (2003). Lessons learned about minority recruitment and retention from the Centers on Minority Aging and Health Promotion. *Gerontologist, 43*(1), 18-26.

Lieberman, M. A., Golant, M., Giese-Davis, J., Winzlenberg, A., Benjamin, H., Humphreys, K., . . . Spiegel, D. (2003). Electronic support groups for breast carcinoma: a clinical trial of effectiveness. *Cancer, 97*(4), 920-925. doi: 10.1002/cncr.11145

Lo, K. (2006, August). *ISP-Moving from dialup to broadband.* Retrieved from feed://feeds.ezinearticles.com/expert/Kwan_Lo.xml

Loma Linda Chamber of Commerce. (2009, April/May). *Loma Linda Report.* Retrieved from http://www.lomalindachamber.com/publications/lomalindareport.htm

Loma Linda University. (2003). *Research Administration: Research involving human subjects.* Retrieved from http://research.llu.edu/HumanStudies.asp

Luker, K. A., Beaver, K., Leinster, S. J., Owens, R. G., Degner, L. F., & Sloan, J. A. (1995). The information needs of women newly diagnosed with breast cancer. *Journal of Advanced Nursing, 22*(1), 134-141.

MacDonald, L. D., & Anderson, H. R. (1984). Stigma in patients with rectal cancer: a community study. *Journal of Epidemiology and Community Health, 38*(4), 284-290.

Maddock, J. E., & Rossi, J. S. (2001). Statistical power of articles published in three health psychology-related journals. *Health Psychology, 20*(1), 76-78.

Manfredi, C., Czaja, R., Price, J., Buis, M., & Janiszewski, R. (1993). Cancer patients' search for information. *Journal of National Cancer Institute. Monographs,* (14), 93-104.

Marietti, C. (1998). Healthcare consumers seize market power. *Healthcare Informatics, 15*(4), 87-88, 90-82, 94.

Massie, M. J. (2004). Prevalence of depression in patients with cancer. *Journal fo the National Cancer Institute. Monographs,* (32), 57-71. doi: 10.1093/jncimonographs/lgh0142004/32/57

Mayer, D. K., Terrin, N. C., Kreps, G. L., Menon, U., McCance, K., Parsons, S. K., & Mooney, K. H. (2007). Cancer survivors information seeking behaviors: a comparison of survivors who do and do not seek information about cancer. *Patient Education and Counseling, 65*(3), 342-350. doi: S0738-3991(06)00295-3 10.1016/j.pec.2006.08.015

McGlynn, E. A., Asch, S. M., Adams, J., Keesey, J., Hicks, J., DeCristofaro, A., & Kerr, E. A. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine, 348*(26), 2635-2645. doi: 10.1056/NEJMsa022615348/26/2635

McGregor, L., Parker, K., LeBlanc, P., & King, K. M. (2010). Using social exchange theory to guide successful study recruitment and retention. *Nurse Researcher, 17*(2), 74-82.

McKnight-Eily, L. R., Presley-Cantrell, L., Elam-Evans, L. D., Chapman, D. P., Kaslow, N. J., & Perry, G. S. (2009). Prevalence and correlates of current depressive symptomatology and lifetime diagnosis of depression in Black women. *Womens Health Issues, 19*(4), 243-252. doi: S1049-3867(09)00051-6 10.1016/j.whi.2009.04.003

McQuail, D. (1983). *Mass Communication Theory* (1st ed.). London: Sage.

Menegoz, F., Exbrayat, C., Sousbie, M., Laforet, C., Colonna, M., Veran-Peyret, M. F., & Schaerer, R. (1999). [Patterns of health care delivery and breast cancer in the department of Isere in 1955]. *Revue Epidemiolgie et de Sante Publique, 47*(5), 443-453.

Meyer, T. J., & Mark, M. M. (1995). Effects of psychosocial interventions with adult cancer patients: a meta-analysis of randomized experiments. *Health Psychology, 14*(2), 101-108.

Miller, S. M. (1995). Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer, 76*(2), 167-177.

Miller, S. M., & Mangan, C. E. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? *Journal of Personality & Social Psychology, 45*(1), 223-236.

Mittman, R., & Cain, M. (1999). The Future of the Internet in Health Care: Five-Year Forcast. Oakland: Institute for the Future, Written for California Healthcare Foundation.

Monnier, J., Laken, M., & Carter, C. L. (2002). Patient and caregiver interest in internet-based cancer services. *Cancer Practice, 10*(6), 305-310. doi: cpa106005

Moving towards establishing a usage environment for next-generation broadband technology. (2007, October 12). *Ministry of Internal Affairs and Communication, 18*, 1-9.

Murray, K. B. (1991). A test of services marketing theory: consumer information acquisition activities. *The Journal of Marketing*, 10-25.

National Cancer Institute. (n.d.). *Cancer center list.* Retrieved from http://cancercenters.cancer.gov/cancer_centers/cancer-centers-list.html

National Center for Health Statistics. (2009, April). *Deaths: Final data for 2006.* Retrieved from http://www.cdc.gov/nchs/deaths.htm

National Comprehensive Cancer Network. (2010). NCCN Clinical Practice Guidelines in Oncology: Distress management. Retrieved from http://www.nccn.org /professionals/physician_gls/PDF/distress.pdf

National managed care companies increase share of HMO enrollment. (1996). *Managed Care, 5*(5), 68.

Newell, S. A., Sanson-Fisher, R. W., & Savolainen, N. J. (2002). Systematic review of psychological therapies for cancer patients: overview and recommendations for future research. *Journal of the National Cancer Institute, 94*(8), 558-584.

Nichols, L. O., Malone, C., Tarlow, B., & Loewenstein, D. A. (2000). The pragmatics of implementing intervention studies in the community. In R. Schulz (Ed.), *Handbook of dementia caregiving intervention research* (pp. 127-150). New York: Springer.

Nichols, L., Martindale-Adams, J., Burns, R., Coon, D., Ory, M., Mahoney, D., . . . Winter, L. (2004). Social marketing as a framework for recruitment: illustrations from the REACH study. *Journal of Aging and Health, 16*(5 Suppl), 157S-176S. doi: 10.1177/0898264304269727l6/5_suppl/157S

Norredam, M., Krasnik, A., & Petersen, J. H. (1999). [Access to Danish health care by immigrant women. Access to hospital care among immigrant women with breast cancer compared with Danish women]. *Ugeskr Laeger, 161*(31), 4385-4388.

Okamoto, H., Ogawara, T., Arihara, F., Kobayashi, K., Inoue, S., Nagahori, K., . . . Matsumoto, Y. (1996). Usefulness of ultrasonography combined with conventional physical examination in mass screening for breast cancer: a retrospective study of Yamanashi Health Care Center results from 1989 to 1994. *Japanese Journal of Cancer Research, 87*(3), 317-323.

Olfson, M., Marcus, S. C., Druss, B., Alan Pincus, H., & Weissman, M. M. (2003). Parental depression, child mental health problems, and health care utilization. *Medical Care, 41*(6), 716-721. doi: 10.1097/01.MLR.0000064642.41278.48

Onitilo, A. A., Nietert, P. J., & Egede, L. E. (2006). Effect of depression on all-cause mortality in adults with cancer and differential effects by cancer site. *General Hospital Psychiatry, 28*(5), 396-402. doi: S0163-8343(06)00091-0 10.1016/j.genhosppsych.2006.05.006

Ormseth, S., Hartoonian, N., & Owen, J. E. (2009, August). *Healthcare utilization and depression among breast cancer survivors: findings from NHIS 2003-2005.* Poster session presented at the American Psychological Association Convention, Toronto, Canada.

Owen, J. E., Klapow, J. C., Roth, D. L., Nabell, L., & Tucker, D. C. (2004). Improving the effectiveness of adjuvant psychological treatment for women with breast cancer: the feasibility of providing online support. *Psychooncology, 13*(4), 281-292. doi: 10.1002/pon.733

Owen, J. E., Klapow, J. C., Roth, D. L., Shuster, J. L., Jr., Bellis, J., Meredith, R., & Tucker, D. C. (2005). Randomized pilot of a self-guided internet coping group for women with early-stage breast cancer. *Annals of Behavioral Medicine, 30*(1), 54-64. doi: 10.1207/s15324796abm3001_7

Palmgreen, P., Wenner, L. A., & Rayburn, J. D. (1980). Relations between Gratifications Sought and Obtained - a Study of Television-News. *Communication Research, 7*(2), 161-192.

Palmgreen, P., Wenner, L. A., & Rosengren, K. (1985). Uses and gratifications research: The past ten years. In K. Rosengren, L. Wenner, L. & P. Palmgreen (Eds.), *Media gratifications research* (pp.11-37). Beverly Hills, CA: Sage.

Pearson, S. D., Katzelnick, D. J., Simon, G. E., Manning, W. G., Helstad, C. P., & Henk, H. J. (1999). Depression among high utilizers of medical care. *Journal of General Internal Medicine, 14*(8), 461-468. doi: jgi06278

Pennbridge, J., Moya, R., & Rodrigues, L. (1999). Questionnaire survey of California consumers' use and rating of sources of health care information including the Internet. *The Western Journal of Medicine, 171*(5-6), 302-305.

Pew Internet & American Life Project. (2009). Trends. Washington, DC: Pew Internet & American Life Project.

Pinquart, M., & Duberstein, P. R. (2010). Depression and cancer mortality: a meta-analysis. *Psychological Medicine*, 1-14. doi: S0033291709992285 10.1017/ S0033291709992285

Pirkola, S. P., Isometsa, E., Suvisaari, J., Aro, H., Joukamaa, M., Poikolainen, K., . . . Lonnqvist, J. K. (2005). DSM-IV mood-, anxiety- and alcohol use disorders and their comorbidity in the Finnish general population--results from the Health 2000 Study. *Social Psychiatry and Psychiatric Epidemiology, 40*(1), 1-10. doi: 10.1007 /s00127-005-0848-7

Polinsky, M. L. (1994). Functional status of long-term breast cancer survivors: demonstrating chronicity. *Health & Social Work, 19*(3), 165-173.

Poveda Monge, F., Royo Garrido, A., Aldemunde Perez, C., Fuentes Cuenca, R., Montesinos de Astorza, C., Juan Ten, C., . . . Oltra Masanet, J. A. (2000). [Anxiety about death in primary care: relationship with frequency of consultation and psychomorbidity of patients]. *Atencion Primaria, 26*(7), 446-452.

Raebel, M. A., Malone, D. C., Conner, D. A., Xu, S., Porter, J. A., & Lanty, F. A. (2004). Health services use and health care costs of obese and nonobese individuals. *Archieves of Internal Med, 164*(19), 2135-2140.

Ragin, D. F., Hwang, U., Cydulka, R. K., Holson, D., Haley, L. L., Jr., Richards, C. F., . . . Richardson, L. D. (2005). Reasons for using the emergency department: results of the EMPATH Study. *Academic Emergency Medicine, 12*(12), 1158-1166. doi: j.aem.2005.06.030 10.1197/j.aem.2005.06.030

Rassin, M., Nasie, A., Bechor, Y., Weiss, G., & Silner, D. (2006). The characteristics of self-referrals to ER for non-urgent conditions and comparison of urgency evaluation between patients and nurses. *Accident and Emergency Nursing, 14*(1), 20-26. doi: S0965-2302(05)00080-9 10.1016/j.aaen.2005.10.003

Rees, C. E., & Bath, P. A. (2001). Information-seeking behaviors of women with breast cancer. *Oncology Nursing Forum, 28*(5), 899-907.

Regier, D. A., Boyd, J. H., Burke, J. D., Jr., Rae, D. S., Myers, J. K., Kramer, M., . . . Locke, B. Z. (1988). One-month prevalence of mental disorders in the United States. Based on five Epidemiologic Catchment Area sites. *Archieves of General Psychiatry, 45*(11), 977-986.

Ribisl, K. M., Walton, M. A., Mowbray, C. T., Luke, D. A., Davidson, W. S., & Bootsmiller, B. J. (1996). Minimizing participant attrition in panel studies through the use of effective retention and tracking strategies: Review and recommendations. *Evaluation and Program Planning, 19*(1), 1-25.

Riolo, S. A., Nguyen, T. A., Greden, J. F., & King, C. A. (2005). Prevalence of depression by race/ethnicity: findings from the National Health and Nutrition Examination Survey III. *American Journal of Public Health, 95*(6), 998-1000. doi: 95/6/998 10.2105/AJPH.2004.047225

Robbins, S. P., Chatterjee, P., & Canada, E. R. (1997). *Contemporary human behavior theory: A critical perspective for social work*. Boston: Pearson & Allyn and Bacon.

Rogers, E. M. (1983). *Diffusion of Innovations* (3rd ed.). New York: Free Press.

Rowland J. (1994). *Interpersonal resources: coping*. In Holland J, Rowland J, eds. Psychooncology: psychological care of the patient with cancer (pp.44-57). New York: Oxford University Press.

Rowland, J., Mariotto, A., Aziz, N., Tesauro, G., EJ Feuer, E. J., Blackman, D., . . . Pollack, L. A. (2004). Cancer survivorship--United States, 1971-2001. *MMWR. Morbidity and mortality weekly report, 53*(24), 526-529.

Rozmovits, L., & Ziebland, S. (2004). What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Education and Counseling, 53*(1), 57-64. doi: 10.1016/S0738-3991(03)00116-2S0738399103001162

Rutten L. F., Moser R. P., Beckjord E. B., Hesse B. W., & Croyle R. T. (2007). *Cancer communication: Health information national trends survey 2003-2005* (NIH Publication. No. 07-6214, pp. 1-80). Washington, DC: National Cancer Institute.

Samarel, N., Fawcett, J., Krippendorf, K., Piacentino, J. C., Eliasof, B., Hughes, P., . . . Ziegler, E. (1998). Women's perceptions of group support and adaptation to breast cancer. *J Adv Nurs, 28*(6), 1259-1268.

Sarver, J. H., Cydulka, R. K., & Baker, D. W. (2002). Usual source of care and nonurgent emergency department use. *Academic Emergency Medicine, 9*(9), 916-923.

Satin, J. R., Linden, W., & Phillips, M. J. (2009). Depression as a predictor of disease progression and mortality in cancer patients: a meta-analysis. *Cancer, 115*(22), 5349-5361. doi: 10.1002/cncr.24561

Schuster, M. A., McGlynn, E. A., & Brook, R. H. (1998). How good is the quality of health care in the United States? *Milbank Q, 76*(4), 517-563, 509.

Schwenk, T. L., Coyne, J. C., & Fechner-Bates, S. (1996). Differences between detected and undetected patients in primary care and depressed psychiatric patients. *General Hospital Psychiatry, 18*(6), 407-415. doi: S016383439600062X

Scutchfield, F. D., Lee, J., & Patton, D. (1997). Managed care in the United States. *Journal of Public Health Medicine, 19*(3), 251-254.

Sephton, S., & Spiegel, D. (2003). Circadian disruption in cancer: a neuroendocrine-immune pathway from stress to disease? *Brain, Behavior, and Immunity, 17*(5), 321-328. doi: S0889159103000783

Settle, R. B., & Alreck, P. (1989). Reducing buyers' sense of risk. *Marketing Communications, 14*(1), 34-40.

Shapiro, D. E., Boggs, S. R., Rodrigue, J. R., Urry, H. L., Algina, J. J., Hellman, R., & Ewen, F. (1997). Stage II breast cancer: differences between four coping patterns in side effects during adjuvant chemotherapy. *Journal of Psychosomatic Research, 43*(2), 143-157. doi: S0022399997800013

Sharf, B. F. (1997). Communicating breast cancer on-line: support and empowerment on the Internet. *Women Health, 26*(1), 65-84.

Somerset, W., Stout, S. C., Miller, A. H., & Musselman, D. (2004). Breast cancer and depression. *Oncology (Williston Park), 18*(8), 1021-1034; discussion 1035-1026, 1047-1028.

Spiegel, D. (1994). Health caring. Psychosocial support for patients with cancer. *Cancer, 74*(4 Suppl), 1453-1457.

Spiegel, D. (1995). Essentials of psychotherapeutic intervention for cancer patients. *Support Care Cancer, 3*(4), 252-256.

Spiegel, D. (1997). Psychosocial aspects of breast cancer treatment. *Seminars in Oncology, 24*(1 Suppl 1), S1-36-S31-47.

Spiegel, D., Bloom, J. R., Kraemer, H. C., & Gottheil, E. (1989). Effect of psychosocial treatment on survival of patients with metastatic breast cancer. *Lancet, 2*(8668), 888-891.

Spiegel, D., & Giese-Davis, J. (2003). Depression and cancer: mechanisms and disease progression. *Biological Psychiatry, 54*(3), 269-282. doi: S0006322303005663

Spiegel, D., & Kato, P. M. (1996). Psychosocial influences on cancer incidence and progression. *Harvard Review of Psychiatry, 4*(1), 10-26.

SPSS Inc. (2007). *SPSS 16.0 for Windows* [Computer software]. Chicago, IL: SPSS, Inc.

Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., . . . Twillman, R. (2000). Emotionally expressive coping predicts psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology, 68*(5), 875-882.

Stanton, A. L., Danoff-Burg, S., & Huggins, M. E. (2002). The first year after breast cancer diagnosis: hope and coping strategies as predictors of adjustment. *Psychooncology, 11*(2), 93-102. doi: 10.1002/pon.574

Steinhauser, K. E., Clipp, E. C., Hays, J. C., Olsen, M., Arnold, R., Christakis, N. A., . . . Tulsky, J. A. (2006). Identifying, recruiting, and retaining seriously-ill patients and their caregivers in longitudinal research. *Palliative Medicine, 20*(8), 745-754. doi: 20/8/745 10.1177/0269216306073112

Stopponi, M. A., Alexander, G. L., McClure, J. B., Carroll, N. M., Divine, G. W., Calvi, J. H., . . . Ritzwoller, D. P. (2009). Recruitment to a randomized web-based nutritional intervention trial: characteristics of participants compared to non-participants. *Journal of Medical Internet Research, 11*(3), e38. doi: v11i3e38 10.2196/jmir.1086

Strine, T. W., Mokdad, A. H., Balluz, L. S., Gonzalez, O., Crider, R., Berry, J. T., & Kroenke, K. (2008). Depression and anxiety in the United States: findings from the 2006 Behavioral Risk Factor Surveillance System. *Psychiatric Services, 59*(12), 1383-1390. doi: 59/12/1383 10.1176/appi.ps.59.12.1383

Sullivan T, Weinert C, Fulton RD. Living with cancer: self-identified needs of rural dwellers. *Family Community Health* 1993;*16* (2):41–49.

Swanson, G. M., & Ward, A. J. (1995). Recruiting minorities into clinical trials: toward a participant-friendly system. *Journal of the National Cancer Institute, 87*(23), 1747-1759.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using multivariate statistics* (5th ed.). Boston: Pearson/Allyn & Bacon.

The Center for Health Enhancement Systems Studies, University of Wisconsin-Madison (2006). *History: A vision for CHESS.* Retrieved from https://chess.wisc.edu/chess /about /history.aspx

The World Health Report. (2000). *Health System: improving performance.* Generva, Switzerland: World Health Organization.

Thorson, E., & Beaudoin, C. E. (2004). The impact of a health campaign on health social capital. *Journal of Health Communication, 9*(3), 167-194.

Travers, K. D. (1997). Reducing inequities through participatory research and community empowerment. *Health Education & Behavior, 24*(3), 344-356.

Trollor, J. N., Anderson, T. M., Sachdev, P. S., Brodaty, H., & Andrews, G. (2007). Age shall not weary them: mental health in the middle-aged and the elderly. *Australian and New Zealand Journal of Psychiatry, 41*(7), 581-589. doi: 779339061 10.1080/00048670701392817

U.S. Census. (2007). Population and housing narrative profile: 2005-2007. Retrieved from http://factfinder.census.gov/servlet /DatasetMainPageServlet?_prograM = ACS

U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (2002). Management of Cancer Symptoms: Pain, Depression, and Fatigue. (AHRQ Publication No. 02-E031). Retrieved from http://archive.ahrq.gov/clinic/epcsums/cansympsum.pdf

U.S Department of Health & Human Services, National Institutes of Health (2009). *Research portfolio online reporting tools: Reports, data and analyses of NIH research activities.* Retrieved from http://report.nih.gov/reportmap.aspx

Watkins, L. O., Weaver, L., & Odegaard, V. (1986). Preparation for cardiac catheterization: tailoring the content of instruction to coping style. *Heart Lung, 15*(4), 382-389.

Weinberg, N., Schmale, J., Uken, J., & Wessel, K. (1996). Online help: cancer patients participate in a computer-mediated support group. *Health & Social Work, 21*(1), 24-29.

Weinberg, N., Schmale, J. D., Uken, J., & Wessel, K. (1995). Computer-mediated support groups. *Social Work Groups, 17,* 43-54.

White, M., & Dorman, S. M. (2001). Receiving social support online: implications for health education. *Health Education Research, 16*(6), 693-707.

Williams, D. R., Gonzalez, H. M., Neighbors, H., Nesse, R., Abelson, J. M., Sweetman, J., & Jackson, J. S. (2007). Prevalence and distribution of major depressive disorder in African Americans, Caribbean blacks, and non-Hispanic whites: results from the National Survey of American Life. *Archieves of General Psychiatry, 64*(3), 305-315. doi: 64/3/305 10.1001/archpsyc.64.3.305

Wilson, T. D. (1999). Models in information behaviour research. *Journal of Documentation, 55*(3), 249-270.

Wilson, T. D., & Walsh, C. (1996). *Information behaviour: an interdisciplinary perspective.* Retrieved from University of Sheffield Department of Information Studies: http://informationr.net/tdw/publ/infbehav/index.html

Winzelberg, A. (1997). The analysis of an electronic support group for individuals with eating disorders. *Computers in Human Behavior, 13*(3), 393-407.

Winzelberg, A. J., Classen, C., Alpers, G. W., Roberts, H., Koopman, C., Adams, R. E., . . . Taylor, C. B. (2003). Evaluation of an internet support group for women with primary breast cancer. *Cancer, 97*(5), 1164-1173. doi: 10.1002/cncr.11174

Wortman, C. B., & Dunkelschetter, C. (1979). Interpersonal Relationships and Cancer - Theoretical-Analysis. *Journal of Social Issues, 35*(1), 120-155.

Wright, K. (2002). Social support within an on-line cancer community: An assessment of emotional support, perceptions of advantages and disadvantages, and motives for using the community from a communication perspective. *Journal of Applied Communication Research, 30*(3), 195-209.

Yancey, A. K., Ortega, A. N., & Kumanyika, S. K. (2006). Effective recruitment and retention of minority research participants. *Annual Review of Public Health, 27*, 1-28. doi: 10.1146/annurev.publhealth.27.021405.102113

Yang, E. V., & Glaser, R. (2003). Stress-induced immunomodulation: Implications for tumorigenesis. *Brain, Behavior, and Immunity, 17 Suppl 1*, S37-40. doi: S0889159102000648

Zabalegui, A. (1999). Coping strategies and psychological distress in patients with advanced cancer. *Oncology Nursing Forum, 26*(9), 1511-1518.

Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psychooncology, 10*(1), 19-28. doi: 10.1002/1099-1611(200101/02)10:1<19::AID-PON501>3.0.CO;2-6

Ziebland, S., Chapple, A., Dumelow, C., Evans, J., Prinjha, S., & Rozmovits, L. (2004). How the internet affects patients' experience of cancer: a qualitative study. *British Medical Journal, 328*(7439), 564. doi: 10.1136/bmj.328.7439.564328/7439/564

Zonderman, A. B., Costa, P. T., Jr., & McCrae, R. R. (1989). Depression as a risk for cancer morbidity and mortality in a nationally representative sample. The *Journal of the American Medical Association, 262*(9), 1191-1195.

APPENDIX A

SWOT ANALYSIS

Strengths

- University affiliated: Very few social support groups are University affiliated. Patients can take advantage of having LLU ties.
- Revenue sources: The support site is available for free.
- Approach to Patient Care: BOL social-networking website provides one-on-one interaction between patients and online facilitators.
- Location: BOL social-networking support group is conducted online. It is convenient for patients to utilize the services directly from home.
- Support: Available 24 hours a day.
- Religiously affiliated

Weaknesses

- Internet access and usability: Race, education, income, and language in Southern California continue to impact Internet usability and accessibility. African Americans and Latinos continue to be limited in both access to and proficiency in use of the Internet.
- Online facilitators are generally fourth and fifth year PhD students, in addition to two licensed psychologists.
- Language: Website material is only available in English.

Opportunities

- LLU affiliation: LLU is known to take a holistic approach to care, and training its psychology students with the same mentality can help BOL to take advantage of its treatment approach.

- Language: Recruit more Spanish-speaking graduate students to help with the study.
- Partnering: Partner with the National Cancer Institute to launch our study on their website.
- Facilitators: Use facilitators more frequently online to increase retention rate.

Threats

- Potential competition: The Cancer Support Community is one of the largest social-networking sites nationwide.
- National Institute of Health Funds: Higher funding for face-to-face support groups than Internet support groups.
- Underrepresentation of adult population: Underrepresentation of older adults on social-networking websites.
- Internal Review Board (IRB): Under University sponsorship, regulations must be implemented in order to protect the rights and welfare of all participants affiliated with the institution. Certain advertising methods may not be approved by IRB.

APPENDIX B

COMPETITOR ANALYSIS

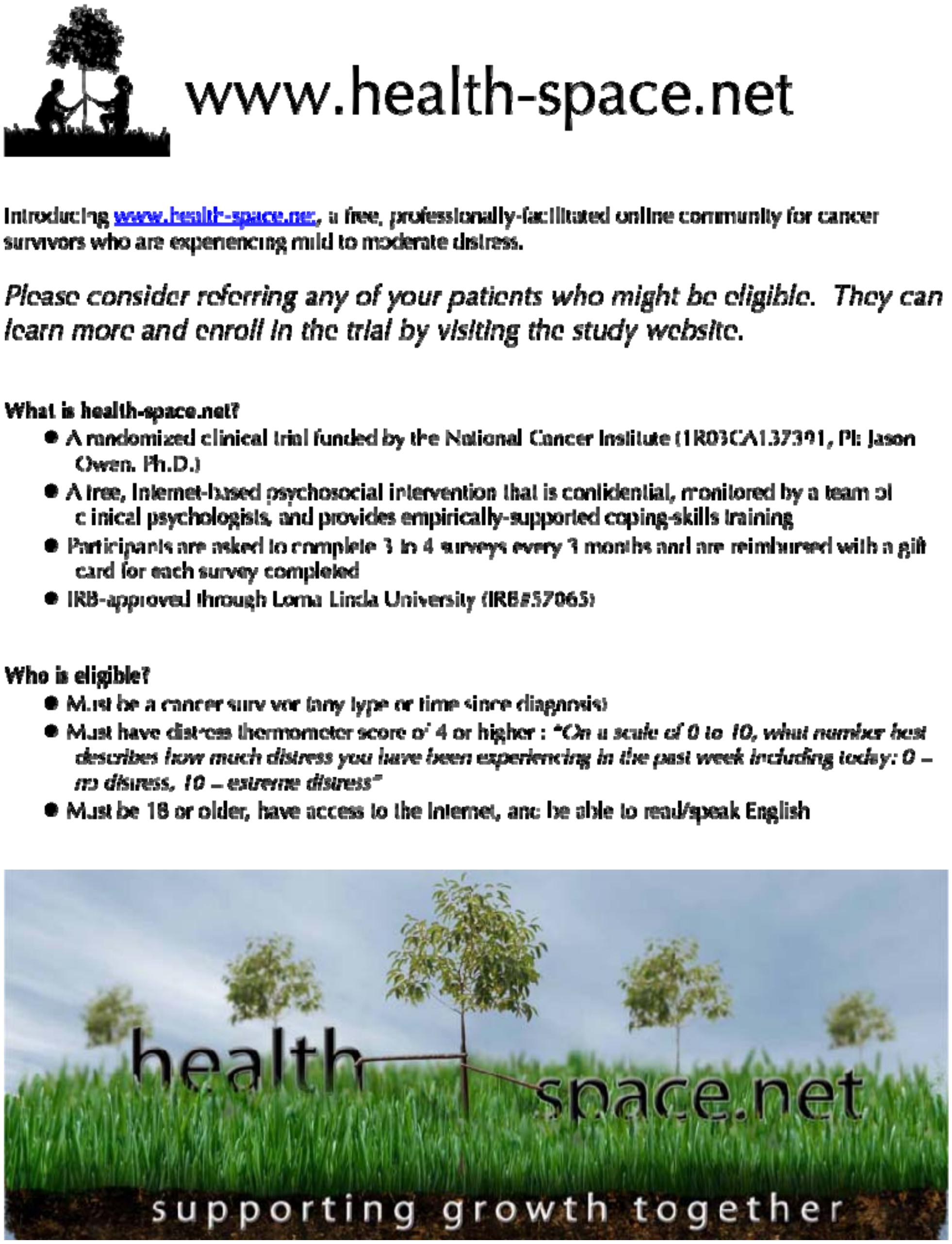
	Unique Visitors (daily)	Members	Daily Time Spent on Site	Daily Page Views/User 3-Month Change	Open Discussion Groups	Support Groups	Personal Journal/ Blogs
The Cancer Support Community	**196/day**	**5107**	**1.9 min/day**	**↑ 30%**	**24 hrs/ 7 days**	**Weekly**	**Yes**
OncoLink	**990/day**	**N/A**	**1.9 min/day**	**↑ 4%**	**N/A**	**Monthly**	**Yes**
Cancer Care	**424/day**	**116,000**	**2.1 min/day**	**↓ 20%**	**24 hrs/ 7 days**	**Daily**	**No**
Cancer Compass	**3241/day**	**60,000**	**3.8 min/day**	**↑ 7%**	**N/A**	**N/A**	**Yes**

Note. Information obtained from alexa.com and whoismark.com

APPENDIX C

ADVERTISEMENT AND PROMOTIONAL MATERIALS

Health-Space.net Flyer



www.health-space.net

Introducing www.health-space.net, a free, professionally-facilitated online community for cancer survivors who are experiencing mild to moderate distress.

Please consider referring any of your patients who might be eligible. They can learn more and enroll in the trial by visiting the study website.

What is health-space.net?

- A randomized clinical trial funded by the National Cancer Institute (1R03CA137391, PI: Jason Owen, Ph.D.)
- A free, Internet-based psychosocial intervention that is confidential, monitored by a team of clinical psychologists, and provides empirically-supported coping-skills training
- Participants are asked to complete 3 to 4 surveys every 3 months and are reimbursed with a gift card for each survey completed
- IRB-approved through Loma Linda University (IRB#57065)

Who is eligible?

- Must be a cancer survivor (any type or time since diagnosis)
- Must have distress thermometer score of 4 or higher : *"On a scale of 0 to 10, what number best describes how much distress you have been experiencing in the past week including today: 0 – no distress, 10 – extreme distress"*
- Must be 18 or older, have access to the Internet, and be able to read/speak English

Health-Space.net Tear-off Flyer

Cancer Distress?

Come join our supportive, online-community!

Health-space.net is a professional and confidential website for those seeking support for cancer-related distress. Cancer patients and survivors may network with one another and are monitored by clinical psychologists from Loma Linda University. Members can create and view personal pages, join in a live community forum, and read about tips for living beyond cancer. There are only limited spaces available for this free, clinical trial! Register now!

To Be Eligible, one MUST:

- Have been diagnosed with Cancer
- Be experiencing some distress
- Be 18 or over
- Have internet access

Be able to read/speak English

www.Health-Space.net

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

www.Health-Space.net
1-800-395-1525

Space.net Business Card

Front of card:

Back of card:

health-space.net

An online community for cancer survivors

Free, confidential, & professionally-facilitated

A clinical trial sponsored by the National Cancer Institute

*Must be 18 or over, speak & write in English, and have enough distress to be interested in joining

Health-Space.net Magnets

Personalized Letter to Participants Recruited from Cancer Registry

LOMA LINDA UNIVERSITY

School of Science and Technology
Department of Psychology

11130 Anderson Street
Loma Linda, California 92350
(909) 558-8577
Fax: (909) 558-0171

Dear Future Participant,

Have you been diagnosed with cancer? Do you feel *worried or stressed* about your health, family, or future (and possibly more)? Would you like to connect with others who can relate to what you are going through? If so, we invite you to join our supportive, online community where you can converse with other cancer patients, survivors, and trained helping professionals. Our confidential site offers personal pages, a live community forum, tips for living beyond cancer, and much more! We are able to offer these services as part of a National Cancer Institute clinical trial conducted by Dr. Jason Owen, PhD, M.P.H, who is affiliated with the Behavioral Oncology Research Lab at the Loma Linda University Department of Psychology.

We know that your time is valuable—and we truly believe that choosing to spend it in our online community will be worthwhile. First, we strongly believe that you may *personally benefit* from the friendships, support, and tips from others that are available here. Second, we believe that your distinct contribution may *help others*. Finally, you may benefit cancer survivors nationwide. The feedback that we gain through your participation has the potential to influence and inform supportive services available for all individuals diagnosed with cancer. Our ultimate goal is to learn how we can best provide supportive services to cancer patients and survivors worldwide.

If you *choose to participate*, you can sign-up (or decline) via our simple instructions attached to this letter. Participation requires the following: a) a cancer diagnosis (all time spans since diagnosis & all types welcome), b) regular access to the internet during our 12-week, free clinical trial, and c) English language literacy. Participation entails interacting with others via the online community as well as completing several questionnaires throughout the study. You will receive a modest *reimbursement* for each questionnaire that you complete. Your decision whether or not to participate in this study will have no impact on your medical care or your relationship with your doctor. Only registered study participants have access to the secure, easy-to-use website. All information will be kept strictly confidential and is protected by law.

We encourage you to contact us if you have any further inquiries about the study or your participation!
Sincerely,

Jason E. Owen, Ph.D., M.P.H.
Assistant Professor of Psychology ***LLU IRB***
#:57065 Loma Linda University
Expiration Date: 12/16/10

Letter Advertisement Included in Potential Participant Mailing Packet.

○ **Website:** www.Health-Space.net ○ **E-mail:** Info@health-space.net ○ **Phone:** 1-800-395-1525

☑ YES I WILL **SIGN-UP** ***for this ONLINE SUPPORT GROUP COMMUNITY!***

Please follow these 3 easy steps to get started now:

✚ Visit website: www.Health-Space.net

✚ Click the “Enroll Now” image on the right

✚ Follow the simple prompts to register for an account

(Optional: Click “Take a Tour” for more information)

For any sign-up difficulties or questions, please email or call us!

⊘No I would not like to participate. Please do not contact me further.

To cease all contacts from www.Health-Space.net, please email or call us and include:

- Your first and last name
- Your request to be withdrawn from the “Health-Space.net study”

Your name and contact information were obtained from the Loma Linda University Medical Center Tumor Registry, which is part of a larger registry maintained by the State of California. The registry was created by the California Legislature in response to public concern that not enough was being done to find the causes and cures of cancer. Every cancer diagnosed in California is required by law to be reported to the California Department of Health Services, which is responsible for the registry. Information on individuals with cancer can only be released for research purposes to qualified researchers who have obtained approval for the study from a federally approved Committee for the Protection of Human Subjects, and have agreed to maintain the confidentiality of the information they collect.

Newspaper Advertisement Scripts.

24-word Ad:

Cancer worries? Survivors and patients please join our supportive online community! Site is professional, confidential, and LLU- affiliated. More information / enrollment at www.health-space.net.

44-word Ad:

Cancer worries? Survivors and patients please join our supportive online community and start “living well”! Site is professional, confidential, and LLU- affiliated. Only limited spaces available for this free, clinical trial. Those 18+ and English-speaking can enroll today! More information / enrollment at www.health-space.net.

55-word Ad:

Cancer worries? Join our supportive online community and start “living well”! Site is professional, confidential, and LLU- affiliated. Create / view personal pages, a live community forum, and tips for living beyond cancer. Only limited spaces available for this free, clinical trial. Those 18+ and English-speaking can enroll today! More information / enrollment at www.health-space.net.

Longer ad:

WWW.HEALTH-SPACE.NET

Worried about your cancer diagnosis or its reoccurrence?

Join our supportive online community and start “living well”! Site is professional, confidential, and Loma Linda University - affiliated. Create / view personal pages, chat with other cancer patients and survivors, and read tips for living beyond cancer. Only limited spaces available for this free, clinical trial.

Must be ready and willing to post to discussion board and chat with others! Those 18+ and fluent in English can enroll today!

More information / enrollment at

www.health-space.net.

Flyer Tailored for Oncologists, Physicians and Mental Health Professionals

health space.net

supporting growth together

Dear Colleague,

We are excited to offer your cancer patients and survivors a FREE, CONFIDENTIAL, SUPPORTIVE online community for those who are suffering from mild to moderate distress. Please consider referring your patients who may be eligible for this clinical trial. Your patients may enroll or learn more about this innovative community by visiting *www.health-space.net*.

ELIGIBILITY CRITERIA?

01.	02.	03.
Adult cancer patients and survivors	**Experiencing distress**	**Internet access in English**
Anyone 18 or older with a history of cancer regardless of cancer type or time since diagnosis	Must have a distress thermometer score of 4 or higher. "On a scale of 0 to 10, what number best describes how much distress you have been experiencing in the past week including today?" (0 = None, 10 = Extreme Distress)	Must have regular access to the internet and be able to read and write in English

INFORMATION

WHAT IS WWW. HEALTH-SPACE.NET?

A randomized clinical trial funded by the National Cancer Institute (1R03CA137391, PI: Jason Owen, Ph.D.)

A free, Internet-based psychosocial intervention that is confidential, monitored by a team of clinical psychologists, and provides empirically-supported coping-skills training

Participants are asked to complete a survey every 3 months for up to a year and are reimbursed with a gift card for each survey completed

IRB-approved through Loma Linda University (IRB#57065)

Contact ▪ E-mail: Info@health-space.net ▪ Phone: 1-800-395-1525 ▪ Website: www.health-space.net

Personalized Letter to Oncologists, Physicians and Mental Health Professionals

Dr. INSERT DOCTOR NAME HERE,

I would like to make you aware of www.health-space.net, a free, professionally-facilitated online community for cancer survivors who are experiencing mild to moderate distress.

What is health-space.net?

- A randomized clinical trial funded by the National Cancer Institute (1R03CA137391, PI: Jason Owen, Ph.D.)
- A free, Internet-based psychosocial intervention that is anonymous, monitored by a team of clinical psychologists, and provides empirically-supported coping-skills training
- Participants are asked to complete 3 to 4 surveys every 3 months and are reimbursed with a gift card for each survey completed
- IRB-approved through Loma Linda University (IRB#57065)

Who is eligible?

- Must be a cancer survivor (any type or time since diagnosis)
- Must have distress thermometer score of 4 or higher : *"On a scale of 0 to 10, what number best describes how much distress you have been experiencing in the past week including today: 0 = no distress, 10 = extreme distress"*
- Must be 18 or older, have access to the Internet, and be able to read/speak English

Please consider referring any of your patients who might be eligible. They can learn more and enroll in the trial by visiting the study website (**www.health-space.net**).

I am including a set of promotional materials for you to use with your patients. If you would like additional materials, I am happy to provide them for you. Just call (800-395-1525) or email me (jowen@llu.edu), and I will send them out to you as soon as possible.

With kind regards,

Jason E. Owen, Ph.D., M.P.H.
Assistant Professor
Loma Linda University
Department of Psychology