BUILDING AN ONLINE COMMUNITY TO SUPPORT LOCAL CANCER SURVIVORSHIP: COMBINING INFORMATICS AND PARTICIPATORY ACTION RESEARCH FOR COLLABORATIVE DESIGN

By

Jacob Berner Weiss

Dissertation

Submitted to the Faculty of the

Graduate School of Vanderbilt University

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

in

Biomedical Informatics

May, 2009

Nashville, Tennessee

Approved:

Professor Dario Giuse

Professor Kevin Johnson

Professor Nancy Lorenzi

Professor Barbara Murphy

Professor Deborah Rowe

ACKNOWLEDGEMENTS

This work was made possible by a training grant from the National Library of Medicine (5 T15 LM007450-07-). I am grateful for the mentorship and wisdom of my advisor, Dr. Nancy Lorenzi, who guided me throughout this journey. Her invigorating brainstorming, supportive prodding, and gracious open door are only the beginning of the example she set for me in my career and life. I found complementary examples and support from each of my committee members, Drs. Dario Giuse, Deborah Rowe, Kevin Johnson, and Barbara Murphy. I could not have found a more encouraging and inspiring committee with whom to begin my career.

I am most grateful for the love and support of my family and friends who spent many hours without hesitation listening to my ideas and struggles over the course of this work. I could always turn my parents, Daniel, and Toyosi when I needed a revitalizing perspective, a hug, or a kick in the pants. I also am thankful for my follow students and jugglers who nurtured my creativity and interest in community-building that allowed this research to be successful.

TABLE OF CONTENTS

Chapter

Appendix

LIST OF TABLES

LIST OF FIGURES

CHAPTER I

INTRODUCTION

Statement of Problem

There are estimated to be 10 million individuals treated for cancer living in the United States today.[1] Even after the completion of a successful course of therapy, cancer survivors are at risk for lower quality of life and struggle with new challenges of clinical and supportive follow-up care.[2] Survivors and co-survivor family and friends lose the constant "safety net" of the health care team, and many individuals are not adequately prepared for what to expect after treatment ends.[3] Patients experience a sudden disruption of their interactions with health care professionals, and support from friends and family may begin to wane [3,4,5,6] During cancer treatment the focus is on survival of the illness, and many survivors must address emotional concerns post-treatment.[2]

Social support has been highlighted as an important component of care for cancer survivors. Descriptive and intervention studies of support groups and education have shown an association between social support and improved quality of life of cancer survivors.[7] However, many social support interventions fail to produce significant results.[7] Correlational research has demonstrated an association between support in natural social networks and well-being, but most interventions have focused on support from strangers, such as peer support groups or one-to-one support, with relatively weak results.[8,9] Additionally, while a range of support resources in the community address the needs of cancer survivors and family members, these resources for supportive care are not fully utilized due to a lack of awareness and referrals.[10] The Institute of Medicine reports that an improved approach to link patients and providers to psychosocial services in the community is a key component in the standard of care for cancer.[11]

Cohen suggests several directions for the design of social support interventions based on the social support literature.[8] Interventions should target an individual's natural social networks, in which changes can produce more long-term supports. Secondly, interventions should target various levels in the social environment. These approaches can include strengthening the individual's intimate and extended ties, teaching the social skills needed to utilize these relationships, increasing social integration in the community, and reducing negative interactions. Kawachi and Berkman argue for further research on the role that collective, community-level constructs, such as social capital, play in social support and the mental well-being of individuals.[9] The sense of community and ecological systems theory provide theoretical frameworks for conceptualizing the nature and influences of social ties and social support in cancer survivorship along the levels of intimate relationships, extended social networks, and community contexts. [12,13,14,15]

Informatics-based social support research and interventions typically focus on peer support groups and most studies do not target the phases of cancer survivorship following the completion of treatment.[16,17,18] Online peer support groups for patients generally use discussion forums, chat rooms, or email lists, often as part of a more complex educational or decision-support intervention.[17] Similar to literature on face-to-face support interventions, only a few of the existing studies show any beneficial effect on health outcomes with a large sample size.[17] These interventions fail to recognize and include the potential supportive roles of existing social networks and local community resources. Evaluation of online support systems has focused on individual-level social support processes,[17] often with minimal impact. Researchers typically have not evaluated outcomes of these systems using community-level and structural measures of support, such as social capital and the sense of community. While the literature highlights descriptive analysis and outcomes research of existing online support systems, only a few studies describe the processes required for the successful design and development of online support communities for cancer survivors.[19]

In order to advance the development of effective online social support interventions for cancer survivors, research should focus on the informatics design and implementation processes that may influence participation and targeted outcome measures. Evidence-based recommendations are needed for the best practices in the design of online support communities for cancer survivorship. Design and evaluation research is needed to understand the role that local communities and existing social networks can play in an online community targeting cancer survivorship.

An important step in any discussion of cancer survivorship is to define the context in which this term is being used. Cancer survivorship has been described as having three phases: the acute phase during diagnosis and treatment, the extended phase following the completion of initial treatment, and the permanent phase of continuing survivorship at which point there is low risk of recurrence.[20,21] The National Cancer Institute's Office of Cancer Survivorship states: "an individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition."[22]

While this definition is inclusive of all patients and caregivers, a tradeoff exists between the inclusive definition of cancer survivorship, useful for cancer advocacy and family support, and a more specific definition of patients who have completed treatment.[23] There is a recognized need for research focusing on the re-entry and long-term phases of survivorship in order to create evidence-based approaches for the completion of cancer treatment.[24,25]

This research recognizes the value of both definitions, and uses the term cancer survivor to refer to patients after the completion of treatment, while also recognizing that cancer survivorship encompasses all patients, family, and friends. The multiple definitions of cancer survivors and cancer survivorship present a challenge for developing community-based cancer support interventions. Therefore the first step in this research will be to form a definition of the "local cancer survivorship community" to be used in the development of an online community for cancer survivorship in middle Tennessee.

Purpose of the Study

The purpose of this research is to evaluate the collaborative design of an online environment for individuals and groups in the middle Tennessee cancer survivorship community.

Prior to beginning an iterative design process, an ethnographic evaluation of the local community's members, relationships, and sense of community was conducted using a triangulation of qualitative methods. The purpose of this initial phase of the research was to determine the key components and roles that should be included in a local online cancer survivorship community, and to determine the community's strengths and areas to areas to improve. Additionally, this initial effort served to build initial relationships with members of the community

With an emphasis on local community involvement, an online community was iteratively prototyped using the principles and processes of agile software development and community-centered development. Due to the iterative, community-based nature of this study, a primarily qualitative, participatory action research methodology was used to evaluate the collaborative design process.

Research Questions

The research question that guides the entire study is:

1. How can an online environment be developed for individuals and groups in the middle Tennessee cancer survivorship community to support each other in their shared needs and goals?

The research questions that guide the pre-design ethnography are:

2. How are the local cancer survivorship community and its membership defined?
3. What are the supportive relationships, communication preferences, and the sense of community in the local cancer survivorship community?

The research question that guides the collaborative design is:

4. What are the processes and challenges for developing an online cancer survivorship community integrated into the local environment?

Specific Aims

Associated with the above research questions, the specific aims of this study are to:

1. Identify the themes and categories of membership and sense of community in the local cancer survivorship community.
2. Iteratively prototype an online community for local cancer survivorship.
3. Develop and evaluate a collaborative design process for the online community using participatory action research methodology.

CHAPTER II

REVIEW OF SOCIAL SUPPORT AND ONLINE SUPPORT FOR CANCER SURVIVORS

A new model of health care is emerging in which individuals can take charge of their health by connecting to online communities for personalized support and collective knowledge.[26] These systems are social in nature and emphasize communication and collaboration among groups and individuals. The increasingly social functions of web-based technologies suggest that social support for patients and families will be an essential component of a comprehensive, online approach to health care. However, in order to take advantage of this opportunity safely and effectively, biomedical informatics must incorporate current conceptual frameworks of social support and community-based research methodologies to address the potential roles and impacts of these technologies.

No gold-standard currently exists for the design and evaluation of informatics-based social support interventions. Studies of existing health-related virtual communities and online support groups have failed to demonstrate a significant effect of these systems on measures of social support.[17] These results may be due to the use of evaluation tools that do not appropriately target the unique forms of support in online environments.[27,28] Adding to the confusion, the concept of social support is historically and operationally complex, with many different definitions and dimensions identified in the literature.[29] The term “social support” is used to describe a range of support processes and structures in social relationships, but it also refers to a specific sub-set of support processes (e.g. informational and emotional support). Informatics research in online support typically focuses only on this more narrow definition, which may not be the type of support most affected by the informatics systems. Before randomized-controlled trials can be used to determine the impact of online support,[17] researchers must adapt the evaluation measures to target the types of support that occur in the online intervention.[27]

In light of the current trends toward patient-centered information systems, it is essential that informatics researchers revisit the fundamental conceptualizations of social support and how these concepts inform the design and evaluation of online support interventions. Coiera calls for a greater awareness of the social context of communication in online clinical communication systems.[30,31] The same amount of social awareness is needed in the informatics systems designed for patients, their families, and their communities. This chapter summarizes the complexities and conceptualizations of social support, current challenges in online support research, and outlines six recommendations for future biomedical informatics research. Six recommendations are illustrated by discussing their application to support for cancer survivors. These recommendations address the connections between online and real-world support and emphasize an inclusive framework of interpersonal and community-based support.

Conceptual Frameworks of Support

The concept of social support includes a range of the support processes and support structures in social relationships. The processes and structures directly and indirectly impact health and well-being in different ways.[32] The processes refer to the “functional nature or quality of social relationships,”[33] including both positive and negative behaviors.[34] Support structures refer to the characteristics of each individual's social networks and the overall bonds of a community. Adding further complexity, there are both behavioral and cognitive components of social support. The conceptual frameworks of support include, but are not limited to, perceived social support (emotional support, informational support, instrumental support, and appraisal support) [7,13], unsupportive social interactions[35], social integration[36], social network structure[13], and social capital (including sense of community and collective efficacy/empowerment)[37]. In order to design and evaluate online support systems, the field of biomedical informatics must recognize and address these complexities of social support as a conceptual framework.

Table 2.1 summarizes the conceptual frameworks of support in the literature and their significance to online support research. The concepts are sorted by their unit of analysis, from the level of interpersonal interactions to social network and community-wide measures of support. Following this table, ecological-systems theory is introduced to address the interdependences between the range of interpersonal and community-level concepts of support. Community-based Participatory Research (CBPR) and action research methodologies are presented as valuable tools for informatics researchers to use in the design and evaluation of online support interventions.

Table 2.1. Conceptual Frameworks of Support and Online Support Research

Concept	**Sub-components of the concept**	**Unit of Analysis**	**Process or Structure**	**Relevance for Online Support Research**
Social Support [7]	Informational Emotional Instrumental Appraisal	Interpersonal	Process	Commonly studied concept of support; measures must be improved and adapted for the evaluation of online environments.
Unsupportive Social Interactions[35]	Distancing Bumbling Minimizing Blaming	Interpersonal	Process	Understudied both online and in real-world environments; the impact on negative behaviors in the real-world should be included in the evaluation of online support.
Social Integration[36]	Number of relationships Type of relationships Frequency of interaction	Social Network	Structure	Understudied in online support research; provides a structural context to evaluating interpersonal social support processes; especially relevant for emerging online social networking environments.
Social Network Structure[38]	Size Density Boundedness Homogeneity Frequency of contact Multiplexity Duration Reciprocity	Social Network/ Community-wide	Structure	Understudied in online support research; provides a structural context to evaluating interpersonal social support processes as well as the broader context of the whole network (or network of networks); especially relevant for emerging online social networking environments.
Social Capital [37]	Sense of Community Neighboring Collective Efficacy Citizen Participation	Community-wide	Structure/ Process	Understudied in online support research; provides a community-wide approach to evaluate the actions and outcomes of online support; research is needed to better understood and adapt the concept for online environments.
Ecological Systems Theory [12]	Microsystem Mesosystem Exosystem Macrosystem	Community-wide	Structure	Understudied in online support research; guides the design and evaluation of online support to include interpersonal, community, cultural, and societal units of analysis; provides a framework for situating online support in real-world, local communities.

Ecological systems theory[12] provides an overarching framework for research to address the range of support concepts. This theory emphasizes that social relationships include a range of interdependent social contexts, including psychological characteristics, interpersonal relationships, neighborhood, organizations, community, public policy, the physical environment, and culture.[39] The broad, ecological perspective guides a more complete understanding of the roles and impacts of social support in both real-world and online environments. Ecological systems theory influences the types of research questions asked, methodology used, and outcomes measured in studies of social support and well-being. For example, community-based participatory research (CBPR) is a collaborative approach to health intervention research that typically employs an ecological framework of the community. While popular in other applied social sciences, CBPR traditionally has not been employed in the field the biomedical informatics.

Current Challenges for Online Support Research

The online support literature emphasizes the interpersonal processes of emotional and informational support and has paid less attention to concepts such as social network structure and social capital. Yet, these structural and community-wide concepts of support may be especially relevant for the networks and communities in emerging online social networking environments. Informatics research often uses the framework of informational and emotional support to evaluate the messages and interactions in online support groups.[40] Several scales of perceived social support have been used in experimental studies to measure the impact of online support groups on patients.[17] However, while the existing scales were validated in real-world contexts, they are not ideal for evaluating social support online. The scales may not accurately measure online support because the survey questions do not address the unique personal and social psychologies that occur in web-based groups and communities.[41]

Additionally, a narrow focus on positive social interactions might limit the potential for Internet-based studies to measure a significant effect on social support and well-being. While negative interactions and messages occur in online groups,[42] few studies have evaluated unsupportive or undermining behaviors in the context of online support groups.[43] The lack of appropriate measures for online social support is a barrier to conducting controlled trials that evaluate the impact of support in informatics systems. Informatics research will require the use of adapted and new measures, methodologies, and principles for the effective design and evaluation of online support systems.

Research that focuses only on enhancing individual coping skills and perceived social support also may overlook potential impacts on community support, such as public policies and the availability of financial assistance.[33] Few studies in the online support literature have addressed measures of social capital or its subcomponents.[44] In addition to interpersonal measures of support and measures of individual characteristics,[45] research in online social support will be better informed by an emphasis on social capital and its components.

The iterative, participatory, and action-oriented characteristics of community-based participatory research match well with the processes and principles of patient-centered, participatory design for information systems.[46] Elements of these participatory principles, such as a shared sense of ownership, can be seen in research on the implementation of clinical information systems in health care organizations.[47 48] Yet, an emphasis on community-wide social change, relationship building, and empowerment rarely is targeted in patient-centered informatics research.

Future Research for Online Support Interventions

There is a correlation between well-being and support from an individual's own social networks, but both online and real-world interventions primarily focus on support from strangers, such as peer support groups, with relatively weak results.[17,8,16,18] Cohen suggests several directions for the design of social support interventions based on the current literature.[8] Interventions can target an individual's natural social networks, in which changes can produce more long-term support. Secondly, interventions should target various levels in the social environment. These approaches can include strengthening the individual's intimate and extended ties, teaching the social skills needed to utilize these relationships, increasing social integration in the community, and reducing negative interactions.[8]

While peer discussion and clinical experts are recognized as important aspects of online support,[49] few studies have addressed the role of real-world social ties in online support networks, and vice-versa.[50,51] Recent models of online support stress the role of family and friend relationships that help patients manage their health and personal health information.[52,53,54] A few research and commercial initiatives are beginning to provide communication tools that integrate many of a patient's various supportive relationships, from clinicians and peers to family and friends.[78,55,15] Involvement of multiple interpersonal and community relationships can influence the overall impact of the online intervention. For example, one study found that participants in a online support group for hearing loss benefited more when their real-world family and friends participated in the online group.[50]

Many online groups and communities are based on shared interests or identity (e.g. cancer support groups), however online communities also can be designed as extensions of geographic or physically-based communities (e.g. online discussions for classrooms).[56,57] Online social support may have the most impact in physical communities in which the internet-based interactions are connected with face-to-face interactions.[58] Development strategies for geographically-based community networks[56] may offer key lessons for guiding the inclusion of real-world relationships in online support systems. Community-based participatory research methodologies may guide informatics researchers to appropriately partner with communities members throughout all aspects of the research process.

Future informatics research needs to employ outcome measures that assess support at various levels of a patient's social networks and community. A holistic approach to the concept of social support will help researchers learn more about support needs from various online and real-world relationships.

Six Recommendations for the Study of Online Support

Based on an inclusive concept of support and recognizing the increasing ubiquity of social networking technologies, we propose a framework of six recommendations to guide future research in the design and evaluation of online support interventions (Table 2.2). This framework emphasizes community-wide conceptualizations of support, and the interdependencies between online and real-world social relationships. These recommendations will be further explained with examples of their application to support for cancer survivors.

Table 2.2. Six Recommendations for the Design and Evaluation of Online Support Interventions

Design	Address the interdependence between online support and real-world support.
	Address the individual's existing social networks (e.g. family, friends, co-workers).
	Target community-wide outcomes and participation of local community groups.
Evaluation	Adapt and/or develop evaluation measures of support specific to online environments.
	Consider all units of analysis (from interpersonal to community-wide measures of support).
Design + Evaluation	Employ ecological systems theory and principles of community-based participatory research.

The first three recommendations target informatics system design directions, while recommendations four and five focus on system evaluation. The sixth recommendation highlights the cyclical, iterative nature of design and evaluation throughout the process of community-based informatics research.

1) Address the interdependence between online support and real-world support.

In the design and implementation of online support interventions, developers and researchers can target the interactions between online communities and real-world supportive relationships. Recognizing the role that online communication can play in real-world interactions,[51] and vice-versa, will lead to new interfaces and approaches to social support interventions.

2) Address the individual's existing social networks (e.g. family, friends, co-workers).

Social support in existing social networks has shown positive effects on health, and negative support in social networks is associated with a negative effect on health.[8] Informatics interventions should improve people's support in an individual's existing social networks and also seek to reduce negative interactions in these relationships. Patients, health-care providers, family, friends, co-workers, neighbors, and others all can be included in the design of an online support system. This recommendation differs from the first recommendation in that these relationships may exist primarily in the real-world, primarily online, or a combination of both.

3) Target community-wide outcomes and participation of local community groups.

In addition to each patient's social networks, local community groups and health-care organizations in the community can be supported in web-based systems and interfaces. Established and respected community-based non-profits and psychosocial programs can play key roles as participants or facilitators in online support systems. Designing systems with the objective of improving the overall community's social capital or sense of community will lead to new technologies and frameworks that can be evaluated for their impact on health and well-being.

4) Adapt and/or develop evaluation measures of support specific to online environments.

The evaluation of online social support can be improved by a better understanding of the similarities and differences between online and real-world social support environments. Future research should adapt existing measures of social support and/or create new measures that are more sensitive to online environments. Participation in online support groups should be evaluated in terms of both online and real-world conceptualizations of support. Unsupportive social interactions in both contexts also should be addressed in these evaluations.

5) Consider all units of analysis (from interpersonal to community-wide measures of support).

Community-wide concepts of support can be employed to greater extents in the evaluations of online support. This evaluation approach expands beyond the interpersonal social support of individuals and includes concepts such as social capital and its subcomponents. As informatics systems are designed to impact support on a community-wide level, the intervention must be evaluated in terms of the relevant community outcomes.

6) Employ ecological systems theory and principles of community-based participatory research.

Grounded in ecological-systems theory,[12] an integrated intervention that includes personalized education, family and friends, a peer patient group, and organizational and community networks may have a greater impact on well-being than each individual component alone. These new directions for online support will require informatics to incorporate research methodologies from social science disciplines such as community psychology. Considering the community from an ecological perspective, and facilitating social support across multiple levels of the community, suggest the use of community-based participatory research (CBPR) for system development and evaluation. Community-based participatory research also emphasizes the continuous evaluation of the collaborative process throughout the development of an intervention. Qualitative and quantitative[59] evaluation of the participatory design process will help to establish principles and best practices for the development of community-based systems for online support.

The following section illustrates each of these proposed recommendations in the context of online support for cancer survivors.

Online Support for Cancer Survivors

There are an estimated 10 million individuals who have been treated for cancer living in the United States.[1] Cancer survivorship is described inclusively as having three phases: the acute phase during diagnosis and treatment, the transitional phase following the completion of initial treatment, and the permanent phase of continuing survivorship.[20,21] Even after the completion of a successful course of therapy, cancer survivors are at risk for physical, emotional, and social issues that may decrease their quality of life (QOL).[2]

There is an association between social support and improved QOL of long-term cancer survivors,[7] but less is known about the role of support immediately following treatment. That being said, relatively few studies have focused on long-term survivorship, and even fewer examine quality of life issues that arise during the transition period following the last dose of chemotherapy or radiation therapy.[60,61] Re-entry into daily life is physically and psychologically distressing for cancer survivors and their families.[2,3] Further research on the re-entry and long-term phases of survivorship is needed in order to create evidence-based guidelines for the completion of cancer treatment.[24,25,62]

Existing informatics applications for cancer patients have focused primarily on diagnosis and treatment phases of care, and do not target the needs of cancer survivors in transition and later phases of care and support.[63] Emerging research and informatics applications are beginning to address these aspects of survivorship through tools such as online survivorship care plans.[64,65] As more information systems focus on the psychosocial needs of cancer survivors living beyond active treatment, the roles of social networks and real-world community support will be even more apparent. The remainder of this paper highlights several existing and potential approaches to online support of cancer survivors based on each of the six proposed recommendations.

1) Design: Address the interdependence between online support and real-world support.

The early phase of post-treatment survivorship has been described as a loss of the "safety net" of treatment.[3] Patients who were closely monitored in the clinic experience a sudden disruption of their interactions with health care professionals.[03] Support from friends and family also may begin to wane if members of the support network do not realize the ongoing, daily challenges of cancer survivorship.[4,5,6] Survivors may continue to experience significant symptom burden and function loss despite cessation of treatment.[66] Persistent health issues may limit their ability to engage in social activities and return to baseline function.[67] For those who were employed at the time of diagnosis, work difficulties and job loss may contribute to a decrease in the survivor's social contact.[60,66]

Cancer survivors have a demonstrated need for re-establishing their real-world, social ties that have been lost or reduced following the completing of treatment. Informatics applications can be designed to reduce social isolation and increase one's sense of control over real-world social engagement. Re-integration in social settings, such as finding a new job, can require the use of larger, loosely connected networks.[68] System developers can address these practical needs of cancer survivors through online social networking interfaces with the intention of impacting real-world relationships. Facilitating employment, volunteering, and advocacy opportunities are all examples of how online networking can blend with real-world interactions for cancer survivors.

Online social support interventions may be especially helpful in the context of cancer caregiving, in which members of the primary support network face social isolation and shifting social roles at the same time as providing care for the patient[.69,70] In addition to managing the patient's information, one computer-based system addresses "caregiver burnout" by allowing caregivers to visualize their frequency of interaction with the patient, in order to better manage their own social and health needs.[52] Other novel interfaces for visualizing the structure and interactions among a cancer survivor's caregivers may provide new ways of addressing caregiver burnout and provide support both for the patient and for family members.

Just as technology has the potential to impact real-world social relationships, the social environment also can affect the manner in which the technology is used.[31] By including members of the support network, patient-centric information systems will require new approaches and technological frameworks for privacy in sharing personal health information.[71,72] Psychosocial support for cancer survivors in the real-world is spread across various individuals and community programs,[73] and this reality must be addressed in the design of consumer informatics systems to achieve effective closed-loop care of these individuals.

2) Design: Address the individual's existing social networks (e.g. family, friends, co-workers)

Cancer survivors have a need for social support even after the completion of treatment. Survivors may be only beginning to face the full emotional impact of cancer diagnosis after the curative focus of treatment ends.[2] These individuals still have high informational support needs[74,75] and benefit from instrumental support from family and friends such as cooking meals, running errands, and financial assistance.[76]

Research on the design of online support systems has not targeted social support from cancer survivors' existing social networks of family and friends. Several online services facilitate the sharing of online journals with a patient's extended social network, but there has not been formal research in this area.[77,78] Informatics research on cancer survivorship has not included technologies that might facilitate the emotional presence of family and friends.[79,80] In terms of improving informational support, emerging web-based technologies such as wikis can be used to develop information resources created collaboratively by cancer survivors, health professionals, as well as family and friends.[81,82] Further research is needed to determine how online social networking frameworks that connect an individual's existing social relationships, such as Facebook[83] and Twitter[84], can enhance the support of cancer survivors.

When designing online support systems for cancer survivors' existing social networks, informatics researchers also must consider the unsupportive interactions that survivors encounter in these relationships. Although the right amount of information can be helpful, family and friends often inundate cancer survivors with too much information, undesired advice, or too much attention.[7,85] On the other hand, family and friends may incorrectly assume that the survivor is "cured" after finishing treatment, and they may not continue to provide the needed support during the recovery process.[2] If friends do not know how to deal with the illness appropriately, they might make inappropriate comments, minimize the problem, or even withdraw from the survivor.[35,86]

As illustrated by these examples, many of the negative social interactions experienced by cancer survivors stem from a lack of information and education about what to expect, and a lack of communication about the support desired by the survivor. Interventions can focus on family and friends to dispel myths, improve communication, and facilitate expressions of needs and feelings.[7] Following the lead of peer support groups, online environments designed expressly for networks of family and friends can be created to foster open communication. Some advantages associated with online cancer support groups include increasing self-disclosure, decreasing misconceptions, and increasing honesty. [87,18,88] Online networks for family and friends may require novel interface designs that facilitate specific types of self-disclosure and education appropriate for cancer survivors.

3) Design: Target community-wide outcomes and participation of local community groups.

Cancer survivors require different types of support from different sources and relationships in addition to family and friends. For example, while they need more emotional support from family and friends, survivors may prefer to receive informational support from health care providers.[7] Some types of emotional support, such as offering reassurance and discussing certain concerns, may be most beneficial when offered by another cancer survivor who does not have a personal stake in the individual's recovery.[7] Support also is provided by a variety of community-based programs. Each source provides a unique type of support for different situations and different individuals.

The design of online support for cancer survivors can expand beyond each patients' existing social networks by addressing a range of interpersonal and community relationships. Informatics applications can target the broader levels of community process and structures, informed by an ecological model of the community.[89] A report by the Institute of Medicine highlights the need to improve cancer patients' and providers' awareness of community support programs and services.[11] New informatics frameworks and interfaces have the potential to play a key role in creating awareness and facilitating referrals to these community resources.[9091] Community resources include local support groups, transportation and financial programs, patient advocacy opportunities, and other social services. Influential community groups and leaders, such as church groups,[92] also may be included in online interventions. The broader cultural environment and societal policies in the community also are part of an ecological approach to designing online support interventions.

Based on the authors' ongoing research, we argue that the design of online social support systems should include active partnerships and collaboration with the local community organizations and services. Rather than design an informatics system independently of the local community, the existing community-based psychosocial programs can be integrated with the online support of cancer patients and survivors. This broader understanding of support suggests a role for online collaboration tools for health care providers and supportive care professionals, in addition to a direct patient component. Informatics applications that facilitate awareness and collaboration opportunities among community professionals may impact the supportive care outcomes of cancer survivors. A few research studies, including the authors' own work, are beginning to address the role of online collaboration tools in state-based cancer coalitions and professional networks.[90,93] Other studies and projects have demonstrated value in real-world initiatives for cancer awareness and community collaboration,[94] suggesting the potential for a community-driven informatics approach to this problem. Informatics-based support for local communities also is being developed for other health contexts,[73,95] which suggests that this direction for informatics design research is applicable to community support and public health in conditions beyond cancer survivorship.

4) Evaluation: Adapt and/or develop evaluation measures of support specific to online environments

The evaluation of online support should consider the differences between face-to-face and online support. For instance, a study of an online cancer listserv found that patients participated in the listserv more only when their real-world support was perceived to be low.[96] Research is needed to understand how online communities provide a unique form of support compared to real-world communities, and what aspects of the virtual environment actually influence the patients' perceived support. Evaluations of complex online support interventions for cancer survivors should distinguish the systems' different core components and their individual roles in health outcomes.[55]

For example, the perceived presence and emotional support of "being there"[85] likely are expressed in unique ways through emerging web-based interfaces[97] such as friend lists, visit logs, and multimedia displays. Knowing how many people have visited one's personal online journal or web page may be important to cancer patients,[52] but this type of support is not targeted adequately in existing evaluation scales. In a study of Alzheimer's patients, Brennan et al. did not find a significant effect on social isolation in patients using an online support system, even though messages and feedback from participants indicated positive experiences of perceived support.[28] Brennan et al. suggest that the lack of effect in the self-reported measure was due to the scale's emphasis on family and friend support, while the intervention focused on internet-based support from peers.[28] Others suggest that related concepts of social capital and sense of community also might require adapted or new measures specific to virtual communities.[98] [99] [100]

In order to effectively measure the impact of support in online environments for cancer survivors, new or adapted measures specifically targeting the unique components of online interactions must be developed. The lack of standardized measures is a major barrier in effectively evaluating online social support and social capital.[27] Both community-wide and interpersonal measures of support need to target the actual interactions and relationships that occur online, rather than only applying measures developed and tested in other contexts.

5) Evaluation: Consider all units of analysis (from interpersonal to community-wide measures of support)

Evaluation research in cancer survivorship has focused primarily on individual-centric outcomes of social support, quality of life, and both mental and physical well-being, with less attention paid to community-level outcomes. The impact of engaging existing community-based support organizations and health-care institutions in online environments is understudied in the literature. Evaluation of online support groups and online social networking interventions for cancer survivors should begin to target community-wide change and measures of social capital.

An example of community-wide emotional support can be found in the "Hugs for Jacey Campaign" on the YouTube video sharing community.[101] In this case, a YouTube member created a public video for another YouTube member whose child had undergone treatment for cancer. The Hugs for Jacey Campaign author created a video in which she called for the entire YouTube community to give virtual video hugs to the child. This creative and unique form of support represents the emerging ways in which emotional support may evolve in online communities, and future evaluation tools for social support should take these behaviors into account.

Researchers can evaluate an online community's social capital as well as the impact of the online community on a real-world community's social capital. Online support may affect cancer survivors' quality of life through changes in community policies and access to supportive care resources. The social capital component of collective efficacy/empowerment[37] may be especially relevant in evaluating online support interventions for cancer survivors and communities. On a local level, members of a geographically-based online network can communicate online to effect changes in key neighborhood policies.[58] Cancer survivors can use online support groups to coordinate efforts to change real-world, local policies. One example is an online group of breast cancer patients who together decided to request a different and less a painful procedure for their post-operation mammograms.[102] Cancer patient advocates work with researchers to support patients' interests in the design of research studies, [103] and online collaboration tools may help facilitate these partnerships. As informatics interventions are developed to support these interactions, research will be needed to evaluate the role that collective efficacy and participation in online initiatives directly or indirectly impact the well-being of cancer survivors by improving policies at local and national levels.

6) Design + Evaluation: Employ ecological systems theory and principles of community-based participatory research

Community-based research principles have been applied to the development and evaluation of real-world cancer prevention and support initiatives.[103] Cancer is a natural fit for community-based research because of the strong sense of identity among cancer survivors[104] and the many community-based organizations that support cancer survivors.[73] Grant funding for community-based participatory research (CBPR) for cancer survivorship is becoming available to support investigators and community programs in doing this work.[105] Informatics researchers can use these examples and opportunities to study online support for cancer survivors in their communities.

The authors' ongoing research in developing and evaluating an online community for cancer survivorship in middle Tennessee uses CBPR principles to guide the informatics research design.[90] Grounded in the development of collaborative partnerships among local community members and organizations, this work illustrates the value of moving beyond patient-centered design to a more relationship-centered[52] and community-centered design. The iterative, qualitative evaluation highlights the strengths and challenges of applying a community-driven approach to informatics applications for cancer survivors.

Conclusion

This chapter has reviewed the concepts of social support, from interpersonal processes to community structures, in the context of online support systems. Six recommendations for informatics research suggest the conceptualization of online social support across various levels of the real-world community. These recommendations call for online support in existing social networks and local communities, and point out that the interdependence between online support and real-world support should be addressed. New and adapted measures will be essential to effectively evaluate the impact of online support interventions. Established community-based participatory research principles and action research methodologies can guide the informatics research design. This approach will require a paradigm shift beyond patient-centered interventions to informatics interventions that empower communities and social networks to improve the support and well-being of their members.

A discussion of social support for cancer survivors illustrates the application of the six proposed recommendations. Research in new directions of online support in cancer survivorship may serve as a model for other areas of health and wellness. We consider research in these new directions significant for the evaluation of existing online support systems, and especially for the development of new online communities and web-based applications. As the social capabilities of the Internet continue to grow, research in online support must also stay informed of the broad and evolving conceptualizations of support in social relationships.

CHAPTER III

METHODOLOGY

This research incorporates a combination of methodologies to accomplish the dual aims of creating an informatics application while also developing and evaluating the collaborative, community-based design process. Software development, qualitative research, and local community-building methodologies are integrated in order to design an online community for cancer survivorship in middle Tennessee.

The theoretical framework that guides the overall study is presented first, followed by an overview of the integrated methodological framework. The theoretical framework of support in this study uses ecological systems theory and the sense of community, a subcomponent of social capital. The methodological framework of this study is based on an integration of participatory action research, agile software development, and the online community-building methods of community-centered development. This integration of methodologies is referred to hereafter as Community PARADE.

Community PARADE is grounded in the naturalistic paradigm of research and uses primarily qualitative research methods. An overview of the naturalistic research paradigm is presented in the context of participatory action research, followed by a discussion of the participatory principles and the cyclical process of participatory action research. Agile software development and community-centered development are then introduced in terms of how they integrate with the principles and cycles of participatory action research. A combined set of principles and cycles illustrates the full integration of the three methodologies in the Community PARADE methodological framework.

The methods for site selection and purposive sampling provide an overview of the research setting and the approach to including participants in the study. The methods for data collection and analysis are described for both the initial ethnographic evaluation of the local cancer survivorship community and for the collaborative design phase. Finally, the specific strategies employed to satisfy the criteria of trustworthiness for qualitative research are described.

Theoretical Framework

Ecological Systems Theory

Ecological systems theory[12] provides an overarching framework for the research to address the concept of support throughout the community. This theory emphasizes that social relationships include a range of interdependent social contexts, including psychological characteristics, interpersonal relationships, neighborhood, organizations, community, public policy, the physical environment, and culture.[39] The broad, ecological perspective guides a more complete understanding of the roles and impacts of social support in both real-world and online environments. Rather than evaluating support only in terms as interpersonal social support, this framework suggests that interpersonal support should be considered in a broader context of the individual's coping strategies and community-wide aspects of support, such as social capital and the sense of community.

Social Capital/Sense of Community

Social capital refers to the cognitive and behavioral relationships that tie a society together. Putnam describes social capital in terms of “bonding” capital, the trusting relationships within societal groups, and “bridging” capital, the coming together of societal groups and organizations.[106] Perkins and Long define social capital by formal/informal and cognitive/behavioral dimensions to create a two-by-two framework that includes the sense of community (informal-cognitive), collective efficacy/empowerment (formal-cognitive), neighboring (informal-behavioral), and citizen participation (formal-behavioral).[37] Community-wide concepts of support, such as social capital, offer promising new directions for social support research.[107,9] McLeroy et al. argue that “appropriate outcomes may not just be changes in individual behaviors but may also include changes in community capacity.”[39]

The psychological sense of community, a subcomponent of social capital, includes the dimensions of feelings of membership and influence, fulfillment of needs, and shared emotional connection.[108] Membership in the community includes a sense of belonging, as well as the boundaries and common symbols that define members of the community. Influence refers to the influence each member feels in the community, as well as the sense of influence that other members in the community have over each other. The fulfillment of needs refers to more than specific practical needs, and includes the needs of recognition and status in the community. The shared emotional connection refers to quality of the relationships in the community, and the bonds formed through frequent personal contact and shared history and experiences.

The four dimensions of the sense of community framework guide the data collection and analysis in this study. The broader concept of social capital, while not directly evaluated in this study, provides a background for how the cognitive sense of community relates to behavioral aspects of empowerment and citizen participation.

Methodological Framework

Community PARADE stands for "Community Building with Participatory Action Research in an Agile Development Environment," and encompasses the three central methodologies used in this study. Participatory action research is described first, and then agile development principles process are introduced in terms of how they can be integrated into the action research philosophy and processes. Finally, this integrated methodology will be described as it applies specifically to the community-centered development of an online community network. The naturalistic research paradigm is explained in the context of participatory action research.

Participatory Action Research

Action research is a class of research methodologies in which theory is tied closely to practice in order to address an immediate, real-world problem. Action research, which has its origins in Lewin's planned approach to change, emphasizes that change requires action and involves an iterative spiral of analyzing the situation, taking action, and evaluating the results of the action.[109] The emphasis is on social change that is initiated and/or supported by the members of the group or community being changed. Contributions of the research therefore are made both to the people in the organization or community ("action") as well as to scientific knowledge ("research"). Baskerville suggests that information systems development is an ideal domain for action research methodologies because the implementation of a new system fundamentally intervenes in complex social and organizational environments.[46] Participatory action research additionally emphasizes increased collaboration in which the researcher and the participants are given equal status and roles throughout the course of the study and intervention.[46] In the proposed study, I play the roles of both a researcher and a developer actively involved in facilitating the collaborative design. The action research methodology is used to generate theory and strategies for the collaborative design process in developing community-based medical informatics systems. Three fundamental aspects of participatory action research that guide the research design are the naturalistic paradigm, the participatory focus, and the cyclical process.

Naturalistic Paradigm

The naturalistic paradigm guides the philosophy of action research.[46] Action research occurs in the participants' natural environment and the researcher's actions are inextricably intertwined with the participants' behaviors during the change process. These characteristics make the naturalistic paradigm appropriate for the proposed action research study. As Kaplan has argued, positivist research designs are not suited to answer the "how" and "why" questions about the processes and social contexts of health information systems.[110] The naturalistic paradigm, as defined by Lincoln & Guba,[111] suggests that there are multiple realities that must be studied holistically, such that causal linkages cannot be determined. This differs from the positivist paradigm, in which there is a single reality that can be studied by isolating independent variables and processes. The researcher and the participants being studied are considered to be inseparable and the interactions between them become a part of the research design. Naturalistic inquiry admits to being influenced by values and choices of the inquirer, paradigm, context, and theory. The research is not intended to produce generalized knowledge, but rather the knowledge is bound to the context of the individual case, which may be transferred appropriately to other contexts.

Because of these fundamental differences from the positivist paradigm, research in the naturalistic paradigm has different criteria for establishing trustworthiness and different approaches to data collection and analysis.[111] For example, research is conducted in a natural setting and the researcher is valued as an adaptable and indispensable "human instrument" in the data gathering process. The naturalistic paradigm favors qualitative methods and a grounded theory[112] approach to iteratively analyzing data as it emerges. As opposed to random sampling, purposive sampling ensures that multiple realities are represented in the research.

This study is anchored in the naturalistic paradigm, and the naturalistic criteria for trustworthiness (described in the later section on trustworthiness) are used evaluate the quality of this research.[111]

Participatory Focus

As noted above, one of the key characteristics that differentiates participatory action research from traditional action research is the emphasis on the participants as equal members of the research team throughout the collaborative process. Participatory action research in a community setting involves many of the same goals, facilitating factors, and barriers as community-based participatory research.[113] The principles of community-based research are especially helpful in clarifying the nature of participation in this research. Although not all of the participatory ideals may be possible to tackle at once, the following four principles guide the participatory approach in this study, drawn from the principles summarized by O'Fallon and Dearry[114] and Israel et al.[113]

1. Define community as a unit of identity
2. Ensure projects are community-driven; Promotes active collaboration and participation at every stage of research
3. Foster co-learning
4. Build on strengths and resources within the community

The role of each of these participatory principles will be illustrated throughout results and the summary of the collaborative process activities.

Cyclical Process

A five step cyclical process guides the linking of theory to practice in action research. The five components of the action research cycle are diagnosing, action planning, action taking, evaluating, and specifying learning.[115] While all five components are important to the process, the final, actually ongoing, step of specifying learning highlights the distinction between action research and purely action, or purely research-oriented, cyclical processes. Specifying learning refers to the principle of applying knowledge to three audiences: informing the organization or community, providing feedback to the researchers for subsequent cycles of action, and contributing to the scientific community.[46] By applying the knowledge in all three areas, action research is a powerful way to evaluate the development process of an online community network during the period in which it is designed and built. Furthermore, the cyclical nature of action research suggests that it possible to combine it with other cyclical research or development methodologies.[46] This characteristic of action research will be further discussed in the context of agile software development methodologies, which typically focus more on "action" than on "research."

Agile Software Development

While participatory action research provides the principles and structure for initiating and evaluating a change process, this methodology alone does not account for processes in which the "action" is based on the development or implementation of information technology. Agile software development methods provide a framework for the programming and design practices that can be integrated into action research. Traditional models of software engineering have involved linear steps of analysis, design, implementation/coding, and testing, an approach that has been criticized for being inflexible by not testing and evaluating until late in the process.[116] Spiral software development methodologies were introduced to counteract these problems of the “waterfall” approach, and involve iterative cycles of objective setting, risk assessment (e.g. prototyping), development and verification, and planning for the next iteration.[116] Agile development models, such as extreme programming, aim to make the iteration cycles much shorter, with the internal steps of determining requirements, coding, and testing conducted in parallel rather than sequentially.[117] Along with the distinguishing emphasis on short (1-4 week) cycles in which simple changes are put into production, the “agile manifesto” outlines four key values[118]:

- Individuals and interactions over processes and tools
- Working software over comprehensive documentation
- Customer collaboration over contract negotiation
- Responding to change over following a plan

Grounded in these values, principles of agile development include: deliver software frequently, work with motivated individuals, work together on a daily basis and face-to-face if possible, keep simplicity in design and only focus on what needs to get done, and reflect on and adjust the development process.[118] These values and principles are very much in line with the approach of participatory action research, and there is a natural connection between the two methodologies.

Community PARADE: Integrated Methodologies

Integrating Research and Development in PARADE

Agile development's emphasis on creating working software and responding to change fits well with participatory action research's emphasis on iteratively enacting change in a real-world setting. The emphasis on customer collaboration and understanding people and their interactions also parallels the "participants as co-researchers" approach of participatory action research. A few studies have proposed approaches to integrate the spiral development model with an action research approach for health-related software applications.[19,119] Similarly, action research has also been used to study an agile (extreme programming) approach to developing a health information system.[116]

In the development of health informatics systems, participatory action research could be used to simultaneously study the software development process *as well as* the community or organizational change process. Sociotechnical approaches to medical informatics,[120] and the naturalistic paradigm in general, suggest that these two intertwined processes should not, in fact, be studied independently. Foth suggests that future research is needed to understand the synergies between methodologies such as action research and participatory design.[121] Understanding how to effectively integrate system development and research methodologies into a unified approach creates new approaches for evaluating the development of medical information systems. The methodology of PARADE: Participatory Action Research in an Agile Development

Environment evolves over the course of this research study and is grounded in the two component methodologies.

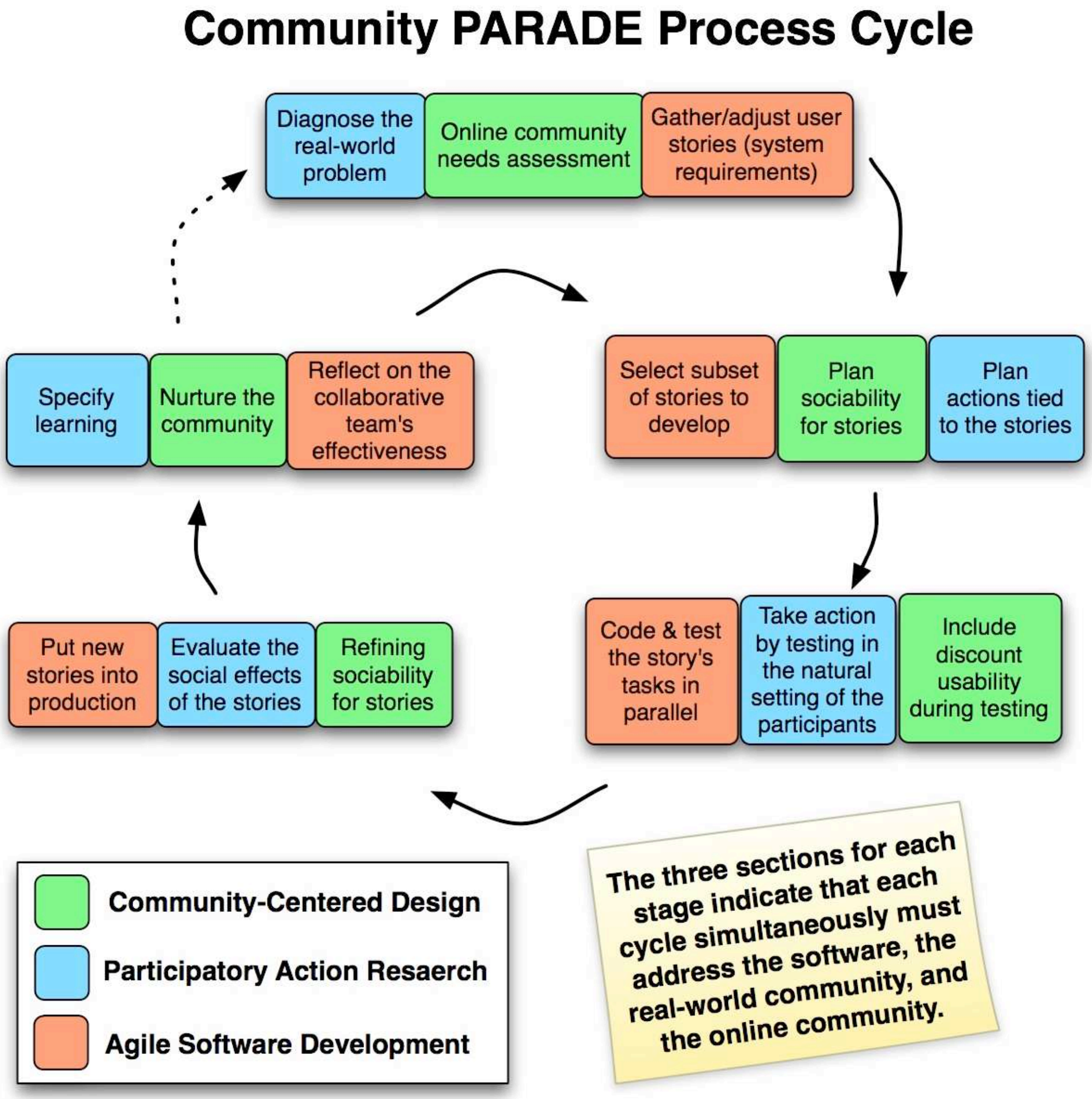
From PARADE to Community PARADE

This study differs from many agile development projects in that it is located in a local community of individuals, groups, and organizations, rather than in a single organization with a single client. Additionally, the focus of the project is on building community, which is inherently different from the task-oriented focus of many business-oriented information systems. Preece highlights the unique needs of a community-oriented development approach in her framework for community-centered development (CCD).[122] Preece describes two main parts of the community-centered development process as software design (or selection) and sociability planning.[122] Software design includes both the programming process and usability testing with the user population. [122] While the rapid timelines of agile development methodologies do not allow for traditional usability engineering cycles, certain discount usability engineering practices[123] can be employed to begin to address usability concerns.[124 ,125] The second aspect of Preece's model, sociability planning, involves processes and principles that guide the social interactions in the online community. [122] While sociability planning may be applied to many different software applications with multiple users, it is especially critical when the entire application centers on interpersonal relationships and community-building. Weiss and Lorenzi previously have suggested that a relationship-centric focus is especially needed in the context of cancer treatment and social support.[52]

Preece's model of community-centered development involves five stages in an iterative process: 1) Community needs assessment and user task analysis, 2) Selecting technology and planning sociability, 3) Designing, implementing, and testing prototypes, 4) Refining and testing sociability and usability, and 5) Welcoming and nurturing the community.[122] Aspects of the needs assessment and technology design already exist in the previously described PARADE methodology, but the sociability design and explicit processes for nurturing the community are lacking. Especially for the design of health-related online communities, sociability concerns must be addressed in the development and evaluation methodologies. Preece, [122] and other experienced community developers,[57,126] offer recommendations for policies and team management practices that facilitate the growth of new online communities. Recent community informatics studies on residential and regional community networks in Australia suggests that the approaches to system design and community need to be reworked and better integrated into a unified methodology.[127,128] Therefore, the Community PARADE methodology includes sociability planning and community nurturing integrated into the agile development and action research methodologies.

Community PARADE Process and Principles

Figure 3.1 illustrates the integrated process model for the Community PARADE methodology:



The three sections for each stage indicate that each cycle simultaneously must address the software, the real-world community, and the online community.

Figure 3.1. Community PARADE Process Cycle

Additionally, the values and principles from the three component methodologies are integrated into the principles that guide this research (Figure 3.2):

INTEGRATED PRINCIPLES OF COMMUNITY PARADE:

1. Emphasize research, real-world action, and changes in an online environment.
2. Employ qualitative data collection and analysis in the naturalistic research paradigm.
3. Employ an ecological focus on community, individuals, and interactions.
4. Build on strengths, resources, and motivations of individuals and groups within the community.
5. Frequently deliver working software, real-world change, and online sociability in an iterative process.
6. Foster co-learning, and specify learning to the community, researchers/developers, and scientific knowledge
7. Welcome changing requirements for the online community, the design process, and the research process.
8. Value simplicity in both the software design and real-world actions.

Figure 3.2. Integrated Principles of Community PARADE

This section has introduced the Community PARADE methodology and suggests the need for an integrated approach from the component methodologies of participatory action research, agile software development, and community-centered development. The three pieces have strong fundamental overlaps, and each method has unique contributions that are lacking or not clarified in the other methods. Participatory action research is used to evaluate both the collaborative software design and development process. Agile development contributes primarily to the "action" part of the research, in the rapid design of the online community software. Finally, community-centered development guides the sociability aspects of the design that likely will impact the sense of community in the live online community. The naturalistic research paradigm serves as the overall framework for the three integrated methodologies.

Site selection and research setting

This study was conducted with individuals and organizations that have an interest in cancer survivorship in middle Tennessee. The “local cancer survivorship community” is a community of place (middle Tennessee), a community of interest (on cancer survivorship), as well as a community of practice (for those who are employed in fields associated with cancer survivorship). Because this community has not been formally defined, the first phase of this research is to define and understand the boundaries and membership of the local cancer survivorship community.

Entry into the community was facilitated through my own university’s medical center and cancer center, where I have conducted research previously. Colleagues in survivorship research and community education with whom I previously worked formed the initial connections into additional recommendations to other local cancer support professionals. Additionally, publicly available contact information for local groups provided the initial connections to more isolated organizations. My personal participation in local community events and activities, as a volunteer or a general community participant, also facilitated more informal connections into the community.

The research was not conducted at a specific organization site. The participants included representatives from cancer survivor organizations and cancer survivors in middle Tennessee. Interviews were conducted either in my own university department's meeting rooms, or in the offices and buildings of each organization representatives. The group design meetings were conducted in the spacious meeting hall of a local cancer support organization. This organization is located centrally in the Nashville community and independently from a medical institution. Many different local organizations use their building for meeting space, and so the setting serves as a more neutral location for the group collaboration.

The target population is the cancer survivorship community as the primary unit of study, and multiple levels of the community are included in the data collection and analysis. The psychosocial support of cancer survivors is a primary focus, but that is not the only level of the community targeted in this study. Communication and collaboration between local cancer support organizations and professionals also are targeted.

Nashville is respected nationally for its health care industry, as well as for its music industry. The Nashville and surrounding middle Tennessee community have numerous resources for cancer survivors, and there is growing interest in improving approaches to cancer survivorship. The local interest in survivorship parallels a broader national awareness of survivorship through organizations such as the Lance Armstrong Foundation. In the Fall of 2006, a cancer survivorship program and clinic was started in the Monroe Carell Jr. Children's Hospital at Vanderbilt, focusing on post-treatment survivorship and follow-up care for childhood cancer survivors. Additionally, the Vanderbilt-Ingram Cancer Center hosted a survivorship retreat in the summer of 2006 which included staff, clinicians, researchers, and survivors. This meeting resulted in a set of recommendations for research, clinical care, education, and outreach and initiated monthly meetings of an interdisciplinary survivorship working group at Vanderbilt.

These activities build on the many support, clinical, and research groups that have been actively involved in survivorship issues in the local community. Several of the recommendations from the 2006 survivorship retreat emphasized a need for improved communication and collaboration between clinicians, researchers, survivors, and other members of the community. Several groups and pairs of organizations currently collaborate to support their shared goals, and many local professionals participate in the state-wide cancer control coalition which held its first summit in 2005. These current partnerships provide a strong foundation for an online community that enhances current and new collaborations in the local cancer survivorship community. The initial phase of research to evaluate the local sense of community provides additional context into the history of collaboration and competition in this research setting.

Sampling

Overall, a purposive and iterative sampling approach was used for this study, with additional self-selected participants drawn from community-wide flyers for the study (see Appendix A). Due to my own involvement and connections as a Vanderbilt University graduate student, many of the individuals initially contacted for participation are from the Vanderbilt Ingram Cancer Center and the community organizations that partner with Vanderbilt. The Vanderbilt-Ingram Cancer Center is well connected to many community organizations. Recommendations were made during the each initial interview for further people and organizations to contact. The design phase participants were drawn from these same participants as well as other individuals or groups recommended by the participants.

Because no formal definition of the cancer survivorship community previously existed, groups and professionals with any interest in cancer support and awareness in the community were included in the sampling. General social service community professionals, while important for the support of cancer survivors, were not targeted for the current study.

Additionally, while the initial emphasis of the study was on cancer survivorship after the completion of a successful treatment regimen, the participants also include long-term survivors and patients currently in treatment, as well as family and friends of these individuals. These individuals still have a role to play in the cancer survivorship community; the long-term survivors have experienced the transition period, and current patients need to prepare for this transition. Cancer survivor participants were reached through the flyers placed in a local cancer support organization and at a cancer survivorship celebration at Vanderbilt University. Other cancer survivor and family participants were recommended as participants by a family member or professional already involved in the study.

Data Collection and Analysis

The data collection and analysis occurred in two phases: the pre-design ethnography and the collaborative design process. Both phases included the author actively participating in, and contributing to, activities in the local cancer survivorship community.

Pre-design ethnography

Data collection

The first phase of the study consisted of key informant interviews and the collection of documents and public web site information. The interviews were transcribed and field notes were recorded for each interview as well as for the collection of information from the documents and web sites. The interviews focused on participants' sense of community and the organizations' assets, gaps, and desires for collaboration and online networking. Documents and informational materials offered by the participating staff were collected to help determine the available resources, missions, and activities of each group. Similar information was collected from the public web sites associated with local groups or programs.

The interview participants also completed an eight-question sense of community survey (See Appendix B, adapted for the local cancer survivorship community from the brief sense of community index[129]). The survey includes a free response sentence completion for: "The middle Tennessee Cancer Survivorship Community…" This same survey was given to each participant in the online community design phase at the beginning of their participation in the study.

Analysis

In-process analysis of the data collected during this phase informed the purposive sampling and creative process for the subsequent online community design phase. The in-process analysis consisted of theoretical field notes recorded in-line with the interview transcription or general field notes, along with initial organization of high-level categories and themes. This phase of the study was essential to make contacts in the community, to diagnose the current communication and collaboration strengths and challenges, and to prepare strategies for including these groups and individuals in the collaborative design phase.

After the completion of the design process, NVivo, a qualitative software analysis program, was used to analyze the interviews, field notes, and survey free response answers. Each interview, ranging in length from an hour to an hour and a half, was transcribed and loaded into the NVivo software. Using a grounded theory methodology, codes were assigned to organize the data into categories and themes to define the types of membership and resources in the local cancer survivorship community. A second analysis of the interview data was used to identify themes and categories within each of the four sense-of-community dimensions. The sense of community index survey responses were analyzed with descriptive statistics, including the average scores and standard deviation.

The full details of this grounded theory analysis are described in the next chapter, prior to each relevant section of the results.

Collaborative Design Process

Data collection

Throughout the design process, data were collected and analyzed iteratively for both the collaborative process and the software design. At the end of the design phase, an in-depth, qualitative analysis was conducted on the overall collaborative design process.

Several times during the design process, cancer survivors and professional participants came together to discuss the current and future directions of the online community functionality, content, and concepts. Individual meetings with participants also guided the design of the online community. I audio recorded and transcribed the group design sessions for both professionals and survivors (conducted separately), and I recorded written field notes during and after the meetings. I also recorded field notes during and after the individual meeting with the participants. I kept a journal of ongoing field notes to provide an extensive log of my observations, experiences, and ideas throughout the collaborative design process. A full description of the design sessions and data collected throughout the process is included in the next chapter, prior to each relevant section of the results.

Prior to joining the collaborative design process, the participants completed the eight-question sense of community survey, if they had not already done so in the key informant interviews. The cancer survivors and family/friend participants also completed a short demographics survey. At the end of the collaborative design, the participants completed a twelve-item collaborative function scales survey.[59]

Analysis

Similar to the pre-design ethnography phase, in-process analysis consisted of theoretical field notes recorded in-line with the design session transcriptions and general field notes, along with initial organization of high-level categories and themes. The in-process analysis helped to guide each step of the collaborative design process, moving from initial ideas to priorities to early design functionality to the final design. The informatics design model for synthesizing the community's wisdom, presented in part three of the results, was developed out of the in-process analysis.

After the completion of the design process, I imported the field notes from the design sessions and the log of my daily notes as sources in Nvivo. I analyzed these notes using grounded theory methodology to discover categories and themes of the collaborative, creative process. I iteratively coded and labeled the data and continually arranged and re-arranged these codes in hierarchical categories. A full description of this analysis is included prior to the fourth section of the results chapter. The collaborative function scales survey responses were analyzed with descriptive statistics, including the average scores and standard deviation.

Methods for Trustworthiness

Trustworthiness of this study was assessed using the criteria for trustworthiness described by Lincoln and Guba for qualitative research.[111] In the naturalistic paradigm of qualitative research, the criteria of credibility, transferability, dependability, and confirmability are comparable to internal validity, external validity, reliability, and objectivity in positivist research.

The following strategies were used to ensure trustworthiness of the study: 1) triangulation of sources and methods, 2) prolonged engagement and persistent observation, 3) member checks, 4) reflexive journaling and natural history of the research, 5) purposive sampling, 6) negative case analysis, and 7) peer debriefing.

Triangulation of Sources and Methods

Triangulation of sources and methods helps to ensure the credibility of the study by representing multiple constructions of reality among the participants. The triangulation of methods also helps to improve the confirmability of the study by providing multiple sources of data which help demonstrate that the findings accurately represent the participants' perspectives, rather than the researcher's biases.

During the pre-design ethnography a variety of methods were used to gather information, including interviews, sense of community index surveys, written free response sentence completion, collected documents, and public web sites. Likewise, various members of the cancer survivorship community were included, such as cancer survivors, family and friends, clinicians, community support professionals, and researchers. This approach to triangulation follows the ecological-systems theory framework of the study by targeting various ecological levels of the community.

During the design phase of the study, the triangulation of sources continued with this ecological framework of the survivorship community by including the same range of participants. The triangulation of methods used to collect and analyze data during the design phase included a variety of group design sessions with professionals and survivors, individual meetings with participants, email and phone design feedback, detailed field notes, testing of the prototype system, and collaborative function scales survey.

Prolonged Engagement and Persistent Observation

Prolonged engagement and persistent observation were critical to establishing credibility in this study. The collaborative design process took place over the course of eight months, during which time I worked closely with the participants in groups and individually. I also participated and volunteered at a number of programs and activities in the community throughout the duration of this study. The study-related and other community interactions helped me build trusted relationships with the participants, which benefited the design collaboration and future partnerships for the online community. As will be discussed in the results chapter, I became ‘someone who gets it’ in the local cancer survivorship community.

Member Checks

Member checks helped prevent misinterpretations of the data by discussing or reviewing the analysis and findings with the participants. During the collaborative design phase, the design directions and in-process analysis were continuously shared with the participants through emailed reports and feedback, individual meetings and conversations, and at each group design session. Aspects of the initial analysis from the key informant interviews were incorporated into the discussions in the first group design sessions and the individual design meetings with those participants. The final group design session and individual meetings specifically focused on feedback on the overall design process. A limit of the member checks in this study is that they were limited to the iterative, in-process analysis, and formal member checks were not conducted at the end of the completed grounded theory analysis.

Reflexive Journaling and Natural History of the Research

Extensive field notes, including methodological notes, theoretical notes, and personal notes were recorded throughout all phases of this research. I recorded a reflexive journal on as many experiences as possible during the study. This journaling process included the sources and inspirations for any design ideas that occured to me during the course of the development, as well as my current thoughts and challenges for the collaborative process. My detailed notes increased the dependability of the study by providing details of the interpersonal interactions and my own internal thought processed that occurred. The reflexive journals also helped make evident my own biases and motivations that influenced my ongoing facilitation of the collaborative process as well as my interpretations of the data.

Purposive Sampling

Purposive sampling occurred throughout all stages of this study by including key members of the local community and by including different types of individuals, such as survivors, family and friends, researchers, community professionals, and clinicians. Other types of individuals or groups identified during the study were continually sought out and included in the collaborative design process. Purposive sampling allowed for rich data to be collected and provided opportunities for thick descriptions of the participants' experiences in the community and in the collaborative design process. This sampling strategy helped to provide detailed descriptions that allow others to judge the transferability of the online community design process to other local cancer survivorship communities or to other heath or community interests.

Negative Case Analysis

During the pre-design ethnography, I interviewed key informants in the community who do not participate in a 'tight-knit' network of other cancer professionals, as well as those who do feel a part of such a network. These individuals either choose not to participate or do not participate due to isolation and limited ability to connect. During the analysis of the interviews, I highlighted several of the negative components of the community, in addition to the many successes. The combination of these perspectives improves the credibility of the pre-design phase of the study.

During the design phase, I observed which aspects of the online community got the participants excited, and I also encouraged discussion of design features about which someone expressed concerns. I also invited participants who could not attend the group design sessions to contribute feedback through individual meetings and conversations. This approach helped include the perspectives of participants who had different and busier schedules.

Peer debriefing

Throughout the study, the preliminary categories, grounded theories, and design approaches were discussed with a fellow graduate student who also uses qualitative methods in the development of informatics systems. The peer debriefer also observed and assisted with many of the group design sessions. The extent to which this discussion was formal and more informal varied throughout the study. However, we had several critical in-depth discussions during the early organization of the categories and themes in the grounded theory analysis after the final design sessions. This process of peer debriefing helped me safeguard the confirmability of the study by bringing to light my assumptions, clarifying my interpretations of the data, and suggesting other possible ways to organize the data.

CHAPTER IV

RESULTS

The results of this research are presented in four sections. Each section addresses a different research question/aim. The relevant background and description of the research activities are presented at the beginning each section, followed by the qualitative analysis. The detailed descriptions of the background and activities provide the context in which to view the results.

Each of the four results sections concludes with a summary and discussion in which the implications for informatics design and development are emphasized. Additionally, initial commentary is woven throughout the presentation of the data and illustrative quotes. Chapter 5, Discussion and Conclusion, synthesizes all four section discussions into an overall, integrated discussion of the results.

The first section of the results focuses on “Defining the local cancer survivorship community.” This section presents the themes and categories that define the local cancer survivorship community, based on the key informant interviews and survey free response answers.

The second section of the results is the “Sense of Community in the Middle Tennessee Cancer Survivorship Community – Strengths and Opportunities to Improve.” This section presents an analysis of the sense of community prior to the start of the design phase. Quantitative results from the sense of community index survey complement a detailed qualitative analysis of existing strengths and challenges in the community. Six opportunities to improve the local cancer survivorship through an online community are presented and discussed.

The third section of the results presents the final design components of “CanConnect: The Cancer Community Connection of Middle Tennessee.” The online community design is outlined through screenshots and text descriptions of each component. The components are discussed in terms of the previously identified opportunities to improve the cancer survivorship community. An informatics model for synthesizing the local community’s wisdom of cancer support resources also is presented in this section.

The fourth section of the results presents “The Community Discovery Framework: A Relationship-based Approach to Discover and Develop Local Community Partnerships for Informatics Design.” This framework outlines seven elements of the collaborative design process that emerged from the qualitative analysis of field notes and design session transcripts.

While the four sections of the results are presented independently, they all work together to form a complete set of findings and conclusions, which are discussed in the following chapter.

Results 1: Defining the local cancer survivorship community

Introduction

Background

This study began in Spring of 2007 with the vision to collaboratively create "an online community for the individuals and groups in the local cancer survivorship community to support each other in their shared needs and goals." The foundation for this online community lies in the existence of the so-called "local cancer survivorship community." But what does that actually mean? Does this community actually exist in the real-world? Who are these individuals and groups and what are their needs and goals?

No standard definition of a "cancer survivorship community" exists in the literature or in practice. The National Cancer Institute defines the terms "cancer survivor" and "cancer survivorship research," but not in terms of the *community*.[22] Additionally, cancer advocacy initiatives may express efforts in terms of activating volunteers or activating the community. Yet still, there is no clear and formal understanding of who and what this community includes. My previous cancer support research efforts, volunteering in local community, and knowledge of the cancer support literature provided me with an initial, but vague, sense of the Nashville-area community members whose passion and work focuses on cancer survivorship and supportive care.

This background provides the context to the first phase of this research, which seeks to formally define and understand the local cancer survivorship community in which the proposed online community will be developed.

Contacting Key Informants

In order to lay the foundation for the collaborative design project, I began by discovering and engaging key informants in the local community who focus on cancer survivorship and supportive care. Most of these professionals and advocates also continued with the online community design collaboration, but first I set out to understand in more depth what they do, what motivates their work, and the other individuals and organizations in the community with whom they connect and partner.

From September through November 2007, I contacted 40 individuals about the study and was able to schedule and conduct a total of 18 interviews with 21 key informants from cancer centers and community organizations. Purposive sampling using both publicly available directories and recommendations from community members ensured diverse participation from different types of organization representatives. Each initial interview led to recommendations of participants for subsequent interviews.

The types of organizations from which participants were found were cancer centers/hospitals, cancer non-profits (for support, advocacy, and prevention), the state cancer coalition, regional affiliates of national non-profits, and cancer-type-specific organizations.

The types of the individual participants included an oncologist; patient education coordinator; survivorship researcher; social worker; non-profit executive director/program coordinator; cancer survivor advocate; advocacy program manager; cancer center outreach coordinator; cancer center community education director; cancer disparities expert/director; state coalition staff; cancer center web master; support group leader; and oncology nurse.

Of the 22 participants interviewed, 10 were associated with the cancer center in my own academic medical center institution. The common location and affiliation made connecting and scheduling these interviews relatively straightforward. With a large cancer center, there are many different sub-groups, roles, and perspectives to include, but I made a conscious effort also to reach as many other groups in the community as possible. With September and October being busy months for many people who work in the local cancer community, schedule conflicts prevented some planned interviews from being conducted.

Interviews, Surveys, and Collected Artifacts

The interviews focused on participants' sense of community and the organizations' assets, gaps, and desires for collaboration and online networking. All but three interview participants also completed an eight-question sense of community survey (adapted for this context from an existing tool), along with a small box to complete the sentence: "The middle Tennessee Cancer Survivorship Community…" (Appendix B). This same survey was given to each participant in the online community design phase at the beginning of their participation in the study. A total of six cancer survivors, four family/friends and fifteen additional professionals joined at this point in the study (one of whom did not complete the survey), for a total of 33 professional surveys and ten survivors/family/friends surveys, or 43 total completed surveys. Of the 43 total surveys, 39 participants answered the free response sentence completion question. Appendix C contains the demographics data collected from the survivor/family/friend participants; no written demographic data was collected from the professional participants.

In addition to conducting the interviews and surveys, I collected samples of information and support resource materials from the participants and their organizations, as well as publicly available materials. These materials included printed and online documents; existing resource directories; lists of locally funded grantees; clinical trials listings; organization partner listings; and various web-based searches. A more complete description of this community discovery process is included in section four of the results.

Defining the "Middle Tennessee Cancer Survivorship Community"

In order to begin to conceptualize the "Middle Tennessee Cancer Survivorship Community," a synthesized definition of the community was created using the community members' own words. The NVivo qualitative software program was used to assign a category code for each word and phrase in the free response text from the 39 survey participants (see Appendix D for full responses). Using a grounded theory approach, these words were assigned into themes and sub-categories based on their meaning or grammatical structure. This coding allowed related phrases to be grouped together, such as all adjectives or all types of organizations. Appendix E contains the excel spreadsheet that includes the original phrases and their assigned theme and category.

This categorization of phrases provided the skeleton to create a synthesized definition of the community by incorporating the words and phrases of many individuals. New sentences were created by stepping through these categories and using as many of the distinct phrases as possible, with a minimal number of filler words added for completing the sentence structure. After all of the sentences were created, a single word label was added to describe that sentence.

Table 4.1 contains the resulting definition of the Middle Tennessee Cancer Survivorship Community using the words of local cancer survivors, family, and medical/community professionals:

Table 4.1. Definition of the Middle Tennessee Cancer Survivorship Community

Theme:	The Middle Tennessee Cancer Survivorship Community...
is comprehensive	It is a comprehensive collection of committed individuals and organizations that come together through both formal relationships and partnerships as well as the common thread they share being touched by/involved with cancer.
is multi-level	It is a large, multi-level network made up of many loose connections-each one offering something special and unique-with small, but strongly bonded groups at its core.
is growing	It is growing, developing, and improving, with members who are active and eager to help, with good intentions as they work hard and collaborate towards a goal in the best interests of survivors.
is fragmented	While this is encouraging, the community still is segregated, fragmented, and territorial, with poor communication and a lack of coordination and awareness, which leads to misinformation and duplication of efforts.
includes individuals	It is made up of many individuals from all walks of life including, but not limited to, cancer patients and survivors at all points along their journey (recently diagnosed, in treatment, remission, life after cancer, long-term survivors); men and women of all ages from children, to teens, to adults; advocates, families, friends, and community members such as students, religious leaders, and others; and the medical and community professionals who serve them-everyone who works as doctors, nurses, oncologists, social workers, nutritionists, counselors, physical therapists, sexual health experts, mental health professionals, psychologists, clinical trial coordinators, caregivers, and outreach workers.
includes organizations	These individuals participate and/or are employed by health-care, support, and community organizations including, but not limited to, adult and pediatric survivorship clinics, medical centers, cancer centers, hospitals, medical service providers and facilities; academia, research groups, and community medicine; support groups, advocacy groups, programs, the state coalition, and cancer-specific non-profits; broader community non-profits and agencies, general supportive services, charities, churches, senior centers, women's and men's groups, and others.
includes locations	The community members include those who are local in Nashville, Davidson County, and surrounding counties, as well as state-wide, national, worldwide, and online.
includes actions	These individuals and organizations strive to meet needs of survivors and serve communities in need by caring, educating, informing, offering opportunities, and supporting each other by working together, true sharing of resources, sharing moments of happiness, understanding when things go bad, and being a source of strength.
includes resources	The resources provided by the community need to be available and easily accessible for both cancer-specific and psychosocial needs including, but not limited to, life after cancer, long-term effects, sexual issues, cancer prevention, screening, and advocacy; as well as housing, transportation, insurance, information, outreach, philanthropy, and what to expect.

The themes in Table 4.1 guided the creation of a single sentence that captures the essence of all nine synthesized sentences, as shown in Figure 4.0.

> “The middle Tennessee Cancer Survivorship Community is the comprehensive collection of many committed individuals and organizations, local and beyond, who have been touched by cancer and who strive to meet the needs of cancer survivors and each other by providing resources and forming relationships in a growing, multi-level network that is strong and active, but also is fragmented and territorial, leading to a duplication of efforts.”

Figure 4.0. Single Sentence Definition of Local “Cancer Survivorship Community”

This definition captures the diverse aspects of entire community, grounded in the original words of the community members. While based on the middle Tennessee community, this definition may serve as a general definition of a “local cancer survivorship community” to complement the existing definitions of “cancer survivor” and “cancer survivorship research.”

The process applied to reach this definition also may be applied to defining other local-based communities of interest and practice in which there is no previously agreed up definition of that community. The goal is not to capture every single element of the community. Rather, this approach gathers responses from a variety of sources to create a working definition that can guide further initiatives and analyses of this community.

Defining the Community: Members, Programs, and Resources

From the synthesized definition of the middle Tennessee cancer survivorship community, two of the most telling adjectives used were “comprehensive” and “multi-level.” Even in the relatively short, written responses, the participants described a diverse range of community members, programs, and resources. The responses also show that while there are many strengths of the community, there also are challenges and opportunities to improve. The eighteen in-depth interviews with key informants were analyzed using a grounded theory approach in order to further understand these aspects of the community. This analysis focused on categorizing the themes of the diverse components that make up of the middle Tennessee cancer survivorship community.

Each interview, ranging in length from an hour to an hour and a half, was transcribed and loaded into the NVivo qualitative analysis software. Each paragraph was assigned one or more codes and the emergent categories and themes were organized and re-organized iteratively throughout the course of the coding process. Although the survey free response definitions had already been coded, the interview analysis began from scratch and not constrained by these categories (although the themes clearly overlap and naturally influenced my approach to coding to some extent). In addition to the interview transcripts, additional field notes recorded about publicly available organization information and community events were also coded as part of this process.

Three themes are identified as contributing to the “comprehensive collection” that comprises the middle Tennessee cancer survivorship community:

1. People (Types of Individuals and Types of Organizations);

2. Activities (Programs/Services and Community Events); and

3. Tangible Resources

Within each theme and its sub-categories, the data are presented and discussed in terms of how and why a flexible and inclusive definition is needed for effective support of the cancer survivorship community. Illustrative quotes from the interview participants describe the reach of the cancer survivorship community throughout many aspects of the medical, non-profit, and general public community in middle Tennessee. Following the presentation of these themes, the implications of these findings for the informatics-based design of an online cancer survivorship community are discussed.

1. People

1.a. Types of Individuals

A cancer support professional began her interview by describing the membership of her community-based organization:

> Folks anywhere along the continuum, whether newly diagnosed, in treatment, chronically in treatment with metastatic or recurrent illness, post-treatment, survivorship, end-of-life or bereavement/grief; anyone who has ever been touched by cancer or who loves someone with cancer.

The phrase, “anyone who has ever been touched by cancer or who loves someone with cancer,” is striking in its simplicity and inclusiveness. This includes all cancer patients and survivors, as well as family, friends, children of survivors and others. This view of membership in the cancer survivorship community fits the National Cancer

Institute's inclusive definition of cancer survivor, which includes family, friends, and caregivers.[22] However, the openness and flexibility of this phrase leaves the door open (literally and figuratively) for any individual to *self-identify* as a member of this support community. This specific, yet broad, view of such individuals helps to identify members of the cancer survivorship community without defining an overwhelming number of characteristics.

More specific descriptions of the diverse range of individuals were also addressed throughout the interviews. The participants described cancer survivors and caregivers in terms of their age, gender, race, ethnicity, sexual orientation, socio-economic status, and other demographic characteristics. Each type of individual was described as presenting their own specific needs for supportive care. For example one leader of a community support organization described individuals whose lack of transportation and coping style represent the target audience to reach:

> … a patient needed to be going for treatment, and they decided not to go because they didn't know how they were going to get there, and they were too proud to ask for help. Those are the people we want to reach, who don't know it's there or are too proud to ask.

Additionally, a range of staff and professional individuals were identified as key contributors to the community. The clinical care team, private doctors, administrators, cancer registrars, grant committee members, lay health educators, life coaches, patient education coordinators, graphic designers, researchers, students, and others medical and community professionals all were identified as relevant members of the community. More importantly, not only are they described as providers of support for survivors, these professionals also are included on the receiving end of support:

> I think there is a very big need in our cancer community for self-care for health-care professionals, for not just health-care professionals, but for oncology-related professionals, whether it's floor nurses, or people at the sign-in desk, or social workers, or whatever that is … People are invited to come here to participate in our stuff, just for their own self care. It surprises people to know that's available for them, and we really haven't had many people take advantage of it. We've had a couple of floor nurses come for laughter group or guided imagery, which is great…

As this quote illustrates, some individuals may not even realize the extent to which they are welcome as members and participants in the local community. The notion becomes increasing clear that a general breakdown of patients, caregivers, doctors, nurses, and support group members represents only the tip of the iceberg in defining the individuals who make up the cancer survivorship community. Defining the community with a too narrow view of the individuals involved would leave out many of those who are considered, or consider themselves to be, part of the community.

1.b. Types of Organizations

In addition to various types of individuals, organizations and groups that support and employ these individuals extend throughout the community.

Organizations were identified within four areas: 1. Academic and Community Medicine; 2. Cancer Support; 3. Special Interest Groups; and 4. Community Influencers.

Academic and Community Medicine

Academic and Community Medicine organizations and groups identified are cancer treatment providers (cancer centers, clinics, and physician networks); medical centers and clinics; mental health clinics; academic and community-based research teams and networks; medical resource councils for non-profits (primarily oncologists and practices in middle Tennessee); and the oncology nursing society.

Cancer Support

Cancer Support organizations include multi-dimensional support organizations, support groups (for survivors and caregivers), and organizations or groups targeting a specific cancer type (e.g. breast cancer, pancreatic cancer, or childhood cancer).

It is important to note that medical and support organizations often are multi-dimensional and include an integrated mix of support groups, services, and initiatives. For example, a supportive care professional in a cancer center described their patient education efforts:

> Patient education, also advocacy, and outreach, it's all tied in together.

A representative for the Office of Minority Affairs in the same cancer center described its office in the following way:

> Its specific function is issues related to cancer disparities that affect racial, ethnic, minority populations are addressed, not only within the cancer center, but in the community beyond the cancer center, so this office functions in several ways as part of a comprehensive cancer center, research, education and awareness, clinical access, informing professionals and the lay community.

The above example demonstrates this multi-dimensional nature of the office and also touches on the inclusion of lay community members in the local cancer community. This organization representative further explained the reach of multi-dimensional cancer support organizations into the general public community:

> Even though we're focused on cancer and people of color and the medically underserved, it reaches beyond that. So it has to reach beyond that because the issues that cross cut in cancer disparities go beyond that specific cancer site and so it's necessary to have an interface with other areas dealing with health or education of other kinds of things that just on their face, if someone were to say "well, what does this have to do with cancer?"…

Organizations identified as special interest groups and community influencers further illustrate how the cancer survivorship community includes the general public.

Special Interest Groups

Special Interest Groups identified as relevant to cancer in the local community include the faith community (churches and other religious settings), senior centers/senior citizen groups, men's/women's groups, cosmetic associations, student groups, and day care centers.

These interest groups provide services (e.g. cosmetic workshops for cancer survivors) as well as fellowship and support (e.g. the faith community). Some community organizations offer a connection to a target demographic whose areas of interest align with the cancer community (e.g. day care centers hosting cancer prevention programs).

Community Influencers

The category of Community Influencers includes organizations in the local community such as the media (local TV and radio shows, publications), religious leadership (clergy, the interdenominational ministers fellowship), the research-based Community Networks Program, government-based organizations, NAACP, Nashville Black Chamber of Commerce, restaurant chains (for fundraisers), businesses/corporations/HR Departments (whose employees may be cancer survivors), and music industry partners.

These influential organizations play an important role as partners in helping the cancer community reach with a wide audience. Many of these organizations provide networking with other leaders in the community or offer opportunities to spread beyond organizations that are primarily cancer-focused or health-based. For example, one cancer support organization representative described the development of their Cancer in the Workplace educational DVD:

> There was a law firm with a partner, a young person, vibrant, who had cancer. They asked us to talk with the partners and how to be supportive to the rest of the staff and how to distribute information in an non-obtrusive way, but very caring way, on what was going on with him, and we started developing that project, we realized discrimination in the workplace is alive and well, not there, but in other places. But we developed the DVD. … We sent about 5000 across the state to organizations and businesses to their HR department. You can order it on our web site people can order it as well… It's designed for managers to watch if you have an employee in the workplace and help them.

This example illustrates how community organizations invite cancer organizations into their membership base, and how cancer professionals also take initiative to reach into these influential organizations. These partnerships and campaigns extend the reach of the cancer survivorship community further into the general population.

2. Activities

2.a. Programs/Services

Organizations in the local cancer survivorship community provide and participate in a variety of support programs and services for cancer survivors and the general public. The local organizations each offer a variety of cancer support programs throughout the year.

Programs and services were identified in four areas: 1. Personalized Supportive Care; 2. Educational Programs; 3. Fun and Informal Programs; and 4. Networking Programs.

Personalized Supportive Care

Clinic-based and community-based organizations offer personalized services that complement the curative focus of primary cancer treatments. As opposed to group activities, these are "things done to or for a person."

The clinical support services identified include cancer survivorship clinics; clinical trials; second opinions; oncology rehab; physical therapy; lymphedema programs; speech therapy; cognitive rehabilitation; nutritionists; psychologists; and symptom control.

The psycho-social support services identified include exercise programs; complementary and alternative medicine; healing touch; massage therapy; family risk; fertility services; social work; college scholarships for survivors; smoking quit line; patient housing; transportation; financial counseling; and toll-free information numbers.

While some of these services, especially the clinical services, primarily serve the clients within a specific organization, other support programs are free to all cancer survivors regardless of where they were treated. For example, the free oncology social work and nutrition consultations offered by one local non-profit provides free-standing services for the entire community:

> That was the next thing we looked at and said, ‘what’s the next need?’ It amazes me, most clinics do not have a licensed dietitian on staff, so there was some interest in it from clinical staff and doctors to say we would refer if you all had a dietician, we would refer and we would love that. So our dietitian covers, her services are available like mine are to anybody, she regularly goes to private-six different clinics and treatment centers … to see patients.

Not only are these services open to anyone in the community, but the organization staff actively reaches out to extend their reach beyond the physical walls of their organization to bring the services to the patients in the patients’ own environment.

Educational Programs

Educational programs identified for cancer survivors and the public include: targeted classes and workshops (e.g. cancer-related fatigue), speakers and presentations, volunteer and advocate training, cancer resource libraries, and edutainment (education + entertainment).

Fun and Informal Programs

While many programs in the community directly address specific patients needs and concerns, several programs provide support through fun and informal activities.

These activities include humor and play workshops, songwriting workshops, cooking classes, art classes, edutainment (education + entertainment), planting a healing garden, camps and retreats, and cosmetic programs.

The leader of a community support organization explained the value of this approach to cancer support when describing a cosmetic program offered in several local venues:

> … group sessions in the Nashville area for women diagnosed with cancer experiencing side effects of disease and treatment, hair loss, skin changes, that sort of thing. … a kit that has all of the cosmetics and make up for a 12-step beauty makeover. It's a very upbeat program, and we've had a lot of feedback from patients who really enjoyed that, because it's different, you know, than going to a support group. It was fun.

The cancer survivorship community provides these opportunities for its members to come together and "hang out" without focusing on their illness. The outside-the-box support programs in the community further illustrate the diverse range of the cancer survivorship community components.

Networking Programs

Networking Programs facilitate connections between individuals and/or groups in the community. The networking programs identified include patient advocacy programs, outreach programs, camps and retreats, health fairs, patient-to-patient mentoring, support group meetings, volunteering opportunities, and survivorship interest/working groups, grant-making programs, and the state comprehensive cancer control coalition.

These programs help connect cancer survivors with other cancer survivors (e.g. support groups), cancer survivors with community professionals (e.g. health fairs), professionals with other professionals (e.g. the state coalition), and the general public with survivors and professionals (e.g. volunteering). These programs show the diversity not only of the individual components of the cancer survivorship community, but also the wide range of relationships and partnership opportunities among the community members.

2.b Community Events

In contrast to programs and services, which are ongoing activities, community events describe special or annual events in the community. Another distinction of categorizing community events is that they typically aim to bring the general public together with cancer survivors and organizations.

Community events were identified in three areas: 1. Celebrations; 2. Personal Significance; and 3. Specialty Benefits

Celebrations

Celebrations identified include National Cancer Survivors Day, church service survivor celebrations, holiday parties, cancer awareness week/month celebrations, and organization or program anniversaries.

These events are a time for the local community to come together to celebrate cancer survivors and survivorship, recognize long-standing community organizations and programs, and for cancer survivors and those who care for them to celebrate the holiday season together.

Personal Significance

Certain events in the community are initiated from an individual's personal passion or the personal significance of their close relationships.

Examples of these public events identified include a specialty license plate drive honoring a loved one, individual middle Tennesseans who ride or walk across the country to raise cancer awareness or to honor a loved one, concerts and other personal fundraising efforts to honor a loved one, and fundraising events and concerts to benefit a particular cancer patient.

These events are especially significant to the heart of the cancer survivorship community, because they show how a single passionate individual can make an impact in this community. The events with a personal significance often represent the cancer community to the general public through publicity and awareness efforts associated with these personal stories.

Specialty Benefits

These events are based around a certain activity or unique format typically designed to raise funds or awareness for a cancer organization or cause.

The types of specialty benefits identified are benefit concerts, sporting events, city-wide rides and races, competition-based awareness events, cancer survivor art exhibits, fashion shows, and template-based fundraisers.

Nashville, known as the Music City, has a rich history of country music and has strong ties to the music industry. Many local events and benefits feature musicians as celebrity participants or as featured performers. These benefit events allow the cancer community to extend its reach into community through the local culture and specialty niches of the community (e.g. athletes, artists, etc.).

3. Tangible Resources

In addition to the people and activities in the community, there also are a range of tangible resources that support communication and interactions between members of the cancer survivorship community. These resources are physical or online artifacts and documents that can be held, read, collected, and shared.

Tangible resources in the community were identified in five areas: 1. Cancer Awareness; 2. Informing and Connecting; 3. Education; 4. Personalized Forms; and 5. Sensory

Cancer Awareness

Cancer awareness tangible resources identified include license plates, state and metro government proclamations, the state cancer plan, and cancer survivor stories and photos.

Informing and Connecting

Informing and connecting tangible resources identified include organizations' calendars, newsletters, meeting minutes, mailing lists, marketing materials, patient resource guides, patient referral plans, cancer speakers lists, business cards, and flyers.

Education

Educational materials identified include books, brochures, magazines, breast self-exam cards and key chains, a patient handbook, printed web documents, videos and DVDs, advocate training manuals, and research journals.

Personalized Forms

Personalized forms include a customized membership plan for members of a community-based support organization, membership application forms, and forms to add a new resource to a listing/guide.

Sensory

In contrast to information-based tangible resources, sensory resources are those that affect an individual through one's senses such as touch, taste, and hearing. Examples of these resources identified in the cancer survivorship community are food at meetings, music, and hugs.

The role and value of hugs were described by one community support professional:

> We get to start and end our day with hugs, we're incredibly lucky… it's really connecting with other people who are walking similar paths that make the difference.

From my own participation in the cancer survivorship community during this study, I found that giving and receiving hugs are natural parts of interpersonal interactions both among professionals and survivors. This "standard greeting" for many members in the community illustrates how the community finds support not only in large events, educational programs, and printed documents, but also through meaningful, physical contact without the need for spoken words.

This quote also illustrates a key point that brings the discussion of tangible community resources full circle back to the individuals that make up the community: the people are the true resources in the community that make the difference. This concept of the people being the greatest resources was stressed during the interviews in the context of survivors connecting with each other, as well as for the success of professional collaborations and partnerships.

Section Summary

From the synthesized definition in the participants' own words along with the analysis of the interviews, it is clear that the middle Tennessee cancer survivorship community does indeed exist. Not only does it exist, but it is comprehensive, multi-dimensional and extends in many ways throughout the local middle Tennessee community. The inclusive concept of "anyone who has ever been touched by cancer" opens the door for nearly any individual to find a connection into the community. Whether through a close personal relationship with a cancer survivor or through more indirect relationships, such as employee relations or fans at a benefit concert, these individuals all can be considered members of the local cancer survivorship community.

Several of the community components identified were surprising. The extent of the music industry's contributions to cancer survivorship, through benefit concerts, songwriting, and other initiatives, was not something I expected from reviews of the existing local resource guides and the cancer support literature. The value of fun and informal activities, in contrast to formal support groups, is another aspect of the community that often is overlooked. Similarly, discovering the significance of giving and receiving hugs and that the people are the key resources of the community helps to underscore the importance of flexibility in defining what is a resource in the community.

The diverse range of components in the community identified by the participants demonstrates that there is no single, agreed upon criteria for defining the cancer survivorship community. Each of the participants contributed or described something unique about the community. This lack of agreement highlights the importance of efforts to clarify and collaboratively define the community in order to begin to work together more cohesively as a community to support cancer survivors. The diverse perspectives suggest a natural opportunity for web-based social networking technologies to bring the comprehensive collection of members together in a centralized, shared space.

Compared to printed resources guides, web-based technologies also allow for flexibility in defining resources for inclusion. Organizations, events, programs, and people all can be listed in the same information system. Without being limited to a certain number of printed pages, an online community can include the many different components of the local community.

This research in defining the cancer survivorship community has additional implications for the design of an online community for cancer survivorship. It is important to be inclusive when defining the types of users and content allowed in the online community, and flexible in the requirements for participating. Also, the range of individuals and organizations discovered in the real-world community suggests appropriate and valuable partners to work closely with the online community. Also this research suggests that simply including listings of organizations as a whole may not provide enough information about the opportunities for support in the community. An online community can create awareness for more resources in the community by connecting users to the specific programs and events offered by each organization

Overall, the cancer survivorship community is comprehensive and is multi-dimensional. Support for cancer survivors extends throughout many aspects of the local community. However, the cancer survivorship community has not yet come together with a cohesive vision and message. In the next section of results, several specific opportunities are identified to improve connecting, cooperating, and creating awareness among individuals and groups in the middle Tennessee cancer survivorship community.

Results 2: Sense of Community in the Middle Tennessee Cancer Survivorship Community – Strengths and Opportunities to Improve

Introduction

The first step of this research defined who and what constitute the cancer survivorship community, and the extent to which support for cancer survivors extends throughout the local community. In addition to identifying the component parts, this study also seeks to better understand the interactions and bonds between these components, and how these individuals and organizations come together as a community.

Using the sense of community as the theoretical framework, a grounded theory analysis of the eighteen key informant interviews was conducted to examine the existing strengths and challenges in the local cancer survivorship community. This evaluation of the local community motivates the need and suggests directions for the design of an online community for cancer survivorship in middle Tennessee. The sense of community analysis also provides a baseline measure against which the live online community can be evaluated for impact and success.

The semi-structured interview questions were guided in part by the four sense of community dimensions (influence, membership, fulfillment of needs, and emotional connection) (see the interview guide in Appendix F). While the first half of each interview focused on the resources, services, and partnerships of the participants and their organizations, the second half of the interview focused on the participants' perceived sense of community. Additionally, near the conclusion of each interview, the participants were invited to share their initial ideas or interests for the design and purpose of an online community for the local cancer survivorship community.

The sense of community index completed by the participants, either during the interviews or before joining the subsequent design phase, provides further insight into a baseline sense of community measure. This survey was adapted for the middle Tennessee cancer survivorship community from the eight-item Brief Sense of Community Index developed by Long and Perkins[130] (see Appendix B).

Both positive and negative characteristics of the participants' sense of community were identified, demonstrating a variety of strengths, but also several challenges and room to improve. Six specific opportunities to improve the sense of community were identified from the interviews, and the implications for an informatics-based approach to address these opportunities are discussed.

Sense of Community in the middle Tennessee Cancer Survivorship Community

The sense of community for the middle Tennessee cancer survivorship, prior to the collaborative design process, is evaluated using both quantitative and qualitative analyses.

Brief Sense of Community Index – Quantitative Analysis

The quantitative analysis includes the categorization of the free response answers into positive and negative characteristics, along with descriptive statistics (mean and standard deviation) of the eight-item brief sense of community index. The responses are totaled over all 43 survey responses, including the 33 professionals and the 10 survivors and co-survivors. The free response definition was completed by 39 total participants.

Free Response Definitions

The synthesized definition of the local cancer survivorship community presented in the previous results section identified initial aspects of the community's strengths and challenges (Table 4.1). The strengths include the multi-level characteristics of strongly-bonded groups and unique offerings, as well as the sense of improvement and members with good intentions who work hard. The challenges include being fragmented, segregated, and territorial, with a duplication of efforts.

In addition to this overall synthesis of the free response answers, I evaluated the positive and negative aspects of each individual response in order to better assess the range of viewpoints. For each participant's free-text definition of the middle Tennessee cancer survivorship community I assigned one of four labels: 1. positive language; 2. negative language; 3; both positive and negative language; or 4. only neutral language. I used the label of neutral language when the response only included descriptive terms of the types of people, groups, and resources. The interpretation and assignment of response into these labels were carried out solely by the primary investigator after organizing the words and phrases into initial categories. It is significant to note that the survey instructions did not prompt the participants to use either positive or negative language in their responses. Table 4.2 presents the results of this analysis.

Table 4.2: Classification of Free Response Definitions

	Positive	Negative	Both Positive and Negative	Neutral
Number of Responses	9	2	13	15

This classification of the responses indicates that while most non-neutral responses were positive, a significant percentage included negative language. Twenty-two (22 of 39) responses were either positive or both positive and negative, while fifteen (15 of 39) were either negative or both positive and negative. Thirteen (13 of 39) individual responses described both positive as well as negative characteristics of the community in the same definition. These values indicate that while there generally are positive views of the community, the participants also are acutely aware of the challenges and areas of need in the community.

Eight-Item Brief Sense of Community Index

The responses from the eight-item brief sense of community index complement the findings in the free response definition. For each question, the participants responded on a five-point Likert scale with choices of Strongly Disagree (1), Disagree, Neither Agree nor Disagree, Agree, and Strongly Agree (5). Table 4.3 presents the mean and standard deviation for the 43 participants who completed the survey questions.

Table 4.3. Brief Sense of Community Index Mean and Standard Deviation

Q1-8	Needs	Needs	Members-hip	Membership	Influence	Influence	Emotional Bond	Emotional Bond
	I can get what I need in the middle Tennessee cancer survivorship community	The middle Tennessee cancer survivorship community helps me fulfill my needs	I feel like a member of the middle Tennessee cancer survivorship community	I belong in the middle Tennessee cancer survivorship community	I have a say about what goes on in the middle Tennessee cancer survivorship community	People in the middle Tennessee cancer survivorship community are good at influencing each another	I feel connected to the middle Tennessee cancer survivorship community	I have a good bond with others in the middle Tennessee cancer survivorship community
Mean	3.58	3.53	3.77	4.16	3.38	3.42	3.47	3.63
St Dev	0.85	1.00	1.07	0.81	1.08	0.85	1.05	0.90

All four sense of community dimensions had average scores that are slightly positive (over 3.0), but still showing room to improve (mostly under 4.0). While only descriptive statistics, these values complement the conclusions from the survey definitions (and, as will be discussed next, the interview discussions), indicating that there are many strengths in the local cancer survivorship community, but also opportunities to improve.

Sense of Community - Qualitative Analysis

While the survey responses provide an overview of the participants' sense of community, the interviews provide more depth into understanding why the participants express these views.

A grounded theory methodology was used to identify themes within each of the four sense of community dimensions. While the analysis is grounded in the data, the theoretical frameworks of sense of community and ecological systems theory helped guide the organization of the codes and categories into higher level themes. Examples of the community's strengths are balanced with examples of the challenges in each dimension. This data are presented to convey the range of both positive and negative perceptions in all four areas, as well as to provide insight into how and why the participants' perceptions of the community are formed. The implications for the design of an online community to improve the sense of community are discussed in each dimension. Following this analysis, six actionable opportunities to improve the sense of community are identified and discussed in terms of their online design implications.

1. Sense of Community Dimension – Influence

Influence occurs at all levels of the community: individual individuals taking initiative, interpersonal mentorship and networking, organizational resources, the collective voices of survivors, and legislative advocacy.

1.1 Individuals taking initiative

Programs in the community often are created based on the passion and personal interest of a particular individual or group. For example, a survivor or volunteer may propose an idea and make it happen:

> We had a volunteer come to us to bring us another event raising funds for breast cancer research, so sure, we'll take it, and we didn't design that one, but it's happened, so now we have two big things in September that are all about breast cancer.

This individual led the creation of a new community event that increased awareness and funds for a local cancer support organization. This example shows how a single person with a big idea can influence the annual traditions in this community.

Community professionals also take initiative to lead the creation of new programs in the community based on identified needs as well as personal interests:

> In the young adult area I really think we've taken some leadership in that. Another step. Not the only leadership, but some leadership in that… It's a particular interest area for us.

As another director of a community support organization explained the role of key individuals in developing new initiates in the local cancer community,

> Everybody talks about it, but what are we going to do about it. I think that a lot of times it takes somebody who will push, to make that push to go.

A single person who makes that push, with or without an official position, can be influential in this community.

1.2 Individual dedication and commitment

In addition to the first push to create a new program, certain members of the community maintain a continual influence through their constant dedication and commitment to efforts in the community. As the outreach coordinator at a cancer center explained,

> People ask me to partner with them. They're asking [my organization], but they're asking me as well, because they know I'm very committed to a project if I say I'm going to do it, to make it a

> success. I believe in all of their missions very much. They know if I'm involved, I keep their mission uppermost as well as ours. I feel very much like I'm a change agent in what I do. I don't take on a project unless I believe in it.

A community partner of the cancer center confirmed this statement, by describing this outreach coordinator and a fellow professional:

> She has a passion, she really cares about cancer… They're the people who make the difference. They take it that second mile.

1.3 Interpersonal mentorship

Individuals have interpersonal influence through personal mentorship, for example a cancer survivorship researchers who advise new researchers and students or an experienced professional who mentors new professionals who join the community.

A director of a community support organization describes her role in mentoring other individuals who want to create their own local support group.

> This happens a lot-people decide they want to start a support group in their hospital, and I get a lot of calls about 'tell me how to do this, we want to start it, and we know you do it and do it well'… so I spend a lot of team mentoring people about what works for us. Some of what works for us wouldn't work in a setting like that … but I'm happy to lend my hard earned wisdom, and I wish them well, and kind of be a consultant.

This example of interpersonal mentorship shows how experienced professionals influence the way in which new support programs are developed throughout the community.

1.4 Connectors and Networking

Certain individuals in the community are influential as 'connectors' through the relationships they have with many people and organizations in the community:

> On a professional oncology level, I see myself as a connector, because I have connections with all of the community organizations, patient support and policy like the [state cancer coalition]. I do community outreach to the community for community education, and also with support organizations.

Doctors also are key connectors between patients and community organizations, who can influence patients' use of support resources. A representative from a community support organization explained:

> My hope is we're going to reinvigorate that group of medical resource council to remember to mention it to their patients and families. There's something about when it comes from your doctor's office, there's an endorsement there that could be really powerful. We're working on getting those folks gathered and come through our new club to see the place and remind them what we're asking them to do.

In a similar way, trusting relationships between professionals increases their influence when referring potential community partnerships:

> If I get an email from somebody that said, '[S.A.] said to contact you,' then I know anybody that [S.] sends over to me, it's worth my time.

These examples illustrate the concept introduced in the previous results section that the people are the greatest resources in the community. The connectors in the community are especially valuable to enhancing trust and awareness between other members of the community.

1.5 Shared organizational resources

Certain organizations influence the community through the available resources that they can contribute to the efforts of other groups and individuals. One type of organizational resource is funding for local grants and programs or the funding of treatment and support for individuals in need. Four organization representatives described their grant-making processes, which range from formal, annual applications to individual appeals or proposals. Two of these organizations fund only breast-cancer specific projects. It is through the work of their local grantees that these organizations influence the community:

> Our grantees, they are out there on the front lines dealing with women who have been diagnosed, women who need mammograms and clinical exams, women who have gone through treatment. They are on the front lines of this disease, and I look at them-they're an extension of our promise, and our promise says we are going to empower people, ensure quality of care for all, we're going to energize science to find a cure.

However, money is not the only resource that organizations can offer other organizations in the community. Other influential contributions identified include providing meetings space for other groups, printed resource guides, resource libraries, as well as manpower for advocacy and volunteering.

1.6 Influencing the general public and government legislation

Beyond the influence an organization has on cancer survivors and other cancer survivorship organizations, the cancer survivorship community also influences other aspects of the local area community. One form of influence on the general public is educating groups and individuals about cancer survivorship (e.g. in the workplace) as well as about cancer prevention strategies. Cancer survivors, professional experts, and community organization representatives speak to groups on cancer education and prevention. These general community groups include students, women's groups, and local-based corporations.

Legislative advocacy is a major goal for some local organizations in the cancer survivorship community. These efforts include advocating to the local state government for policies and funding (e.g. smoke-free legislation), as well as on a national level in Washington DC.

1.7 Challenges for Influence

These examples show the many ways the community members perceive influence, from individual and interpersonal efforts to community-wide advocacy and education. While these strengths can be the foundation of further efforts, it is important to recognize that there also are many challenges to positive influence in the community, especially in the specific areas of survivorship and supportive care.

One challenge for influence by survivorship-focused efforts is that they still represent only small component of the general conversations on cancer in academia-led efforts. One cancer survivorship researcher described this challenge in the context of the state cancer coalition:

> I see a lot of activity that goes on, but it isn't well coordinated with a lot of the other groups that target survivors. That may also be because they have a different mission, of which survivorship is a part of it.

> They are mostly concerned with prevention and control. Survivorship is a different issue.

The focus on cancer survivorship, especially after treatment is complete, is a relatively recent emphasis for cancer care at a national level, and this is reflected in the local community as well. Related to less emphasis on survivorship in state-wide efforts, another challenge to influence in the cancer survivorship community is being new to the community and not being aware of how to exert influence. The coordinator of a community-based support program, in her position for only a month, described this challenge:

> …that might be that I'm new. I don't have any connections with the whole community yet, so I don't feel like-even if I did have something to say, I wouldn't know how to do it.

Other participants also describe that it takes time to develop the connections, experiences, and respect to have a strong say about what goes in the cancer survivorship community. This presents a challenge when combined with the frequent turnover of staff, which was identified as another characteristic of the local cancer survivorship community.

Finally, it is important to recognize that the influence exerted is not always perceived in a positive light by those who are influenced. The coordinator of a new support organization explained her experience on the receiving end of influence:

> People are good at influencing each other. Yes, and I think that can be for good and not for good. I don't think people realize how important their role is. Well, I've had an experience with a couple people … who have not been as welcoming … They expressed an unhappiness that we were doing things similar to their support programs.

This response illustrates that it is not just the existence of influence among support professionals, but the quality and type of influence that is significant to the perceived ability of people in the community to influence one another. This example shows that the influential members of the cancer survivorship community need to welcome the passion and interests of new individuals and programs while simultaneously encouraging these new members of the community to address the most needed gaps in the existing local support services. This 'dilemma of duplicate work' will be discussed further in terms of the six specific opportunities to improve the sense of community.

1.8 Summary of Influence

The participants described a wide range of ways that people influence the local cancer survivorship community. However, there is still room to build on these successes to bring a greater awareness to survivorship and supportive care efforts in the community. Additionally, the opportunities to improve co-operative and duplicative efforts should take into consideration the style of influence between the experienced and the rising people and programs.

1.9 Informatics Design Implications

Informatics systems such as an online community have several opportunities to improve the sense of influence in the local cancer survivorship community. An online community can provide a platform for individuals who take initiative to create awareness for their efforts and connect with potential partners. An online community that gives equal voice to all members may be especially valuable to individuals with a passion that are not associated with or employed by any existing support organization.

Furthermore, by including a diverse range of members, the online community can offer a platform for the collective voice of local cancer survivors and professionals to publicly engage local officials to influence legislation affecting the middle Tennessee cancer community. Similarly, the online community content can highlight cancer survivorship and supportive care, in order to create awareness and visibility for these topics among academic and community-based professionals.

The implementation of the online community should seek to engage the key connectors in the local community who are influential in making connections between various individuals and organizations. Furthermore, the design of the online community may offer social networking functionality that facilitates these individuals' ability to network and connect in the community. Similarly, the online community can help connect new members of the community to experienced survivors or professional mentors.

In these ways, the online community may become a symbol of influence in the community as a shared community resource that provides a variety of opportunities for other organizations' to enhance their own efforts. At the same time, it is important to be aware of keeping the online community a welcome and *positive* influence on others, rather than it being viewed as dominating or controlling. For example, if a local organization is interested in enhancing their own web site or developing a new online initiative, the online community and its representatives should find ways to support and enhance the organization's vision, while also suggesting natural partnerships with the existing online community. By considering its influence as extending beyond the boundaries of a specific web site, the online community may sustain a positive and respectful influence in the local cancer survivorship community.

2. Sense of Community Dimension – Membership

What does it mean to be a member of the middle Tennessee cancer survivorship community? McMillan and Chavis describe the dimension of membership as having five attributes: boundaries, emotional safety, a sense of belonging and identification, personal investment, and a common symbol system.[108] This analysis focuses on the community's boundaries, a common symbol, and a sense of belonging and identification as three attributes that an online community may be able to address.

The analysis identified a lack of clear boundaries that define the local cancer survivorship community, which allows for an inclusive range of members but also makes it less clear who is and isn't a member. Membership occurs in multiple levels and capacities. No common symbol was found that identifies a person or group as a member of the survivorship community.

2.1 Boundaries

The synthesized definition of the local cancer survivorship community presented earlier uses the inclusive phrase "anyone who has ever been touched by cancer." Yet, beyond this strategically ambiguous boundary of membership, no agreed upon, unifying boundaries were identified for this community. A range of boundaries were identified that classify particular sub-components of the community, and even these boundaries are not clear cut.

Even the language describing the boundaries between cancer patient and cancer survivor is used by different people in different ways. A cancer survivor advocate described the transition after treatment, before long-term survivorship.

> To me, there's an acute treatment, then there's a year where it's something else, not long-term survivorship.

A community support professional added that even post-treatment survivorship is not always a simple and clear boundary for patients,

> I'd caution you, when you do survivorship stuff, specifically targeting people post-treatment, how are you going to manage recurrence?

It is for this reason that prevention, both of initial cancers and of recurrence, can be considered an aspect of the cancer survivorship community. Similarly, local cancer survivors serve as key advocates for cancer awareness and prevention among the general public. However, another professional, who studies cancer survivorship and supportive care, more clearly defined the boundaries of survivorship from other aspects of the cancer community.

> … they do more cancer prevention, which is not survivorship, that's pre-survivorship… They are mostly concerned with prevention and control. Survivorship is a different issue.

Coupled with the various viewpoints on the phases of a patient's care and survival, the inclusion of "co-survivor" family and friends further complicate the boundaries of the community. One community support professional explained her feelings of membership in the community:

> I'm not a cancer survivor myself, but I do feel like a member of the community because of my experiences with cancer with loved ones, in a sense I am a survivor … and also now in my position here, I'm helping other people in their survivorship, so I feel a sense of belonging even though I'm not a survivor.

Other types of boundaries identified within the community include age (children, teens, young adults, and adults), gender (women's and men's cancers), cancer type (e.g. the breast cancer survivorship community), length of survivorship (e.g. long-term vs. newly diagnosed) and the different focuses of academia vs. community support.

Additionally, even the geographic boundaries of the "local" or "middle Tennessee" community are not universally defined. For example, while mostly focused on Tennessee, one cancer center representative described that they reach into southern Kentucky and northern Alabama as well. Professionals who primarily serve the Nashville area want to reach out beyond the local city:

> I wanted to get out more in rural, community. That's where I'm really trying to expand now, getting out more outside Nashville. Our mandate really is to serve the state.
>
> …we tend to be more focused on middle Tennessee, we need to know about what's going on in Knoxville, Jackson, Memphis, Chattanooga, and little places in between.

One participant described a more specific eleven county coverage area served by their breast cancer community organization. Yet, other professionals describe their roles participating in national cancer survivorship committees, and one social worker explained her role both nationally and internationally:

> So we'll pull geographically from a national base and the international base-this was a man in Italy whose mother lived here in the states, and he called and said, you need to help my mama, and of course we're happy to help

As seen in the earlier analysis of the diverse range of members, programs, and resources, this analysis further identifies the challenges of clearly defining the boundaries of membership in the local cancer survivorship community.

2.2 Common symbol

Similar to challenges of identifying the boundaries in the diverse community, I did not identify obvious common symbols shared by the entire cancer survivorship community. In some senses, cancer patients share the cancer diagnosis, treatment, and/or the completion of treatment as a rite of passage that serves as a common symbol. However, this symbol is not shared in the same way by the other inclusive members of the community who are not the patients themselves.

The cancer professionals and survivors in the local community have not come together with a single shared symbol of membership. A representative from the state cancer control coalition explained the coalition membership:

> We wish we had more survivors, but we don't. We have the community that serves survivors. They are two different animals, I think, but linking them would be excellent.

Another local cancer professional who is not active in the state coalition describes this distinction further:

> I think there are several communities and they don't talk to each other effectively. I think there's the genuine community of survivors and the resources they bring to the table [and…] the survivorship community in academia …

Currently, the community of survivors and the community that serves survivors are not fully linked. Even among the professional community, there is a lack of a common symbol that unites the community. Membership in the state coalition serves as a common identity for some members of the statewide cancer community, but some community members who are more survivor-focused do not feel as actively engaged by this network.

There exist several cancer survivors day celebrations and events in the local community. This day serves as a common symbol to cancer survivors worldwide, but these events are not unified across the local organizations. One long-standing community support professional described the history of the local cancer survivors day celebrations:

> when I was doing survivors day, I finally got the whole city to do it together … Now everyone is back to doing their own thing. … you sometimes have had your radiation here, and this treatment here, and your surgery there, then you're torn when the day comes to celebrate. So if everything is in one pool, then everybody goes to one place and celebrates that.

While at least one major local celebration welcomes all survivors and professionals to participate in their celebration, it is not a fully community-wide collaboration. This pattern of multiple events by different organizations continues throughout the year, with each organization hosting their own celebrations and awareness or fundraising events. This is especially the case in the numerous community-wide events and activities dedicated to breast cancer research and awareness, as one community professional describes:

> October is breast cancer awareness month, and everybody does something. Wouldn't it be better to maybe do one big thing… quit reinventing the wheel, quit duplicating each other's services.

The lack of a common symbol of membership in the local cancer survivorship community suggests a gap that can be filled by a more visible and concrete symbol to represent the individuals and organizations that identify themselves as members in this community. One potential common symbol might be found in collaborative, community-wide events presented jointly by all cancer-related organizations in the community. Similarly, an inclusive, welcoming, and collaborative online community may be able to provide this common symbol for the middle Tennessee cancer survivorship community.

2.3 Sense of Belonging

The sense of belonging refers to feeling acceptance and fitting in as "part of the group."[108] In the local cancer survivorship community, some participants identify as feeling like they are part of the cancer survivorship community, while others were less sure of this sense of belonging.

One reason for not feeling a part of the group is feeling that the community only refers to the cancer patients. As described previously, community professionals don't realize that support programs in the community often are intended for use by cancer professionals as well as cancer survivors. Similarly, when I first contacted the key informants to participate in the interviews for this study, several professionals who do not work directly with cancer survivors did not initially understand the reason for their inclusion in this project. Likewise, some professional participants who completed the sense of community survey asked if they were answering the questions as if they were a survivor. This confusion seems to illustrate how professionals may not always feel sure of their belonging as members of a cancer survivorship community.

The participants described that underserved patient populations may not feel part of the cancer survivorship community when they do not see reflections of themselves in the public images and stories of survivors. One professional described a calendar that features stories and photos of African American breast cancer survivors:

> … we don't hear stories from women of color, and so we want to be able to document those stories. So this calendar... features 24 breast cancer stories, synopses of their lives, through their own words, and focuses on life lessons that come along with cancer. …to make apparent and aware that breast cancer does touch communities of color, African American communities, so it is an issue. Another thing, to let people know that women of color, African Americans, can survive is important, given that often women of color demise from cancer at higher rates. And also to inspire people in terms of their own health-seeking behavior, for preventative treatment.

This initiative illustrates the approach of creating awareness for underserved populations as a way to recognize, celebrate, inspire, and affirm their membership in the cancer survivorship community.

Several participants described that as professionals, they feel a part of the cancer survivorship community when they talk and listen to cancer survivors and in doing work to support survivors. The director of one community organization explains the value of professionals listening to the stories of cancer survivors in the community.

> I do feel like that, that I'm a member of that survivorship community because of my personal connections to breast cancer survivors and the fact that there's rarely a day that goes by that I don't meet someone in this office. They walk through that door or they call on the telephone, and when you hear their stories or you sit and talk to them, you become a member of the community, you really do, and it's hard not to.

It is through this role of supporting, listening to, and working on behalf of cancer survivors that many members of the community feel a sense of belonging in the community. As a researcher doing this collaborative project in the community, this sense of belonging is one way in which I identify myself as a having become a member of the middle Tennessee cancer survivorship community.

2.4 Summary of Membership

The lack of clear boundaries helps explain the challenge of defining membership in the local cancer survivorship community. The ambiguous boundaries allow for individuals in a variety of roles to inclusively self-identify as members of the community. At the same time, the vague definition of boundaries leads some individuals not to fully realize the extent to which they are welcome and invited to participate as members in the cancer survivorship community. Similarly, the lack of a common symbol across the entire community of patients, professionals, and volunteers in the general public limits the sense of membership in the community. Creating awareness of survivors from underserved populations and awareness of opportunities for professionals to participate may help improve these individuals sense of belonging and membership in the community.

2.5 Informatics Design Implications

Because the boundaries of the local cancer survivorship community are multi-dimensional and ambiguous, an online community may be a natural way to bring together all of the members in a shared home. The personalized, yet integrated approach of social networking technologies can bring together cancer patients, long-term survivors, family, friends, professionals, and any other individual that identifies as having been touched by cancer. Rather than limiting the community only to cancer survivors, the design of local-based online communities can be more inclusive in their requirements for membership. The flexible nature of online environments can provide private spaces for each group while also integrating across all types of members. Additionally, the online space is not bound by geography, which allows for networking with individuals and organizations from regions outside of the immediate area, as desired by the members. Each individual may self-identify with different labels over time, and the online community should recognize and address the flexibility of how people define their own cancer survivorship.

An online community also may serve as a common symbol that is inclusive of these various individuals and organizations in the local community. Being a registered member or user of the online community can represent a neutral, common ground for the members of the local cancer survivorship community. The community members can display a link to the online community on their own web sites as a way to self-identify themselves as cooperative members and/or partners that support and value cancer survivorship.

The online community also can feature content for underserved populations in the community (such as men, minorities, etc.) as well as professionals and volunteers, to help these members feel a sense of belonging as part of the cancer survivorship community. Participating together as members of the online community may help welcome these members into participating in more activities in the real-world community.

3. Sense of Community Dimension – Fulfillment of Needs

The fulfillment of needs refers to more than just receiving helpful, practical support and resources from others in the community. This concept refers to the broader, psychological concept of needs that reward and reinforce the individuals' and groups' passions and motivations to continue to do what they do in the community. McMillan and Chavis describe the fulfillment of needs in terms of 'reinforcers' such as shared values, status, and competence. Additionally, the concepts of appreciation and recognition were identified as significant to the fulfillment of needs in the local cancer survivorship community. These concepts are presented in terms of how and why they are significant to the local cancer survivorship community. Together, they help to tell the story of what drives people to come together and continue to participate in this community.

3.1 Shared values

The shared values of supporting cancer survivors, as well as preventing and eliminating the threat of cancer for future generations, drive individuals to participate in the local cancer survivorship community. Many professionals share a personal passion to work in this community, as one cancer outreach coordinator explains:

> …for so many of us, usually people are in oncology because they have a passion…

This personal mission is confirmed by another cancer support professional:

> They're not thinking about just their little red wagon, they really care about who's affected by cancer.

It is through their work towards this common priority that the cancer support professionals' can move beyond any negative feelings of competition and come together as a community. The cancer outreach coordinator continues by stating:

> And we all want each other to succeed, because then there are services for patients. We'll say, what's important here is the patient … they're all trying to raise money, so there's some competition from that standpoint, we all know that exists, but… we know that by collaborating then the patients ultimately benefit.

The director of another cancer support organization confirmed this importance of highlighting these shared goals in moving past competitive interests with other organizations:

> I think what's been real helpful in developing those collaborations and working together has been to very openly talk about it not being competition, we're all working for the same goal, early on-get over any thoughts like that, about the ownership, let's work together. I think we've made good strides in that.

This approach to getting the community to work together is based in openly talking about wanting to avoid competition and reminding one another about their fundamental goals of benefiting cancer survivors in the community. Similarly, hearing stories directly from cancer survivors is a powerful way to remind professionals of these goals.

> … you can read about clinical research and trials and this and that, and we can show you the size of a tumor…, all of that we have to know, but it's when someone comes in and relates her story, that you know why you're here.

The value of transparent discussions and frequent reminders of these shared priorities should not be underestimated in the real-world environments of non-profits and academia, where the need to receive funding and advance one's career can distract from these ideal values.

As one participant describes, the organizational structure of academia in particular creates the potential for one to lose sight of truly working for the cancer survivors' best interests:

> [In the survivor groups], I don't see their hierarchical structures being about anything but the interest of the survivor and maximizing the quality of time that their members have here on earth, and that is not the bottom line in the academic community….

While the individuals in the cancer survivorship community share strong and passionate values, other competing interests and organizations structures can shift these priorities in some areas of the community. The following discussion of status in the community as a fulfillment of needs emphasizes the complexities of this challenge.

3.2 Status

In the local cancer survivorship community, the reinforcement of a professional's status in the community may in fact serve as a barrier to following the shared priorities of the community, especially in academia. As the participant quoted above continues, the ambitions of one’s professional, organizational, and academic careers may overshadow the desire for transparent collaborations in efforts that benefit cancer survivors.

> The survivorship community in academia I feel is largely proprietary and is largely about egos. I think the people doing the work are not getting the credit they deserve and are not being placed in leadership roles, even though they have the knowledge, the experience, the ability, and the contacts in the community. And there’s a lot of taking credit for other people’s work in survivorship. I think that’s in part because this is now on the national political agenda, and money is mobilized through the NCI to focus on the horrible effects of cancer on people afterwards. And the academic communities, with the exception of [some], I don’t think people really have the survivors’ best interest at hand. They have their reputation that’s the highest interest, and their ability to build a portfolio.

These strong words indicate the extent to which the culture of academia and the national political agenda can have a negative impact on the members of the local community. The emphasis on status and career in these fields not only affects the individuals who try to balance their career and the community goals, but the competition and lack of trust also affects the attitudes of those who work with these professionals and organizations. As this example illustrates, it is easy for well-intended individuals to grow weary of participating in certain collaborative efforts when they struggle with issues of trust and trying to keep the focus on the survivors. In this way, status in the academic and organizational domains of the cancer survivorship community may have a negative impact on an individual’s fulfillment of needs and motivations for participating in the community.

On the other hand, some forms of community status may be a positive force for the local community members. A representative of a local breast cancer non-profit described the status of their national organization in the cancer survivorship community:

> if you google breast cancer, we're going to come up, because we are the leading private fundraising organization in the county. The only one that gives more money to breast cancer research is the federal government. So we're going to be right on the top of that list.

The status of the national organization provides a sense of pride and reinforces this individual's efforts and work with the local affiliate and community. It is significant to note that the status is bestowed up the organization, rather than the individual. This distinction may serve to keep the focus on the community that the organization serves, rather than emphasizing the individual's own career and ego.

A cancer support organization's status in the local and national cancer survivorship communities also supports the organization's overall mission:

> The staff has remained consistent and steady, and I think that has helped. And we work extremely collaboratively. I think we have a good reputation, and beyond. [With the grant] we were one of ten in the nation, and they mentioned the strong reputation that [we have] as part of the reason they felt comfortable giving us this two year grant.

The organization's respected status and reputation reinforces the work done by the organization and its staff, both through a validation of their efforts and also garnering continued financial support through grants and partnerships.

This recognition on a national level relates to a similar reinforcement that occurs on a more personal level among the local community members who work hard to serve cancer survivors in the community. The appreciation and recognition of individual efforts is identified as another 'reinforcer' for the fulfillment of needs in the community.

3.3 Appreciation and Recognition

While status in the local and national cancer survivorship communities provides an important motivation for professionals, it is a more personal type of recognition that deeply reinforces and drives the passion of these individuals. This recognition is the appreciation expressed by cancer survivors in the community for the difference that a person makes in their lives.

For a professional whose priorities are grounded in working hard to support cancer survivors in the community, this appreciation means more than any other professional or financial award. One participant described the personal significance of an honor she received from a local cancer survivorship organization.

> I could not stop crying, because it meant so much to me. Of all the kinds of awards I've gotten for my work, and athletics when I was little, none of that mattered like this. … the incredible acceptance and gratitude … for being someone who 'gets it'. And that's my biggest role in the community, to be seen as a leader who can be trusted, who has integrity, gets it, and knows what they're doing. That's what that award meant to me. I could not spot crying.

This honor, given by the cancer survivors for whom she works, represents a powerful symbol of appreciation that confirms the value of her efforts, even when those efforts do not always seem to be appreciated by her colleagues.

While the previous example illustrates appreciation in the form of an award, other types of appreciation can be expressed more informally from cancer survivors and professional colleagues. One community support professional described the need for oncology professionals to support and recognize each other's efforts:

> This is such hard work, that there's really not an existing forum to support one another through it, or to fill each individual's cup up. … Support, nurturing… Something replenishing.

A representative from another local non-profit explained the personal significance of providing support and assistance to appreciative patients and caregivers in need.

> And also, we get those phone calls from someone whose wife has just found out she has breast cancer, and he wants to know how he can support her. Those come in daily. We just have to talk to them, a lot of times they just want someone to talk to, you know, but we will also give them our resources of where they can go to find such and such. … A lot is just sitting and listening to people, and that is the part of the job that I find the most rewarding. It kind of makes me remember why it is that I'm here doing this.

A genuine 'thank you' on the phone or the implicit expression of gratitude by a patient or caregiver may be the most rewarding and reinforcing aspect of a professionals' work.

Each of these examples underscores the real value in recognizing and expressing sincere appreciation for the volunteers and community professionals that contribute their passion and energy to the local cancer survivorship community.

3.4 Competence

Finally, the key competencies of the cancer survivorship community members help fulfill the needs of the community through strategic partnerships and advising.

By combining competencies, community partners are able to create successful programs and initiatives that are bigger than the sum of their parts. As one support professional explains

> Almost every project we've done we've called a partner and asked for their expertise.

One way to combine competencies is when one group provides funding and resources and another group brings the people and setting:

> So I've got some money, a speaker, the resources to advertise. Our graphic designer is a huge resource for things. They've got the place and the population. It meets both of our goals.

Event planning is another example of an expertise which combines naturally with organizations that have grant funding and an idea:

> She had the support and venue and know how to put on a conference, and we had the money and idea and willingness to make it happen.

Money, ideas, and expertise come together to fulfill a need in the community. Another example of this type of combination is between local organizations that give grants, and their grantees who apply for the funding.

In addition to these strategic organizational partnerships, individual volunteers with key competencies enable an organization's ability to offer essential support programs for the community, such as financial classes and counseling for cancer survivors and families:

> I know one of our volunteers is an estate attorney, he volunteers his time and he works with another guy who's a financial advisor, and they answer questions… One of our facilitators ran a pain management program at one of the large local hospitals, and she works with us as a volunteer to do this.

Long-term experience in the community is itself a key competency that helps the new members of the community fulfill their needs. A new executive director of a community organization described the mentorship she received from the experienced staff in other local organizations:

> …those two places have truly shared with me information and support for being a new ED of an organization. Those two have been very willing to talk with me, advise me and share with me information.

As described earlier, the people are the true resources of the community. It is the same both among professionals and among survivors. New patients rely on the competence of experienced cancer survivors, as a community support professional described their organization's membership:

> That's really what [this organization is]-a community that is supporting each other, learning from each other, relying on each other, and it's our belief and philosophy that our experts are our members. Folks who are living it are experts in what they are learning along the way, and have a whole lot to teach each other, and learn from each other.

3.5 Summary of Fulfillment of Needs

The fulfillment of needs in the local cancer survivorship community is grounded in the shared values and priorities of doing what is best for cancer patients and their families. Many individuals work passionately and devote their lives to supporting this community, and the most important reward is the sense of genuine appreciation from the cancer survivors that they support. Recognizing the volunteers and professionals who contribute to the community is not taken for granted by the organizations who owe so much to their efforts. It is through the community members' combined competencies and expertise that many essential services and programs in the community are developed and sustained. Additionally, professionals' general awareness and frequent interactions with local cancer survivors reminds them of their purpose and focus.

However, some members of community may not share these same priorities, such as those professionals whose organizational or academic status and culture distracts from this explicit focus on the cancer survivors. The perceived differences in values and priorities between the academic-based and community-based cancer communities create a barrier to fulfilling the total needs of all members in the local cancer survivorship community.

3.6 Informatics Design Implications

The online community can bring together the local professionals and cancer survivors in a shared environment. Professionals can reinforce their priorities and shared values through more frequent awareness of cancer survivors' stories and experiences shared in the online community. The online community also can provide opportunities for survivors to express appreciation for the local professionals, as well as provide an opportunity to thoughtfully recognize the meaningful contributions of the community professionals and volunteers.

Additionally, the online community can serve as a networking tool to discover other members of the community who have key competencies and interests that may be a good match for a collaborative effort or mentorship. Personal and organizational profiles, forums for querying the community, and other targeted types of online communication interfaces may assist the community members is these efforts.

4. Sense of Community Dimension – Shared Emotional Connection

The final dimension of the sense of community is a shared emotional connection and bond between the members of the community. McMillan and Chavis describe the shared emotional connection in terms of several attributes, three of which are discussed here in terms of the middle Tennessee cancer survivorship community. These attributes are the shared history, the quality of interactions, and the contact hypothesis.

4.1 Shared history

The members of the local cancer survivorship community share an emotional connection through a variety of shared experiences and history.

Cancer survivors, family, and anyone who has been ever been touched by cancer, all share a bond through their experiences of diagnosis, treatment, and survivorship. One participant described how this bond exists not only in cancer support groups, but also throughout other local, communal settings, such as religious institutions:

> I tend to see it more in a church, or a religious type setting where they just happen to have a support system for a church member going through this, and a group of women who are survivors or a sister of a survivor and feel like they have something they can contribute to this person.

This shared history also is found among many of the cancer support professionals in the community, who are cancer survivors themselves or who have faced cancer through their family experiences. Several community non-profit board members and staff identified themselves and others as cancer survivors, and this history helps them to connect with other cancer survivors and to educate the general public. A director of a local non-profit described her colleague's role in educational presentations on breast cancer in the community,

> [She] relates her mom's story, and that her mother realized that something wasn't right. And that says to me, she knew her body well enough to know that. That's one of the things we have to get out there and tell people.

Additionally, even professionals who have not experienced cancer on a personal level feel an emotional connection to the cancer community through their history of working in the field, as one participant explained:

> I have a particular fondness for the cancer community, only because I worked as an oncology administrator for almost 20 years out in California. It's a field near and dear to my heart, not because of any personal experience, [but] because I've spent so much time in it. So I feel a real affinity to anyone who works in the field, so because of that I think it's easier for me to begin to develop relationships.

This affinity for fellow professionals exists independently of geographical location, and the implicit bond facilitates the development of new relationships in the local community. This common ground is especially valuable for new staff members who are starting new programs.

The professionals who have worked in the local community for a number of years share an additional bond through their shared history of working together in the same town and with the same people. As one oncology nurse describes:

> Twenty-seven years I've been working in oncology, and most of that is in Nashville. So, most of us have a lot of years working in oncology. It's a pretty small community, so we kind of know everybody, we know social workers, we know nurses at all the different places, doctors at the different hospitals, we've sat on [non-profit boards] with them…

The breadth of relationships and professional affiliations developed over time in the community creates a bond between the local professionals. Combined with the breadth of relationships, the participants also explained the depth of their relationships and the importance of close emotional bonds that form over time:

> There are some people that I have a closer affinity too, it goes back to a long standing history with them. … So we have a working relationship, but we also have a personal relationship that extends beyond our work here in the cancer center. So I'm ever endeared to her, and she's endeared to me, because of that. So that's one example, even though we don't get together and socialize, but there's very much that kind of connection.

The shared history in meaningful personal relationships provides strong emotional connections among professionals in the community. It is the quality of the interactions, and the deep trust between individuals, that the participants described as valuable assets to their work and lives in the community.

4.2 Quality of interactions

Several participants described the role that this personal emotional connection plays in successful collaborations and partnerships in the local cancer survivorship community. As one community support professional explains:

> I'm quicker to partner with people that have been successful partnerships in the past, or people that I just like to hang out with, because I know they'll pull their load and do their stuff, and it's really a partnership, … I'll do anything with her, for the rest of my life, I'll do anything with her. And luckily, there are several people I could name like that. And then you've got other people who are newer and are unknown players. Cause for me it really is all about relationships, it just is. That's what our training is, that's what our job is, as a human being, that's where I live.

Other participant explained further how the quality of the relationship facilitates transparent, collaborative efforts in the local community:

> I think it definitely helps. I end up calling the ones I know best to say, you know me, I know you, we know each other, we can do this, let's make this happen. … 'What do you think? I've got this idea,' and if you're already very friendly they can go, 'no that's already being done,' or 'that's the dumbest thing I've heard of,' so it makes a difference.

Being able to share ideas in an informal context, as friends as well as colleagues, reduces the barriers to getting others involved in the early planning stages of a project. These bonds facilitate synergy between organizations by prompting the creation of events and programs that are firmly grounded in a joint effort.

However, when that level of personal connection and trust is missing, an individual's collaborative energy and openness to share ideas are stifled. One participant described her experiences in the academic cancer survivorship community very differently from the previous examples:

> All these organizations and groups of friends that work together, operate in a silo, and necessarily so. Because ideas have been taken, people have scooped out, there's not trust. Cancer is big bucks in terms of research community activity and lining people's pockets out of treatment. So whenever there's money involved, you get all of this weirdness. So I've had to be very careful, because I feel like people are going to scoop my ideas, and I'm not going to get any credit. All those intangibles that you can't put your finger on, but they're there and your gut is screaming something isn't right here. So in the community, there's so little trust, because there's all these ulterior motives and then there's the superimposition of the southern culture where you're always being so nice and not gonna offend anybody, and then you stab them in the back. And there's a lot of that going on.

This perceived sense of competition also exists in the relationships between community-based organizations, which may be competing over the same pool of donors, members, and other funding opportunities. A representative from a community-based organization explained:

> I sometimes get the feeling like we have our own turf, and we will play well with one another if we have to. To me, when it comes to ending cancer, whether it's breast cancer or whatever, there should be no turf. Yes, we have our own organizations and we have our own programs of service, but in order for us to truly bring about education and to end cancer in all its forms, we have to play nice with one another, we can't have turf, we have to develop partnerships, and I don't know if that will happen because most of us being non-profits, everybody thinks about funding, and if I partner with them, is someone going to give them more money than they give us, and there has to be a way to overcome that.

These examples illustrate the potential for the local cancer survivorship community to come together when grounded on strong relationships and interactions, as well as the barriers to collaboration that stem from a lack of transparency and trust in these relationships.

In spite of the existing competition over funding and programs, the quality of interactions and relationships in the community is maintained by openly recognizing and accepting the role of competition in the natural order of the cancer survivorship community. As the quote above illustrates, each organization has its own programs and services, but they also need to play nice with one other. Another participant described the importance of having appreciation for other organizations' programs, while also continuing one's own efforts in the community.

> We want to be respectful of doing what we're doing, but we're not going to stop setting up support programs, because there's enough

> need for us to all exist in this space, there’s room for all of us in this town. … and I think we all should feel free to benefit from one another, to share services, to not feel like it’s not ok to have the same thing going on. Of course the goal is to not duplicate services if it’s not necessary, but sometimes it is.

This example illustrates the attitude that there is enough need in the cancer community for multiple groups to offer similar programs, while at the same time, not duplicating efforts unnecessarily. This “dilemma of duplicate work” presents a challenge of determining which situations are appropriate for collaboration or referral, and when it is necessary to create a new program despite a partial overlap with existing programs. Developing sincere and transparent relationships is important to communicating a mutual understanding on this sensitive balance in which each individual’s passion and personal investment in the community are involved.

4.3 Contact hypothesis

The contact hypothesis suggests that people in the community will develop close relationships as they have more opportunities for personal interaction. The participants describe several aspects of the cancer survivorship community that promote greater interaction leading to these relationships.

Professionals come together in professional societies which offer opportunities to get to know each other and share information in an informal context:

> …the nurses, because we all go to [the oncology nursing society] together, we all know each other, and half of us have moved around the city in oncology, we’ve worked with each other at one place or another at one point in time. So the nurses pretty well if there’s

> something going on tell each other, share it, give information, and social workers are the same way.

Participating on community non-profit boards offers another opportunity for professionals to develop relationships:

> …we all know one another and we all serve on each other’s boards or serve in each other’s activities in one form or fashion.

Community-wide events also provide an opportunity for contact, such as settings where multiple organizations have a booth or table:

> We see each other at health fairs or events or whatever and we have a great relationship and we can talk.

The local aspect of the middle Tennessee cancer survivorship community leads to more casual interactions outside of a work atmosphere. One participant describes a chance encounter with another local community professional:

> I saw [her] in the produce department in Kroger about two weeks ago, and it was great, it’s like we’re on the same page, just this common thread, and it was personal, a personal visit, but because of our profession.

This brief informal interaction complements the more intensive formal collaborations that bring the members of the community together. A representative from the state cancer coalition describe how the collaborative work on coalition events and committees helps to build close relationships among the active coalition members:

> In the coalition they are very, very close. … We work together on producing the summit. … and we all work together on whatever project you have to do today, what’s your crunch. I feel very connected, and very blessed.

While the tight-knit group that does this work becomes very close, other busy professionals who cannot attend due to scheduling conflicts do not have these opportunities to connect and build relationships.

> I think a lot of the reasons they aren't involved, because the way the coalition is doing business right now is having a meeting, and if you can't get away for the meeting, a lot of people can't take that big block in the middle of the day. If they're not of the meeting, they don't feel part of the group. I don't think they're disinterested. I think it's staffing and time.

When formal meetings are a primary opportunity for group interaction, certain professionals inherently may be left out of the group. People with flexible schedules, such as those in academia or individuals whose job description specifically includes community outreach, will have more frequent contact, while others, such as clinicians or cancer survivors with daytime jobs, are not as easily included.

When one is not included in these opportunities for these group interactions, a person can make assumptions about the motives and values of other individuals and organizations. The simple step of making personal contact with other members of the community goes a long way towards preventing misunderstandings and competitive assumptions about other members of the community.

> …it's almost like if someone doesn't know you, if you don't know somebody, say a person in an organization besides us… they think they have a sense of who we are and what we do from someone else, it colors their perception of us, and it brings out that territorial thing a bit more. Where if someone could just walk in the door and if we could all do that, really actually connect on a personal level with people, instead of getting caught up in the political stuff, if we all got to know each other on that level and focused on what we're here to do, then we could get past that stuff, and we would see that it's not a territorial thing, and we all want to do the same thing, and it's not about us, it's about the people we're trying to reach out to.

Creating opportunities to connect on a human level may help the local cancer survivorship community move past some of their competitive assumptions to come together for their shared values of supporting cancer survivors in the community. This is not unlike the importance of connecting with survivors on a personal level to remind professionals of their purpose and priorities. It is this genuine human contact that provides the foundations for relationships and partnerships to develop in the cancer survivorship community.

4.4 Summary of Shared Emotional Connection

Strengths of the local cancer survivorship community are that both the cancer survivors and the professionals feel an affinity for one another due to their common experiences of fighting cancer. This shared history provides a common ground for relationships and partnerships to develop. Additionally, because of its local nature, the professionals in the community share an additional bond through the history of working with the same people and the same institutions. These bonds can grow into endearing and transparent personal relationships with individuals who work closely and share a mutual respect for one another.

However, the shared history of distrust and local competition over funding creates a barrier to the community members forming emotional bonds and coming together to collaborate. One organization’s strategy to avoid competitive feelings is to explicitly talk about their non-competitive intentions and to actively seek outside opinions when planning a new initiative. Another approach to handling the local competition between similar programs is to value and respect each program's role in the community, while sensitively discussing mutually beneficial ways to avoid duplicating efforts in certain areas.

In spite of the potential politics and competition between organizations, when the individuals in the community have an opportunity to interact on a personal and human level, they can begin to move past their assumptions and differences. This genuine connection between human beings, both among professionals and survivors, is a valued and desired approach to creating a shared emotional connection in the local cancer survivorship community.

4.5 Informatics Design Implications

A local-based online cancer survivorship community can tap into the emotional bond of the members based on their shared experiences with cancer and history of collaboration. The online community can build on this emotional connection by emphasizing the common experiences shared by all members of the community, rather than focusing on a single cancer type or demographic.

While enhancing the bonds of the overall community, the online community also can enhance interpersonal connections between individuals who have existing, trusted relationships. For example, rather than treating all individual contacts the same, the online community can include functionality geared towards nurturing these relationships and partnerships. This functionality might be as simple as allowing for private online messages between such individuals, or more targeted communication tools also can be developed.

The online community developers and implementers also must be aware of potential areas of distrust and competition between the community members. The online community should provide a safe environment for sharing in which the community members do not fear being taken advantage of competitively by other members of the community. This is by no means an easy task, but it is an aspect of the online community design that should be addressed.

Finally, one of the most natural ways that the online community can enhance the shared emotional connection is by providing additional opportunities to meet and connect with other members of the community independent of scheduling and geographical constraints. These opportunities might involve formal collaborative discussions, as well as the ability to interact in a more personal context (e.g. through personal profiles, photos, etc.). Perhaps the ability to send a “virtual hug” to another member of the community might be a natural way to greet one another in this type of online community. The online community can include a variety of ways to make contact with other members of the community in order to support the community’s shared emotional connection.

Sense of Community – Overall Summary

The qualitative analysis of the key informant interviews confirms the findings from the synthesized definition of the community and the brief sense of community index statistics. The middle Tennessee cancer survivorship community exhibits many strengths and successes within the sense of community framework, but the analysis also identified several challenges and areas to improve.

Each dimension of the sense of community suggests several implications for the system design of an online cancer survivorship community. The sense of community analysis is valuable for discovering the strengths of the community on which the online community can build, as well as the potential barriers to a collaborative design process. However, the four dimensions work together and overlap in a variety of ways, such that it would be difficult for the online community design to target a specific dimension independently of the others.

In this regard, six cross-cutting areas were identified to improve the overall sense of community in the middle Tennessee cancer survivorship community. These opportunities were acknowledged in the interviews by the participants as significant aspects of the community to address. The identified opportunities also represent key areas of the local community for which an online community may play a significant role.

Six opportunities to improve the sense of community through informatics

The six identified opportunities to improve sense of community for the middle Tennessee cancer survivorship community are 1. Awareness; 2. Connecting; 3. Collaboration & Co-opetition; 4. Community & Survivorship Focus; 5. Knowledge/Relationship Management; and 6. Underserved Populations. Each of these six areas is presented in the context of the interview data, and implications for the proposed online community are discussed.

Awareness

The community members desire more awareness of local programs, news, and events, and the community's successes and connectedness. This awareness is needed by the members of the community (professionals, survivors, etc.) as well as by the general public.

Ideas for awareness identified by the participants include survivor stories, volunteer recognition, a shared calendar to prevent conflicting event schedules, knowing where fundraising dollars are going, navigating organizational affiliations for partnerships, finding similar initiatives and programs to avoid duplication and fill community-wide gaps, local news and activities, visibility of underserved populations, and clarifying public relations to address assumptions about an organization and about cancer survivorship in general.

An online community can address this awareness through a community-wide events calendar, a community-wide news blog that includes original content as well as aggregating stories from other sources, a listing of local resources and programs, and providing other opportunities for individuals and organizations to share their stories or clarify their purpose in their own words.

Connecting

The local cancer survivorship community can improve opportunities for individuals and organizations in the community to connect. Awareness is the first step towards this connection, but the next level of facilitating actual interactions is also needed.

Types of connections identified to improve are connecting with rural and smaller groups, facilitating referrals to support services in the survivors' local region, finding reliable speakers for seminars and events, matching individuals for peer mentorship (both professionals and survivors), recruiting for research studies and clinical trials, informal socializing and networking among professionals, emotional support among professionals, survivor feedback for program evaluation, and facilitating referrals from doctors to support services.

An online community can address these connections by providing a variety of social networking functionalities, such as a match-making database and facilitation of matches, a local speakers database, a safe and private environment for professional partnering, opportunities to announce research studies, and trusted recommendations for regional support service referrals.

Collaboration & Co-opetition

The local community can build on its existing collaborative successes while finding more opportunities to create at atmosphere of cooperation between currently competing entities. There is a need to build trusted and transparent relationships among the professionals and organizations who serve the survivors. The concept of "co-opetition," which refers to simultaneously competing and co-operating[131], captures the essence of this opportunity to improve the sense of community. Organizations and professionals can co-operate to raise the status of the entire cancer survivorship community, in which they then can compete by offering quality services and programs. The participants indicated that this co-operation should include jointly produced programs as well as mutual support for each organization's own efforts. Each program should be valued and appreciated for its unique contributions, while at the same time efforts should be made to avoid unnecessary duplication of local efforts.

Examples of improved collaboration and co-opetition identified by the participants include hosting community-wide educational events and celebrations, having cohesive messages and coordinated media campaigns, sharing and pooling resources, openly discussing potentially competing efforts, sharing meeting spaces, and collaborative grant applications.

An online community can provide community partners with opportunities to share ideas and network to discover collaborative opportunities. Aggregated listings of programs, news, and events can help the community identify potential duplications of efforts and community-wide gaps in services. In the spirit of co-operation, the online community can avoid content and functionally that represent areas of competition between organizations (e.g. soliciting donations).

An online community can foster co-opetition by creating more awareness for *all* local programs and organizations and celebrating the many opportunities for support available to cancer survivors. Within this shared space, organizations can compete in the form of offering a variety of unique programs and services that provide real value to the community. Rather than holding onto clients and members by not sharing information about competing programs, organizations can direct their members to the neutral online community in which they market their programs. Each organization has the potential to gain new clients and participants, and the priority of working in the best interest of the survivors is emphasized over the self interests of competing organizations.

In order for this type of co-opetition to be successful, the online community should be grounded in a real-world commitment to one another. The online community should be designed and managed through a transparent, collaborative effort of the local community. Finally, the developers and managers of the online community should be open to collaboration and co-opetition with other online initiatives with similar purposes of bringing the local cancer community and resources together.

Community & Survivorship Focus

The participants express a need to shift from an academic and treatment-focused model of care to a more community-based culture that emphasizes holistic support and survivorship.

Aspects of this community and survivorship focus identified by the participants include support for the transition following the completion of treatment, long-term survivorship, survivorship and supportive care research, support for cancer in the workplace, transportation and housing support, and highlighting other psycho-social services.

An online community can address this opportunity by emphasizing content and functionality geared towards community-based cancer survivorship. By including academicians and researchers in the online community, professionals and organizations that typically are focused on curative treatment can increase their awareness of cancer survivorship needs.

Knowledge/Relationship Management

The local community needs an improved approach to managing knowledge of support resources and collaborative relationships over time.

The participants identified challenges to knowledge management such as sharing each individual's 'personal database' of contacts and resources, difficulties in updating information online and in print, turnover in non-profit staff positions, and informing patients of resources through means other than a stack of brochures, capturing feedback for organizational decisions, and needing more accessible online interfaces for local resource listings.

An online community can address knowledge management by providing a shared archive of past programs, events, and news. The online community can also provide automatic checks to discover broken links or information that hasn't been recently updated, and the online community members themselves can update outdated information. Social networking approaches, such as a shared web site bookmarking tool,[132] may help individuals share and pass on their personal knowledge databases to trusted relationships. Creative visualization, tools such as a Google map interface for geographical mashups[133], can also help by synthesizing the knowledge into more manageable pieces.

Underserved Populations

The local community can improve on its efforts for underserved populations in the cancer survivorship community.

The populations identified by the participants as underserved in the community include minorities, low socioeconomic status, men, families, younger generations, long-term survivors, and certain cancer types other than breast cancer.

An online community can support underserved populations by including them as equal members of the online community and also by creating awareness and visibility for their stories and needs. Additionally, an online community can include individuals who do not have access to a computer or the internet by creating real-world components to the online environment. This approach might include printed calendars and newsletters, or printed forms on which a cancer survivor can contribute their story to share online.

Section Summary

The theoretical framework of the sense of community highlights the strengths of the community's relationships and how the community comes together as a whole. As this analysis demonstrates, the framework is especially valuable for designing local-based online communities and social networking technologies for health, because the system developers need to understand the complex dynamics of the real-world community, and not just a list of individual needs.

The sense of community analysis informs the online community design choices as well as the collaborative development process with the local community members. In addition to highlighting potential barriers to collaboration, this analysis provides the foundation for the collaborative effort and the online community to build on the existing strengths of the local community.

A limitation of this analysis is that it is primarily based on interviews with professionals in the community, with only one cancer survivor advocate included at this point in the study. While several professionals also are cancer survivors and many of the professionals work closely with cancer survivors, a study that focuses more directly on the sense of community of local cancer survivors will offer a valuable complement to these findings.

The next section of the results presents the collaborative design of an online community for the middle Tennessee cancer community. The design components of the online community are discussed in terms of the six opportunities to improve the local sense of community presented in this section of the results.

Results 3 - CanConnect: The Cancer Community Connection of Middle Tennessee

After identifying and forming initial relationships with the community members through the key informant interviews, we began the collaborative design process to create an online community that can address the opportunities to improve and bring the local community together. A thick description of the evolving activities in the collaborative design process is presented first, with details of the design participants, group design sessions, and individual meetings. The resulting design components then are described, along with comments on how each component addresses to the six opportunities to improve the community identified in the previous results section. Finally, the online community design resulted in the formulation of a medical informatics model for synthesizing the local community's wisdom on psychosocial support resources. This four-part model is summarized, and the need for informatics technology that fits this model is highlighted.

Development and Launch

Collaborative Design Participants

For the design phase, I contacted the same potential participants as I contacted for the previous phase of interviews. Several cancer survivors were recommended by the interview participants and volunteered to participate. Several cancer survivors also had signed up expressing interest at my booth at a local cancer survivorship event in June, and they were invited to participate. Including the cancer survivor advocate who participated in the key informant interviews, a total of 11 survivors consented to participate in the design phase (see Appendix C for the Demographics). Of the 20 professional/staff interview participants (not counting the cancer survivor advocate), 14 continued on to the design phase, along with 15 new professionals (for a total of 29 professionals). In the design phase, 18 professionals were from my own medical center institution, and 11 were from other organizations. Not all of these participants joined before the first design session; several joined later in the design process.

Collaborative Design Sessions

Over the course of eight months, we conducted five collaborative design sessions for both the staff/professionals and the survivors/family participants. The sessions were held at a community-based support organization that volunteered their large dining room space for this project. The first four survivor meetings were held on Tuesday evenings (dinner provided), and the first four professional meetings were held the same week on Wednesday afternoons. The fifth design session brought the professionals and survivors together in one group for the first time. The main focuses of the meetings were the same for the survivors and professionals, with a few slight differences on the specific discussions. For example, the sessions with the professionals included more discussion of partnerships between professional organizations, while the survivor sessions included more discussion of communicating with family and friends. The participants indicated that they appreciated having separate meetings for the survivors and the professionals.

The design sessions were intended to be efficient and productive, but also welcoming and supportive for the participants. I facilitated the discussions at each meeting and presented initial results. I gave special attention to encouraging transparent dialogue and collaborative among the participants. Rather than treating the design sessions as "focus groups," where the participants provide me feedback to help me design the online community, I considered the group sessions to be our collaborative planning meetings for us to design our online community. This perspective is both how I viewed this project, and how I sought to convey the collaboration to the participants. This attitude, grounded in the principles of working together for both community action and research knowledge, guided many aspects of my approach during the collaborative design.

The audio recording from each design session was transcribed along with written field notes analyzing the collaborative process. In between each meeting I conducted an ongoing analysis of the process, I iteratively developed and programmed the web-based software components, I analyzed the action items and conclusions from the group discussion, and I prepared reports for the participants to review from the meeting. These reports allowed participants who missed a meeting to stay involved throughout the design process and contribute feedback via individual emails or telephone calls between the participant and myself (See appendix G for a sample of these reports). I also engaged many of the participants for individual brainstorming and targeted feedback in between the group design sessions.

The design session timeline is summarized as follows

1. December 2007 – Initial brainstorming: “Starting with a blank slate”

This purpose of the first design session was to capture a wide range of perspectives on the vision and purpose of the proposed online community, as well as specific ideas for design and functionality.

Two survivors participated in the Tuesday night meeting, and eleven professionals participated in the following Wednesday meeting.

I first introduced myself to the participants and introduced the design project and the research study. The participants introduced themselves to each other, as gave a quick introduction of their role in the community.

Using a nominal group technique, the participants wrote their ideas on a worksheet and then each person contributed one idea at a time to be recorded on a large display board. The participants were invited to comment briefly on the ideas as they were presented, but discussion was kept to a minimum for the most part. The worksheets prompted the participants, “Let’s imagine communication and collaboration in the future…” in the following relationships: Among local cancer organizations, for general community awareness, between cancer organizations and their members/survivors, among local cancer survivors, and between cancer survivors and family/friends/coworkers (see Appendix H and Appendix I for the survivors’ and professionals’ worksheets). These areas of discussion were influenced by the initial interviews with participants as well as the individual to societal components of ecological systems theory.

The final part of this first design session included a more interactive brainstorming task, using markers and a blank web site template, with which the participants drew initial concrete visions for the online community design.

Soon after these initial sessions were conducted, I tabulated the contributed design ideas in an Excel spreadsheet, along with the specific ideas suggested during the pre-design key informant interviews. I assigned each idea a score of 1-5 for my estimate on programming/development difficulty, for sociability/implementation difficulty, for my own initial thoughts on priorities, and for estimating critical mass needed for the idea. I also noted the ideas which could be a good match of interests and skills with certain professional participants whose background I knew from the earlier interviews.

I then used a grounded theory approach to group the ideas into categories and themes which could be presented back to the participants (see Appendix J). While this organization helped summarize the results from the design session, it did not facilitate choosing priorities between the ideas. The ideas were re-organized into categories that asked a specific design question, in which a subset of ideas could be compared and prioritized. Appendix K shows the priorities worksheet that was created from this re-organization.

The process of filtering the total list of ideas into a presentable format of specific design choices for the participants to discuss was one of the most challenging tasks of the entire design process. This effort was done independently by me until the final small adjustments, with feedback from a few other members of the research team (e.g. my PhD advisor) and one or two participants.

2. February 2008– Choosing initial priorities

The priorities worksheet described above was essential to have the critical design decisions made through voting and group discussion by the community member participants. Several low-hanging fruit in the suggested design ideas were not included in the priorities worksheet or discussion if I had marked the feature as one to be implemented regardless. Including a site search toolbar in the design, for example, was a simple task and therefore not part of the group discussion. In the limited time of two hours together as a group, efficiency and transparency were carefully balanced in this design session.

Four survivors participated in the Tuesday night meeting, and eighteen professionals participated in the following Wednesday meeting.

For each category of the worksheet discussed, the participants were allowed to check one or sometimes two of their top priorities. These meetings featured lively and dynamic discussions with participants openly discussing various advantages and disadvantages of the design features. The focus at this design session was on the conceptual design and functionality, rather than the particulars of the look and feel.

Initial development of some design concepts, such as the Google map "mashup" that displays the local cancer survivorship organizations on an interactive map, were presented to aid the participants in better understanding the possible design choices. Also, cartoon storyboards were presented and discussed to illustrate an example of a cohesive vision combining multiple design features (see Appendix L). I developed the storyboards based on the results of the December design meeting and pre-design interviews. The purpose of these visual strategies was to help make the complex informatics design concepts more tangible to a group of community members who were relatively inexperienced with web-based applications. The participants indicated that they enjoyed and appreciated these aspects of the collaborative process.

3. April 2008 - Focusing on targeted areas

The next design session was scheduled in April, two months after the February design session. This time allowed me to develop a wireframe mockup of an initial web-based interface design based on the priorities selected by the participants (see Appendix M). Additionally, I continued to program the initial design functionality and necessary backend installation and preparation of the content management software with which the web site is developed. These initial steps were shared with the participants at the April meeting, along with a proposed timeline for the remaining design components (see Appendix N).

Four survivors participated in the Tuesday night meeting, and eleven professionals participated in the following Wednesday meeting.

I presented the wireframe design to the group and explained what each proposed section would include, referring back to the conclusions from the February priorities discussion. This meeting confirmed the selected priorities and offered the group a chance to discuss the current directions of the project. This meeting was important not only for me to gain approval for my next big programming task, but it also allowed the group to come together and further develop their shared vision. I also met individually with several participants who could not attend this meeting to include their input at this stage in the process.

At the end of this design session, I presented six focus areas that required additional, more targeted discussions and decisions (see Appendix O). These areas were text, content, testing, marketing, categories, and rules. The participants were invited to participate in one or more of these "steering committees." While these committees did not officially meet as a group, I engaged the participants individually via email, telephone, and face-to-face meetings to discuss or comment on their specific areas. Certain key participants, such as the experienced cancer web site developer, were especially active and helpful individual collaborators during this time.

4. May 2008 – Finalizing the mission and design

The next design session was scheduled for May, when most of the software and design was completed. The development progress was shared with the group to confirm their approval on and to offer another chance for minor comments and suggestions. For example, one critical decision was to finalize and confirm the privacy levels, such as the types of users who had access to certain user-generated content (e.g. survivors/co-survivors, professionals, and the general public).

Four survivors participated in the Tuesday night meeting, and four professionals participated in the following Wednesday meeting.

The primary focus of this design session was to collaboratively develop the mission statement to be publicly displayed as part of the live online community. I created a draft mission statement based on the current directions of the project and my own understand of how the participants shared vision had developed. The participants generally agreed with and approved of this draft, and helped to tweak specific phrasings and bullet points into the final, published mission statement.

Also, at this meeting we discussed what the participants would like to see evaluated in the live online community. We discussed the goals and measurable outcomes in order to ground future evaluation and measures of success in the desires and expectations of the actual community members.

The collaborative effort to create the mission statement and determine the goals was a fitting completion to these initial design sessions, in which reaching a shared vision together was emphasized and valued.

The participants also appreciated and approved the title of the web site to be "CanConnect: The Cancer Community Connection of Middle Tennessee." In the December design session, one participant had suggested the name "Cancer Community Connection." Then, a fellow graduate student friend of mine suggested the simpler title of "CanConnect" prior the May meeting.

5. July 2008 – Final Feedback

The live online community web site was officially launched on June 8th with a booth at a local cancer survivorship day community celebration. This was a soft-launch, to begin to get initial users while still receiving individual design feedback from the study participants. The users who registered on the live site were not considered part of the research study and their data was not used in the research evaluation.

In July 2008, the final design session of the study was held as both a celebration of the successful web site launch and as an opportunity for the participants to share final feedback on the collaborative design process. This meeting included both the professional and survivor participants.

Three survivors and eight professionals participated in this meeting. Additionally, I engaged feedback from ten participants who could not attend this meeting via individual meetings and phone conversations.

Following this meeting, I continue to maintain live web site, with a larger launch and marketing/outreach effort planned for after the completion of my PhD, at which point the community members will be re-engaged in the collaborative process.

Comments on the Collaborative Design Process

The collaborative design process included four sets of meetings prior to the initial launch of the online community, and one meeting following the initial launch. Starting with a blank slate, the community member contributed a wide range of exciting ideas, from which initial priorities were then decided. Initial iterative development was completed while getting individual feedback and group input on key areas of the design. Before completing the final steps of the design, emphasis was placed on simultaneously finalizing the shared vision for the mission and goals of the online community. Soon after the initial launch, the design phase participants were brought together to comment on the overall collaborative design process and the final design.

A repeated theme of the collaborative design process is the effort in finding ways to present complex technological concepts and design decisions in ways that the participants can grasp the ideas and make informed decisions. The goal was not just about receiving approval to move forward with the project, but the intent was to facilitate transparent discussions and decisions so that we as a group can move forward with a shared vision. The approach to building transparent relationships and synergy among the participants (and myself as the researcher/developer) is discussed further in the next section of the results.

The strategies and structure of the collaborative design process evolved as the shared vision and iterative system development progressed. While the goal of the June launch was targeted from the beginning of the project, the specific focus of each design session evolved as needed to reach this deadline. This process serves as a guide and example for future collaborative informatics design efforts working with a similar timeline.

The eight principles of the integrated Community PARADE methodology (Figure 3.1) guided this collaborative design process. In addition to conducting qualitative data collection and analysis throughout the process, the collaborative effort produced a real-world action in the creation of the online community. The process focused on fostering relationships with the community members and building on their strengths, while also valuing and including them as the clients to test and use the developed software. The flexible approach to the process allowed for all participants to contribute input and design suggestions throughout all phases of the development. Additionally, this process included opportunities for the participants to learn more about the local community and learn new strategies for online technologies in cancer support.

The integrated cycles of the Community PARADE methodology also guided the process, although the initial design process discussed in this research only represents the initial cycles of the online community development. The cyclical components of nurturing the participation in the live online community, planning sociability, and improving the usability of the interface design all continue throughout the early launch of the online community.

Design Components that Address Opportunities to Improve the Community

The final design components of the online community are described below, along with brief comments on how each component addresses to the opportunities to improve the community identified earlier in this study.

Mission Statement

> **CanConnect's mission** is to bring together local cancer survivors and community partners through a shared vision and innovative online collaboration.
>
> CanConnect currently covers the middle Tennessee/greater Nashville community. **Our goals include:**

Connecting cancer patients, survivors, and any individuals who are touched by cancer through personal shared stories, experiences, and wisdom.

Increasing awareness and participation in cancer-related events, news, resources, and programs through a community-driven network.

Producing multimedia content (video, articles, etc.) that highlights the people and programs in our local community.

Connecting partners in health-care and community organizations to collaborate and share strategies and knowledge.

CanConnect recognizes the cancer survivorship community includes all people living with cancer (from diagnosis to beyond treatment), their family, friends, and co-workers, as well as the health care and community professionals, fundraisers, and volunteers.

Main/Home Page

Learn how CanConnect can help you

I am a...

- Cancer patient, survivor, family, or friend
- Community partner
- Health care professional
- Volunteer/general public

October is
Breast Cancer Awareness Month
in Middle Tennessee

Overview & Stories

1. View all breast cancer links
2. Breast cancer survivor stories

News & Events

1. Local breast cancer news
2. Community calendar of events

Programs & Groups

1. Breast cancer non-profits
2. Programs and services
3. Breast cancer support groups
4. Hospitals and clinics

Other Resources

1. Post-treatment and survivorship
2. Financial assistance
3. Mammograms

Click here for CanConnect's September Theme of the Month

Click here for CanConnect's June-August Theme of the Month

Dunkin' Donuts Family Fun Run and Walk-A-Thon (1 day)

A Celebration of Colo-rectal Cancer Survivorship (3 days)

Kidney Cancer Group (6 days)

VICC's Hal Moses receives national and local honors

Video of Nashville Predators Hockey Fights Cancer Night on Oct 25

Figure 4.1. CanConnect Home Page

The main CanConnect home page features the theme of the month in the center, user login and CanConnect-focused links on the left, and upcoming events and recent news on the right.

Opportunities addressed:

- *Underserved Populations (gender-neutral color choice to include men, as well as women)*

Theme of the Month

October is
Breast Cancer Awareness Month
in Middle Tennessee

Overview & Stories

1. View all breast cancer links
2. Breast cancer survivor stories

News & Events

1. Local breast cancer news
2. Community calendar of events

Programs & Groups

1. Breast cancer non-profits
2. Programs and services
3. Breast cancer support groups
4. Hospitals and clinics

Other Resources

1. Post-treatment and survivorship
2. Financial assistance
3. Mammograms

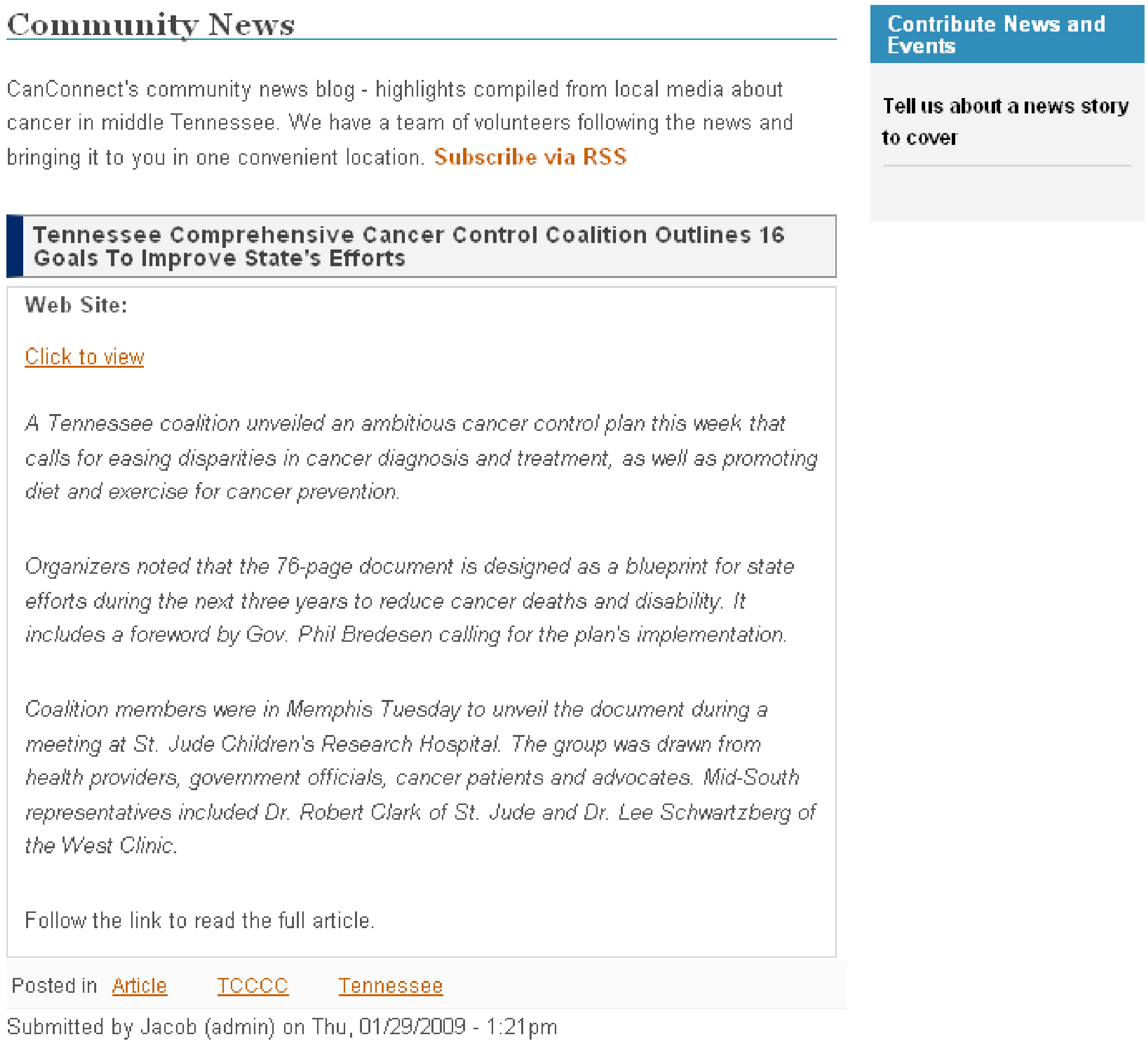
Figure 4.2. Theme of the Month

The theme of the month provides a space for featured topics, such as the nationally-recognized cancer awareness months, or other highlighted aspects of the community. The theme can include profiles of local cancer survivors, volunteers, and professionals, as well as relevant organizations, news, and events. The initial topics for the theme of the month were determined and approved by the research participants.

Opportunities addressed:

- *Awareness (of cancer awareness months and local individuals and organizations)*

Community News Blog



Community News

CanConnect's community news blog - highlights compiled from local media about cancer in middle Tennessee. We have a team of volunteers following the news and bringing it to you in one convenient location. **Subscribe via RSS**

Tennessee Comprehensive Cancer Control Coalition Outlines 16 Goals To Improve State's Efforts

Web Site:

Click to view

A Tennessee coalition unveiled an ambitious cancer control plan this week that calls for easing disparities in cancer diagnosis and treatment, as well as promoting diet and exercise for cancer prevention.

Organizers noted that the 76-page document is designed as a blueprint for state efforts during the next three years to reduce cancer deaths and disability. It includes a foreword by Gov. Phil Bredesen calling for the plan's implementation.

Coalition members were in Memphis Tuesday to unveil the document during a meeting at St. Jude Children's Research Hospital. The group was drawn from health providers, government officials, cancer patients and advocates. Mid-South representatives included Dr. Robert Clark of St. Jude and Dr. Lee Schwartzberg of the West Clinic.

Follow the link to read the full article.

Posted in Article TCCCC Tennessee

Submitted by Jacob (admin) on Thu, 01/29/2009 - 1:21pm

Contribute News and Events

Tell us about a news story to cover

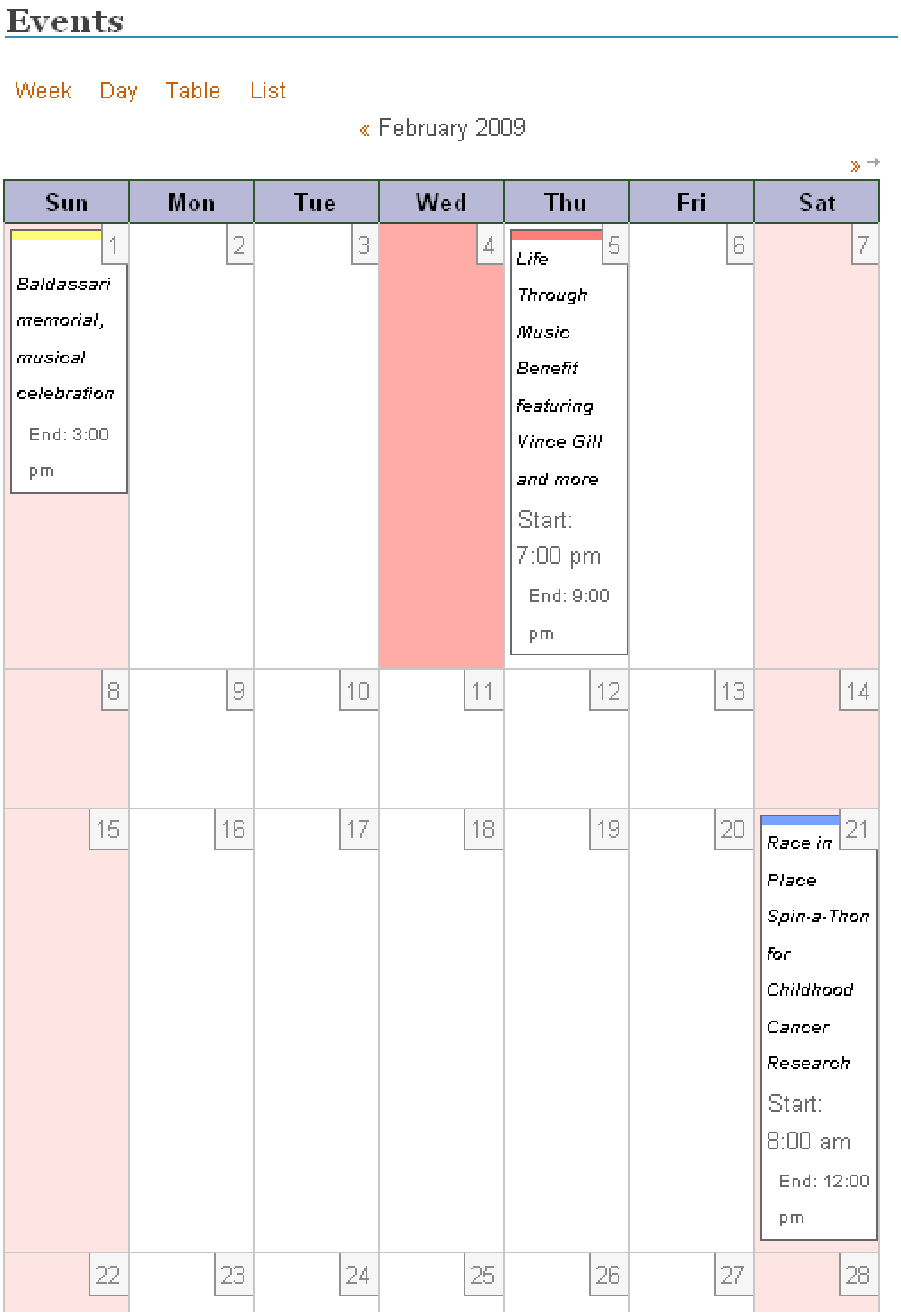
Figure 4.3. Community News Blog

The CanConnect community news blog features local community announcements and links to local cancer-related news from other online news media, organizations' web sites, and identified news from real-world newspapers and advertisements. Combined with the event calendar, the news blog is the main design component that follows the pulse of the local community. A submission form is included for any individual to submit news stories to feature.

Opportunities addressed:

- *Awareness (of current announcements, local cancer-related news, and conversations in the community)*
- *Knowledge and Relationship Management (archiving history of local news, announcing new staff and programs)*

Events Calendar



Events

« February 2009 »

Sun	Mon	Tue	Wed	Thu	Fri	Sat
1 *Baldassari memorial, musical celebration* End: 3:00 pm	2	3	4	5 *Life Through Music Benefit featuring Vince Gill and more* Start: 7:00 pm End: 9:00 pm	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21 *Race in Place Spin-a-Thon for Childhood Cancer Research* Start: 8:00 am End: 12:00 pm
22	23	24	25	26	27	28

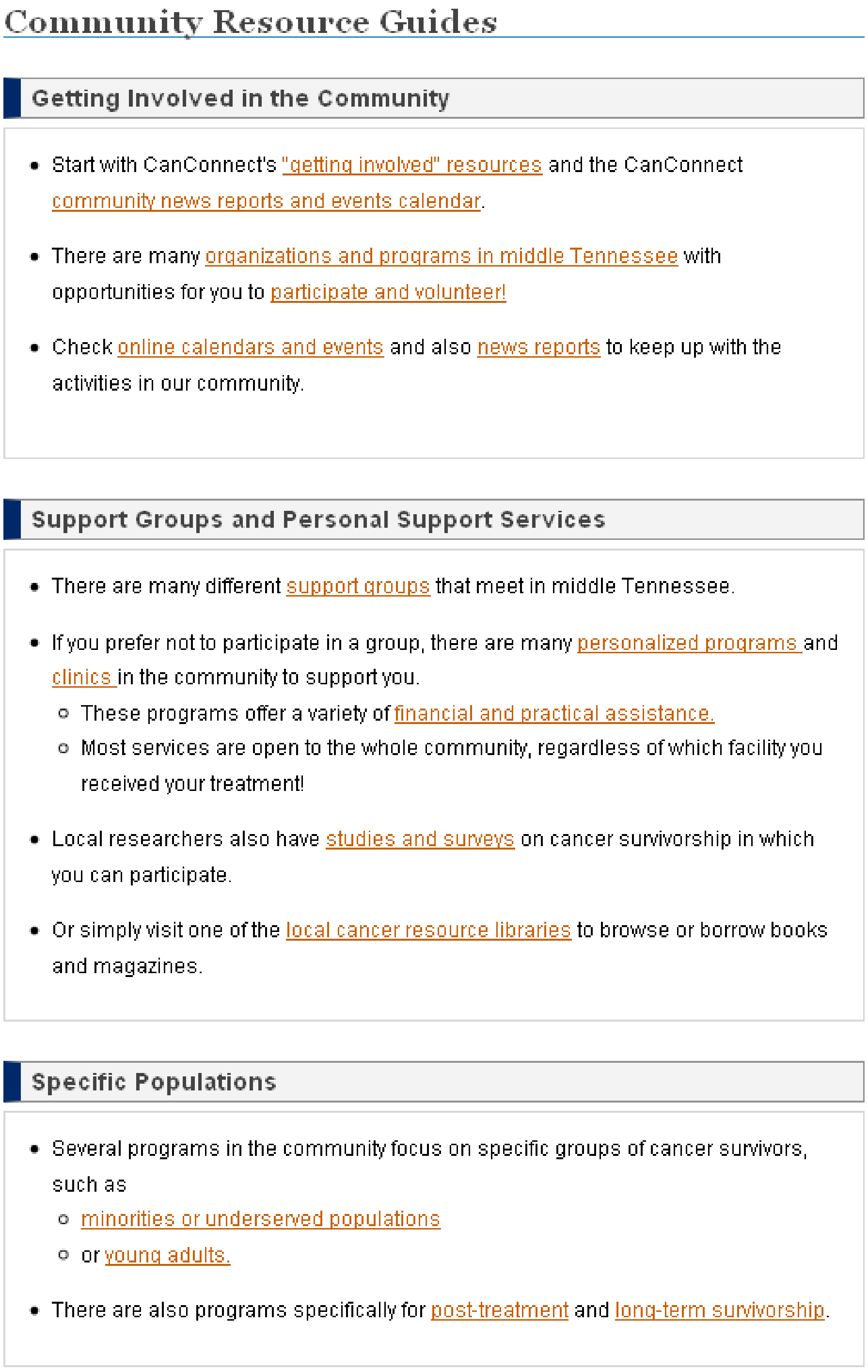
Figure 4.4. Events Calendar

Along with the news blog, the events calendar includes upcoming cancer-related events from all local organizations. This feature is similar to the news blog, but specific to events with a specific date and time. For example, the announcement of a new support program would be included on the news blog, while the date and time for each meeting or activity would be included on the calendar.

Opportunities addressed:

- *Awareness (of current events)*
- *Knowledge and Relationship Management (archiving history of local events)*

Text-Based Resource Guide



Community Resource Guides

Getting Involved in the Community

- Start with CanConnect's "getting involved" resources and the CanConnect community news reports and events calendar.
- There are many organizations and programs in middle Tennessee with opportunities for you to participate and volunteer!
- Check online calendars and events and also news reports to keep up with the activities in our community.

Support Groups and Personal Support Services

- There are many different support groups that meet in middle Tennessee.
- If you prefer not to participate in a group, there are many personalized programs and clinics in the community to support you.
    - These programs offer a variety of financial and practical assistance.
    - Most services are open to the whole community, regardless of which facility you received your treatment!
- Local researchers also have studies and surveys on cancer survivorship in which you can participate.
- Or simply visit one of the local cancer resource libraries to browse or borrow books and magazines.

Specific Populations

- Several programs in the community focus on specific groups of cancer survivors, such as
    - minorities or underserved populations
    - or young adults.
- There are also programs specifically for post-treatment and long-term survivorship.

Figure 4.5. Text-Based Resource Guide

young adult, teenagers

- Life Coaching for Living Beyond Cancer (LCFLBC)
- Welcome Back: Facilitating the Return to School for Children with Cancer
- AYA Cancer Patients and Survivors: Teenage, Adolescent and Young Adult on Facebook
- TEAM UP Tennessee: HPV Toolkit
- Katie's Helping Hand
- Planet Cancer - Cancertainment
- Make-A-Wish Foundation of Middle Tennessee
- CoolPeopleCare.org
- 1st Annual It's Always Something Essay Contest
- Code Pink

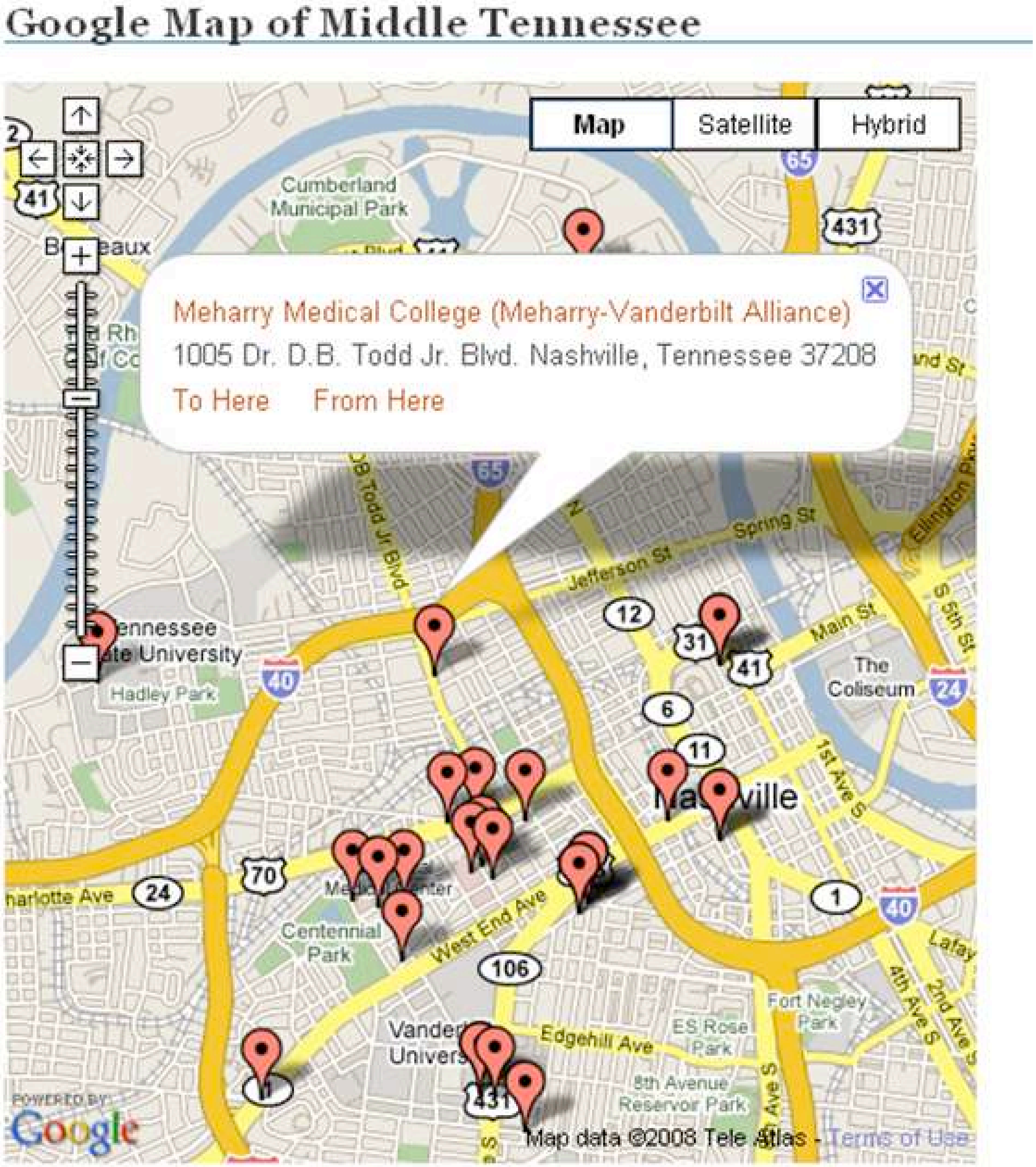
Figure 4.6. Text-Based Resource Guide Listing of Resources

The resource guide provides links to all cancer survivorship and supportive care resources identified in the local community that have been added to the database. The resources range from an organization to a specific recurring program to a web site or video. The resources are categorized by tags assigned when adding the resource to the database. The resources listings are accessed through synthesized links and descriptions (“windows” into the information). The links point to all resources labeled with a certain tag or combination of tags. The full details of each resource includes a text description and web site link, user comments, tags, and the display of when the resource was last updated.

Opportunities addressed:

- *Awareness (of community-based resources)*
- *Knowledge and Relationship Management (categorizing and synthesizing a database of community resources and organizations)*

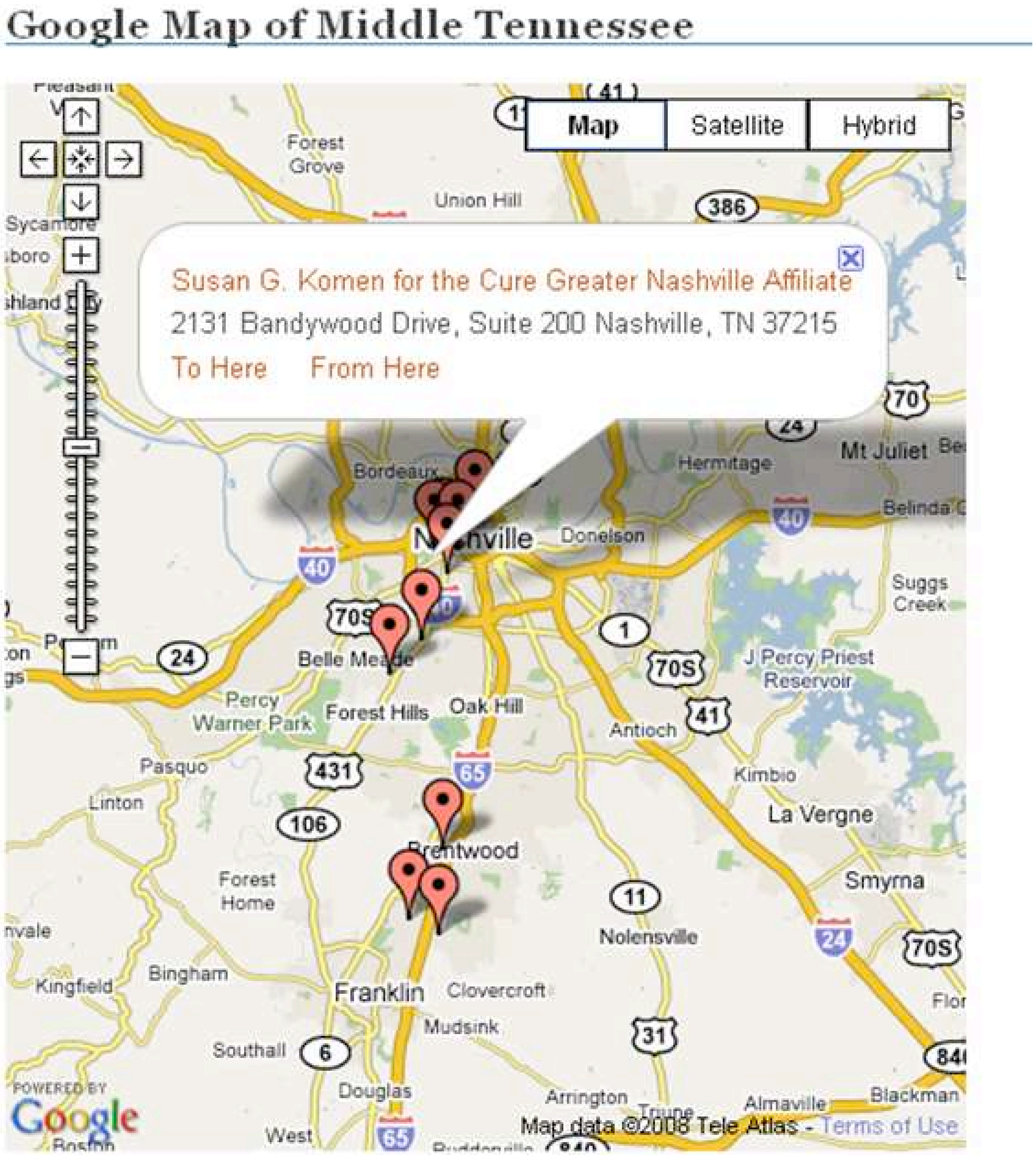
Google Map



Google Map of Middle Tennessee

Meharry Medical College (Meharry-Vanderbilt Alliance)
1005 Dr. D.B. Todd Jr. Blvd. Nashville, Tennessee 37208
To Here From Here

Figure 4.7. Google Map of Middle Tennessee



Google Map of Middle Tennessee

Susan G. Komen for the Cure Greater Nashville Affiliate
2131 Bandywood Drive, Suite 200 Nashville, TN 37215
To Here From Here

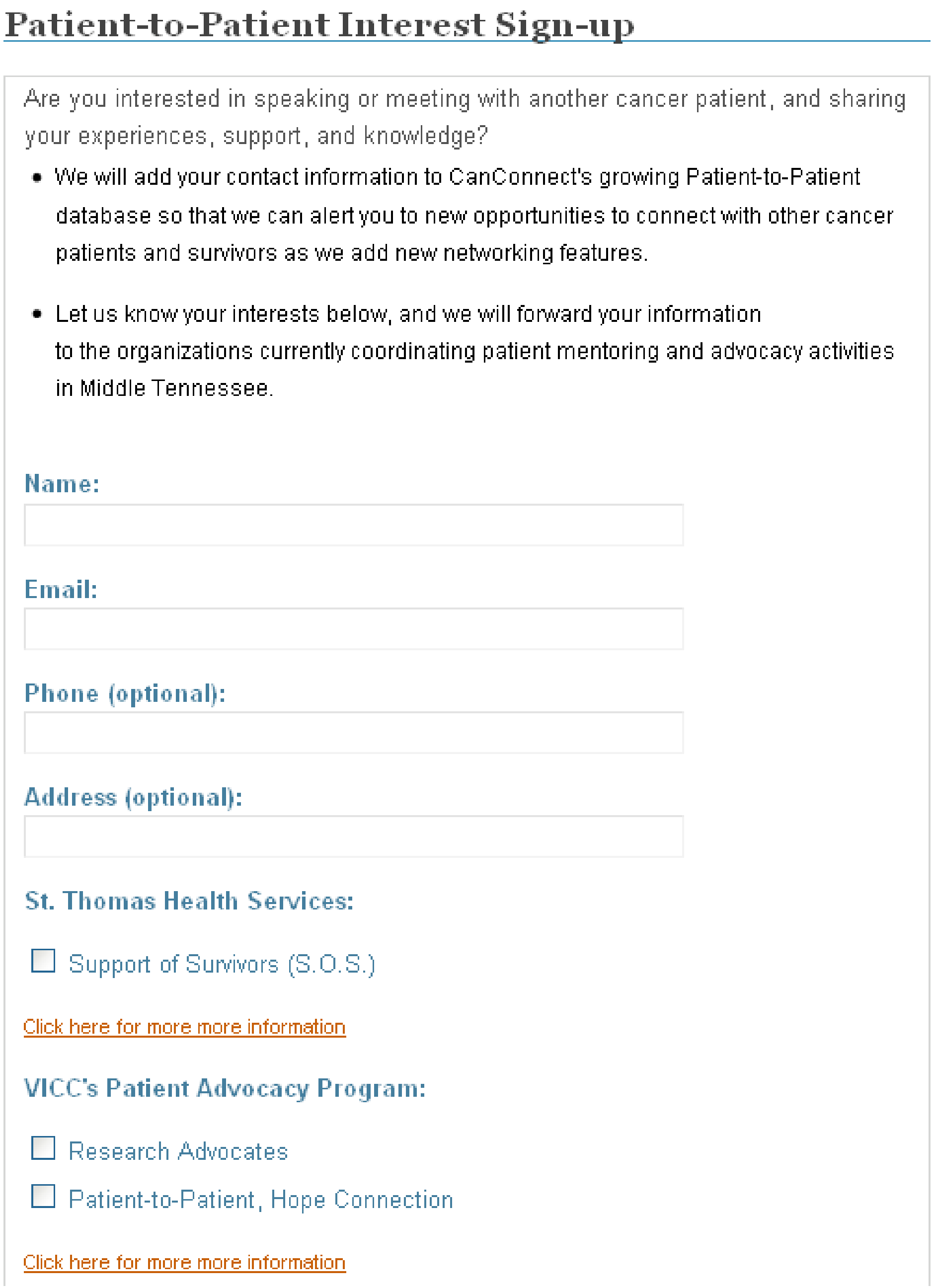
Figure 4.8. Google Map of Middle Tennessee Filtered for Breast Cancer

Any organization or group resource that has been assigned a geographic/street address also is displayed on the Google map of the community. The icon for a specific organization links to the full resource description of that organization. The map also can display only the organizations assigned to a certain tag category (e.g. “breast cancer” or “childhood”). This component provides a more visual, location-based view into the resources available in the community.

Opportunities addressed:

- *Awareness (of geographical locations and nearby organizations)*
- *Knowledge and Relationship Management (visualizing community organizations)*

Get Involved



Patient-to-Patient Interest Sign-up

Are you interested in speaking or meeting with another cancer patient, and sharing your experiences, support, and knowledge?

- We will add your contact information to CanConnect's growing Patient-to-Patient database so that we can alert you to new opportunities to connect with other cancer patients and survivors as we add new networking features.
- Let us know your interests below, and we will forward your information to the organizations currently coordinating patient mentoring and advocacy activities in Middle Tennessee.

Name:

Email:

Phone (optional):

Address (optional):

St. Thomas Health Services:

☐ Support of Survivors (S.O.S.)

Click here for more more information

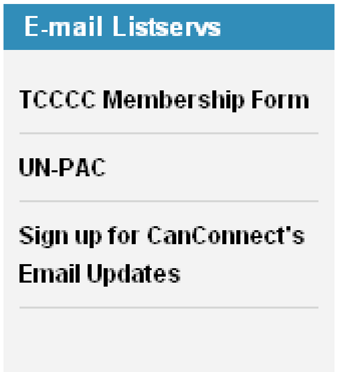
VICC's Patient Advocacy Program:

☐ Research Advocates

☐ Patient-to-Patient, Hope Connection

Click here for more more information

Figure 4.9. Get Involved Patient-to-Patient Sign-up


E-mail Listservs

TCCCC Membership Form

UN-PAC

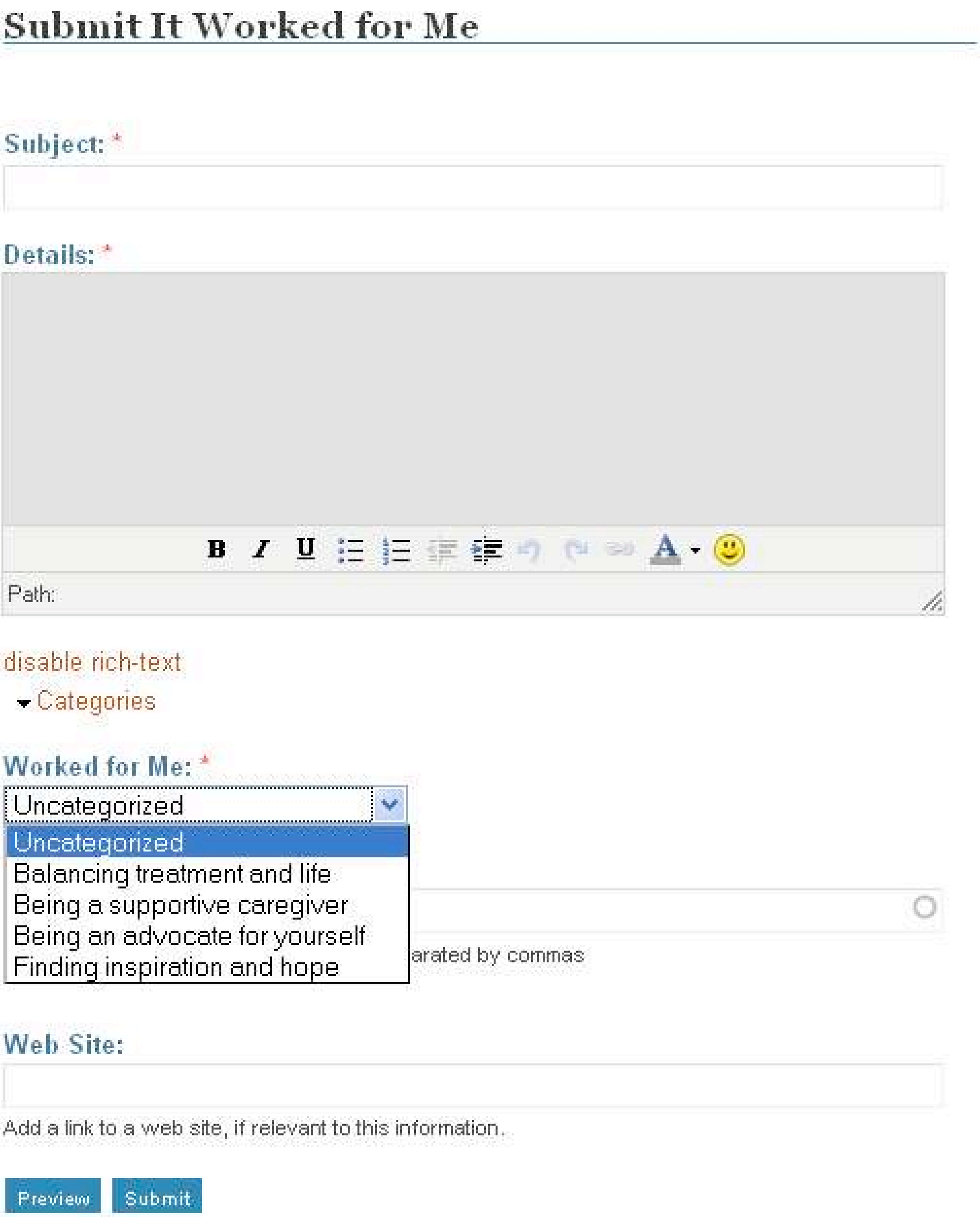
Sign up for CanConnect's Email Updates

Figure 4.10. Email Listservs

The Get Involved section provides links to connect with local community resources and organizations tagged as involving volunteering and advocacy opportunities. Additionally, a cancer survivor can complete a form to express interest in being a patient mentor to a new patient. This feature facilitates survivors connecting with the patient-to-patient opportunities offered by each of CanConnect’s partner organizations. The survivor’s request is forwarded to the representative from the selected organizations. Additionally, this section includes links to sign up for other local cancer-related email listservs.

Opportunities addressed:

- *Awareness (of community involvement opportunities)*
- *Connecting (to volunteering opportunities and local email lists)*



Submit It Worked for Me

Subject: *

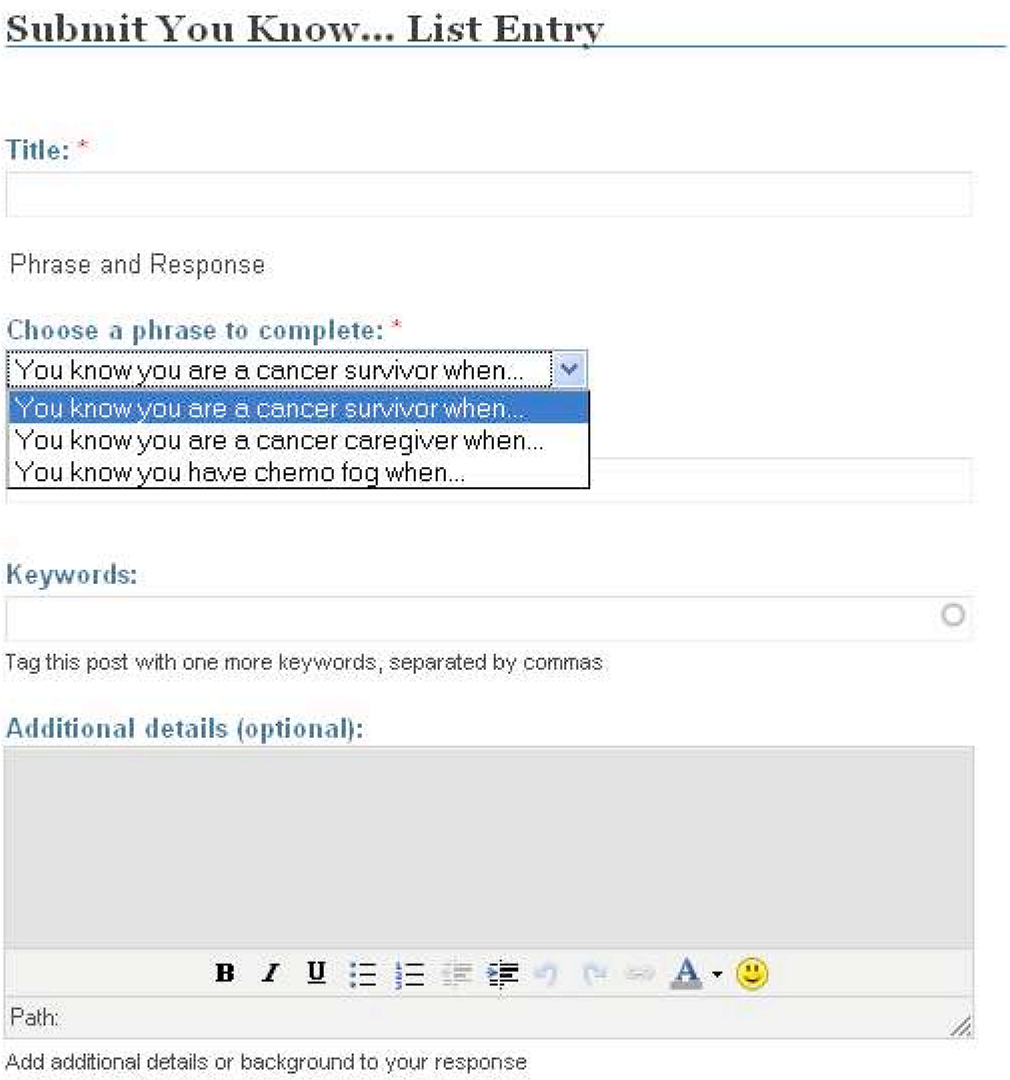
Details: *

Path:

Worked for Me: * Uncategorized

Add a link to a web site, if relevant to this information.

Figure 4.11. It Worked for Me Survivor Form



Submit You Know... List Entry

Title: *

Phrase and Response

Choose a phrase to complete: *

You know you are a cancer survivor when...

You know you are a cancer survivor when...
You know you are a cancer caregiver when...
You know you have chemo fog when...

Keywords:

Tag this post with one more keywords, separated by commas

Additional details (optional):

Path:

Add additional details or background to your response

Figure 4.12. Hope Through Humor Survivor Form

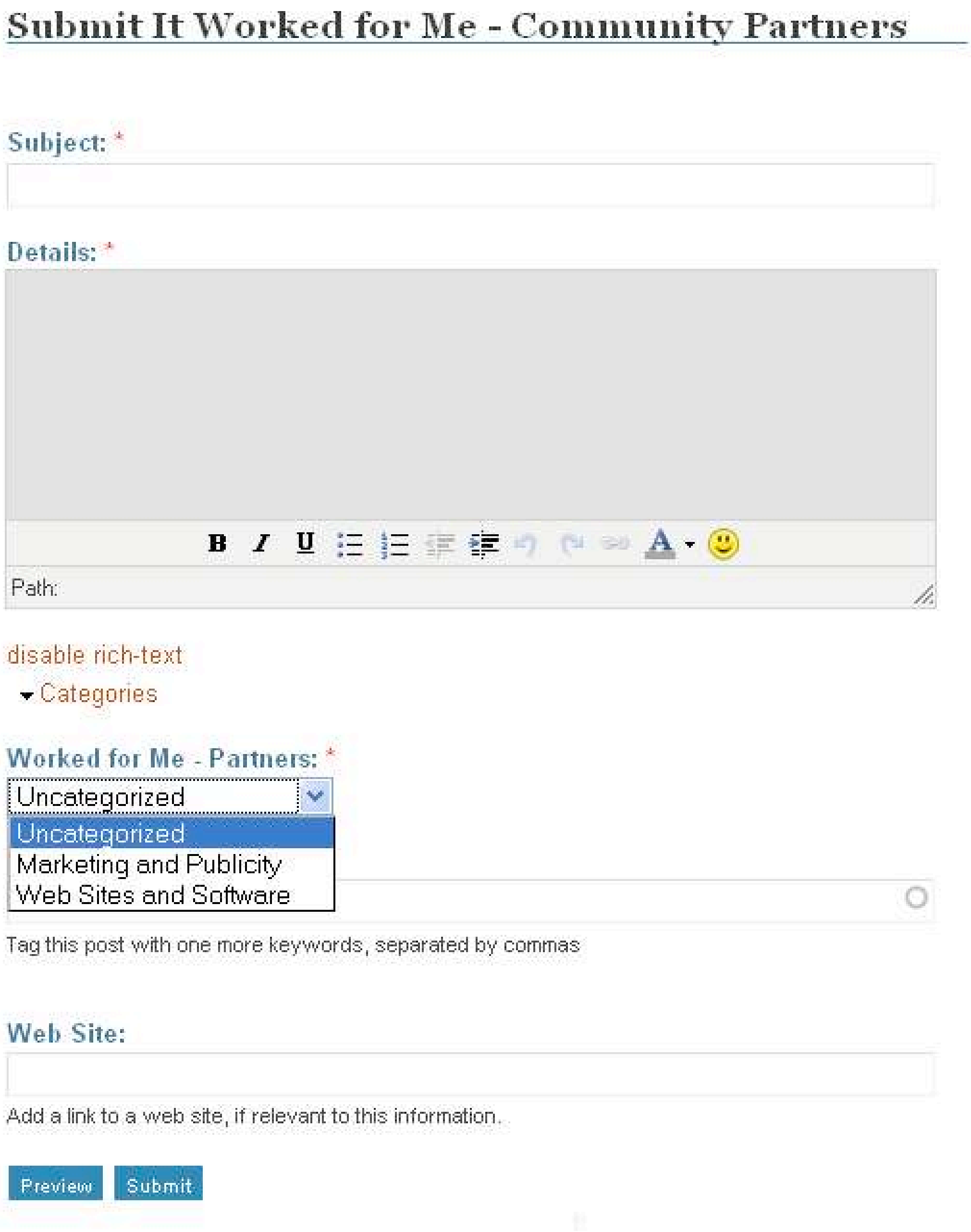
The design sections described up to this point all are accessible by the general public without registering as a user and logging into the online community. Sharing Hope can only be accessed by registered CanConnect users, and only those users registered as cancer survivors or co-survivors can contribute content.

The Sharing Hope section allows survivors to share their wisdom and stories related to cancer survivorship. The two components are “It Worked for Me” (practical tips and strategies), and “Hope through Humor” (humorous stories shared by completing sentences such as "You know you are a cancer survivor when..." or "You know you are a cancer caregiver when...").

Opportunities addressed:

- *Awareness (of cancer survivors’ experiences)*
- *Connecting (with fellow cancer survivors)*
- *Knowledge Management (compiling of experiences)*
- *Community & Survivorship Focus (on practical tips and hope, rather than medical issues)*

Community Partners



Submit It Worked for Me - Community Partners

Subject: *

Details: *

Path:

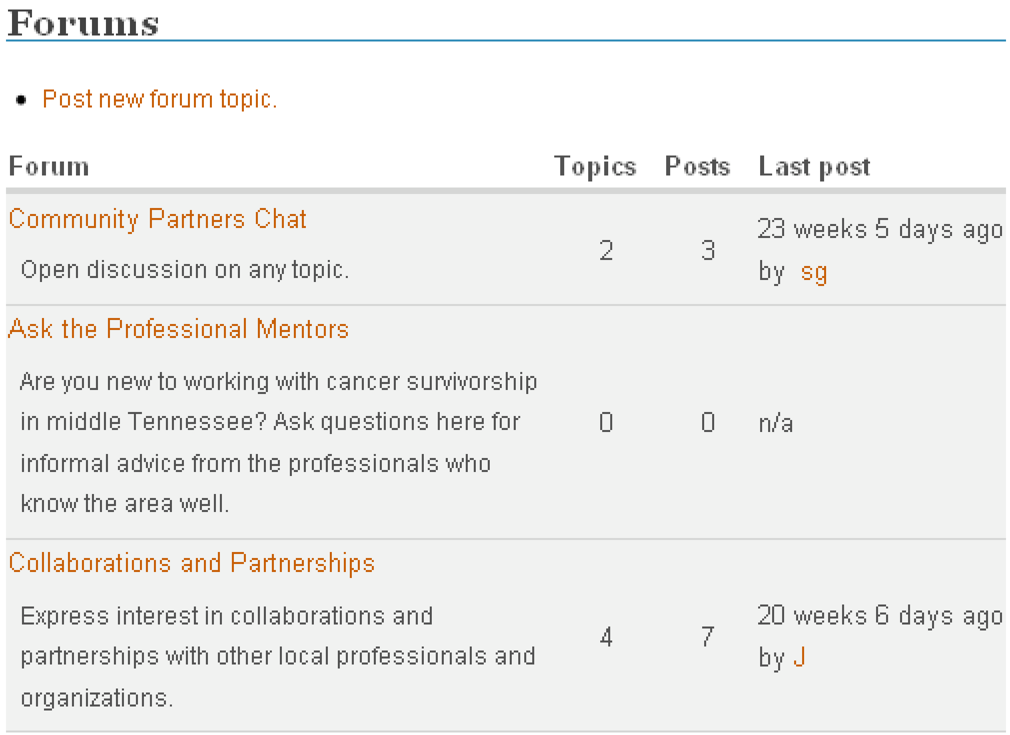
Worked for Me - Partners: * Uncategorized

Tag this post with one more keywords, separated by commas

Web Site:

Add a link to a web site, if relevant to this information.

Figure 4.13. It Worked For Me Community Partner Form



Forums

- Post new forum topic.

Forum	Topics	Posts	Last post
Community Partners Chat Open discussion on any topic.	2	3	23 weeks 5 days ago by sg
Ask the Professional Mentors Are you new to working with cancer survivorship in middle Tennessee? Ask questions here for informal advice from the professionals who know the area well.	0	0	n/a
Collaborations and Partnerships Express interest in collaborations and partnerships with other local professionals and organizations.	4	7	20 weeks 6 days ago by J

Figure 4.14. Community Partner Forums

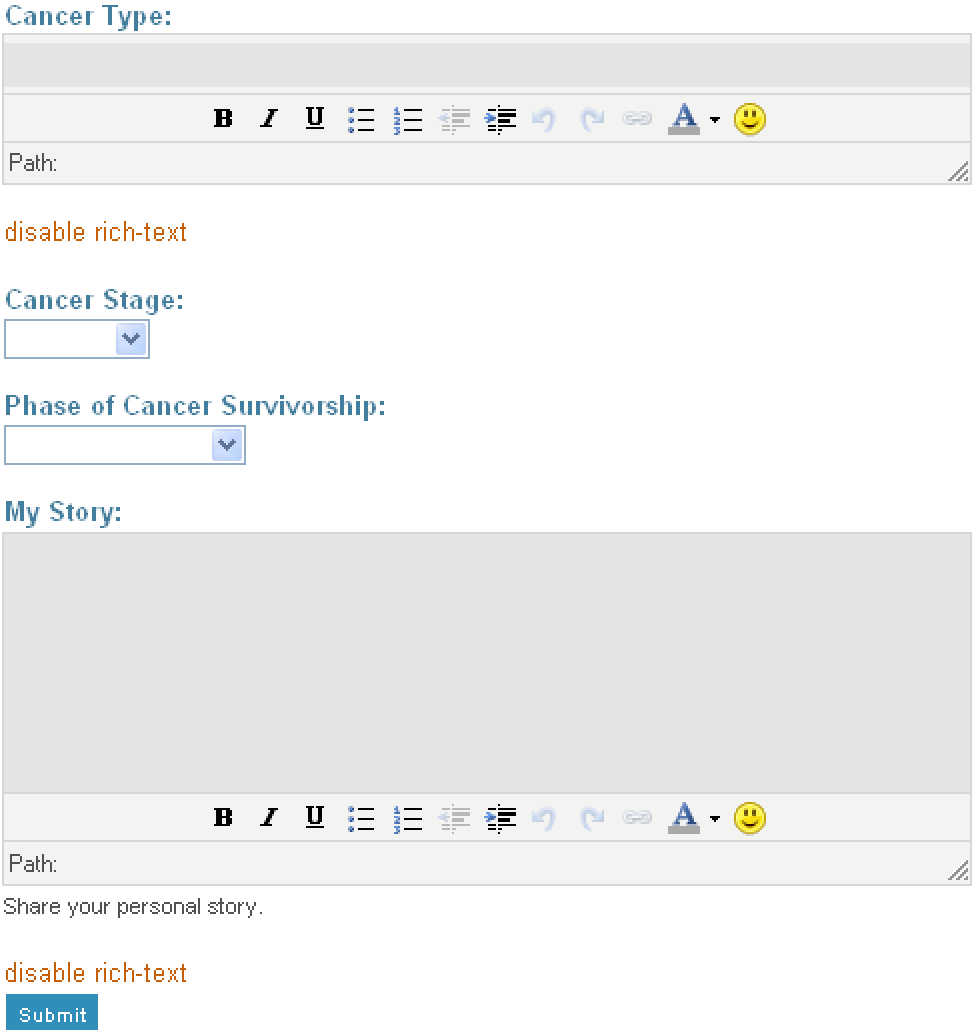
The Community Partners section is a private area only accessible by the users actively assigned by the CanConnect administrator/manager. Users are given access to this system after meeting or speaking with a CanConnect representative in person or via telephone. The purpose is for this section to be a safe environment in which the local professionals feel comfortable sharing information, connecting, collaborating with each other.

The forum is a standard discussion forum that allows new topics or questions to be posted by any community partner. The “It Worked for Me” is the same concept as with the survivors, but focused on sharing practical tips and strategies between professionals. These tips might include local places to submit press releases, tips for sending email surveys, etc.

Opportunities addressed:

- *Awareness (of each other's interests and efforts)*
- *Connecting (with other professionals)*
- *Collaboration & Co-opetition (sharing knowledge and creating synergy between community partners)*

User Profiles



Cancer Type:

disable rich-text

Cancer Stage:

Phase of Cancer Survivorship:

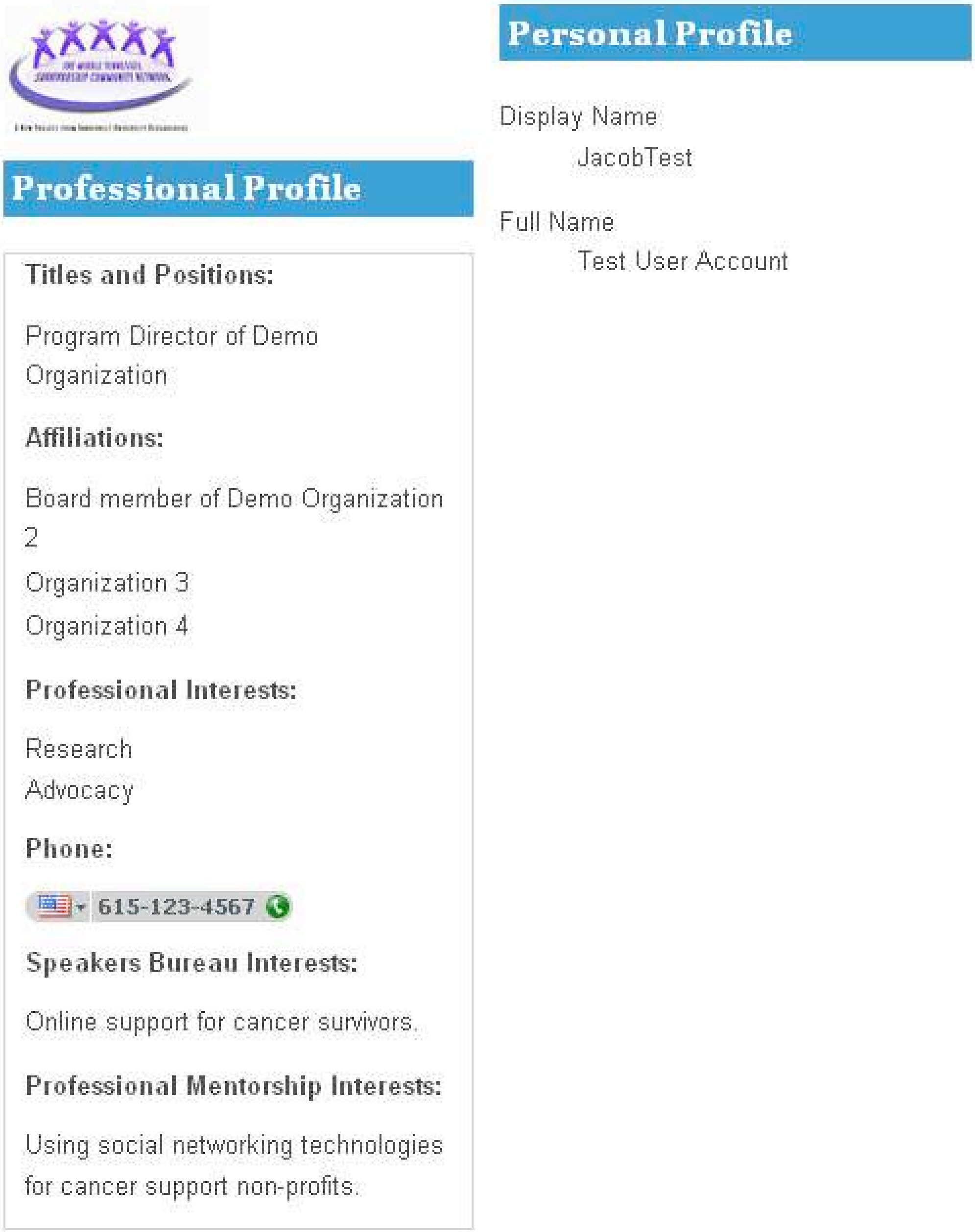
My Story:

Share your personal story.

disable rich-text

Figure 4.15. Cancer Survivor Profile

Registered cancer survivors and co-survivors can complete a personal profile that can be accessed and read by other registered cancer survivors. This profile can include general cancer type and time of diagnosis, as well as a free-text area to share one’s story.



Professional Profile

Titles and Positions:

Program Director of Demo Organization

Affiliations:

Board member of Demo Organization 2

Organization 3

Organization 4

Professional Interests:

Research

Advocacy

Phone:

615-123-4567

Speakers Bureau Interests:

Online support for cancer survivors.

Professional Mentorship Interests:

Using social networking technologies for cancer support non-profits.

Personal Profile

Display Name
JacobTest

Full Name
Test User Account

Figure 4.16. Social Networking Personal Profile

Registered community partners can create a professional profile that can be accessed and read by other community partners. This profile includes sections for professional affiliations, interest in mentoring other professionals, and interest in speaking in the community. The purpose of these profiles is to facilitate awareness of each other's work and interests and to make it easier to connect with other professionals in the local community.

Opportunities addressed:

- *Awareness (of others' stories)*
- *Connecting (with peers and colleagues)*

User Types

As mentioned in the previous descriptions, a user can register for the site in a different types of self-assigned roles. When registering for a user account on CanConnect, individuals can assign themselves to one or more roles: 1. Cancer Patient/Survivor; 2. Family or Friend; and 3. Professional or General public. As described previously the Cancer Patient/Survivor and Family or Friend (co-survivor) types can submit content to the Sharing Hope section. The other user type is Community Partner, which is assigned separately by the site administrator.

Opportunities addressed:

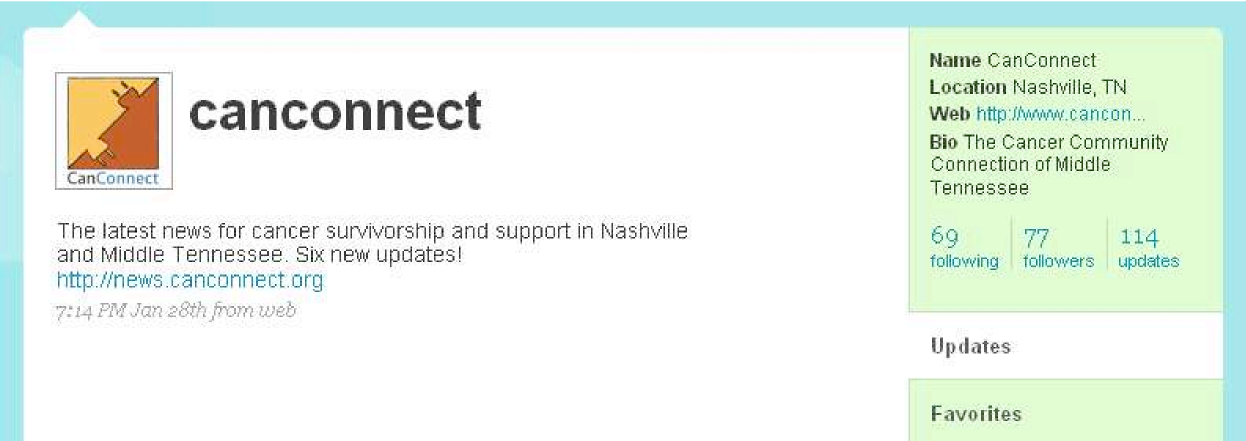
- *Follows the inclusive definition of the cancer survivorship community*

Social Networking/Social Media Extensions

The final components of the online community design are the extensions of CanConnect into other existing social networking (aka social media) web sites.

CanConnect profiles on other social media sites allow the CanConnect online community to extend its reach by listening and participating in the existing conversations occurring online by the local and global communities.

The design of the CanConnect online community includes profiles on Facebook, Twitter, MySpace, and YouTube. These profiles allow for sharing news/events, creating awareness (for CanConnect and cancer survivorship in general), and aggregating content relevant to the local cancer community (e.g. MySpace friends and YouTube videos associated with cancer and middle Tennessee).



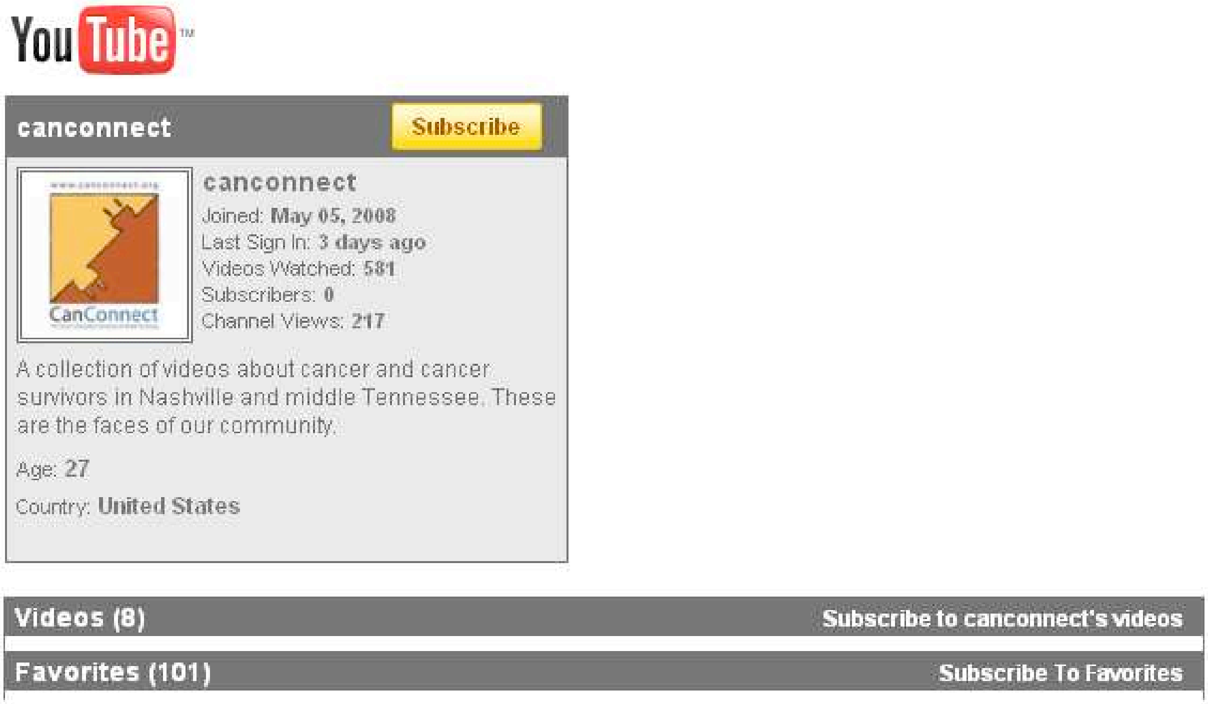
canconnect

The latest news for cancer survivorship and support in Nashville and Middle Tennessee. Six new updates!
http://news.canconnect.org
7:14 PM Jan 28th from web

Name CanConnect
Location Nashville, TN
Web http://www.cancon...
Bio The Cancer Community Connection of Middle Tennessee

69 following
77 followers
114 updates

Figure 4.17. CanConnect Twitter Profile



canconnect

Joined: **May 05, 2008**
Last Sign In: **3 days ago**
Videos Watched: **581**
Subscribers: **0**
Channel Views: **217**

A collection of videos about cancer and cancer survivors in Nashville and middle Tennessee. These are the faces of our community.

Age: **27**
Country: **United States**

Figure 4.18. CanConnect YouTube Profile

Similarly, paper-based Sharing Hope cards were designed to be placed in partner organizations locations, to allow local survivors to contribute their wisdom without needing access to the Internet. Likewise, general CanConnect display cards designed for local partner organizations extend the reach of the online community further into the real-world community.

Opportunities addressed:

- *Awareness (listening to and sharing the existing cancer-related conversations)*
- *Underserved Populations (printed cards in partner organizations for those with limited Internet access)*

Summary of the Design Components

The components of the design address several of the identified opportunities to improve the community, most noticeably improving awareness of the local cancer survivorship community. The design of the online community creates awareness for local news and events, current cancer awareness months, as well as awareness of local people, programs, and resources that are available in the local community. This awareness is complemented by interface features that facilitate the next step of connecting to volunteer and/or participate in local community efforts. By improving awareness and connections throughout the local cancer survivorship community, these design components serve to enhance both participation and recognition of the many existing support programs. In these two areas alone, the online community can contribute significantly to the community-wide needs of all local programs by facilitating their outreach efforts through a centralized effort.

Additionally, the online community provides an archive of this community's shared history through the local events and news stories. This aspect of the design helps to manage the community's knowledge over time. Also supporting knowledge management, unique interfaces such as Google maps help visualize and synthesize the local information into manageable and accessible knowledge. Rather than merely existing in the "personal databases" of certain local experts, the online community makes this knowledge and history available to all members of the local community.

A significant aspect of the overall design is that it brings together the many diverse members of the local cancer survivorship community, including cancer survivors, family, friends, medical and community professionals, and the general public. The mission statement, user roles, and the multi-dimensional nature of the different components match the inclusive definition of the cancer survivorship community. While bringing the diverse members together, the design also recognizes the need for specialized spaces for cancer survivors and family members to share their experiences and stories. Additionally, a separate private space allows community partners to create connections and discussions that build synergy and collaboration. Finding a balance between unifying all members of the community and providing targeted functionality for each type of member is a key success of this design.

The use of social networking and social media components provides the backbone to the functionality in the overall design of online community. User profiles and user contributed content create new opportunities for conversation within the online community, and the extensions into other social networking web sites (and real-world activities) allow the online community to participate in the existing conversations. By integrating the new online community with existing community spaces, the online community is able to better represent and include all types of local community members and groups. For example, the general public and community volunteers may be included more naturally through the extensions into existing social networks, rather than directly through the main CanConnect web site.

The design components and their respective opportunities address are summaries in Table 4.4.

Table 4.4: Summary of Design Components and opportunities addressed

Design Component	Opportunities addressed
Main/Home Page	• Underserved Populations (gender-neutral color choice to include men, as well as women)
Theme of the Month	• Awareness (of cancer awareness months and local individuals and organizations)
Community News Blog	• Awareness (of current announcements, local cancer-related news, and conversations in the community) • Knowledge and Relationship Management (archiving history of local news, announcing new staff and programs)
Events Calendar	• Awareness (of current events) • Knowledge and Relationship Management (archiving history of local events)
Text-Based Resource Guide	• Awareness (of community-based resources) • Knowledge and Relationship Management (categorizing and synthesizing a database of community resources and organizations
Google Map	• Awareness (of geographical locations and nearby organizations) • Knowledge and Relationship Management (visualizing community organizations)
Get Involved	• Awareness (of community involvement opportunities) • Connecting (to volunteering opportunities and local email lists)
Sharing Hope	• Awareness (of cancer survivors' experiences) • Connecting (with fellow cancer survivors) • Knowledge Management (compiling of experiences) • Community & Survivorship Focus (on practical tips and hope, rather than medical issues)
Community Partners	• Awareness (of each other's interests and efforts) • Connecting (with other professionals) • Collaboration & Co-opetition (sharing knowledge and creating synergy between community partners)
User Profiles	• Awareness (of others' stories) • Connecting (with peers and colleagues)
User Types	• Follows the inclusive definition of the cancer survivorship community
Social Networking/Social Media Extensions	• Awareness (listening to and sharing the existing cancer-related conversations) • Underserved Populations (printed cards in partner organizations for those with limited Internet access)

The Community Resource Synthesis Model

Over the course of the collaborative design process, a new medical informatics model was developed for synthesizing the local community's wisdom of community-based resources. The Community Resource Synthesis Model focuses on one role of the multi-faceted online community: creating more awareness and opportunities to connect with the local resources for cancer survivorship and supportive care. As previously identified in the community's opportunities to improve, there is a need for cancer survivors and their medical providers to be more aware of and connected to community-based support resources. The four components to this model are 1. Grounding in community; 2. Resources; 3. Tagging; and 4; Synthesis. Figure 4.19 shows a graphical illustration of the Community Resource Synthesis Model.

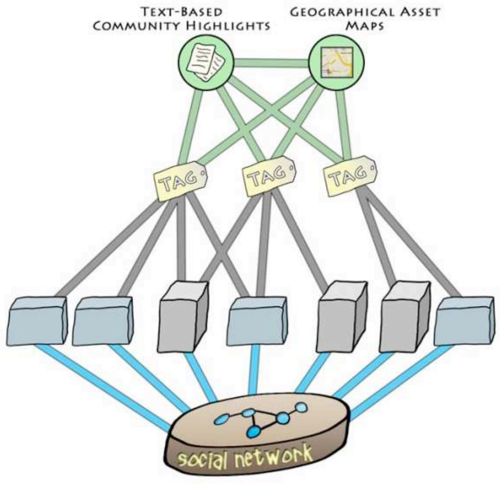


Figure 4.19. The Community Resource Synthesis Model

Grounding in Community

The first, bottom-level component of the Community Resource Synthesis Model suggests the informatics system should be grounded in relationships in the community. This includes trusted partnerships with organizations and volunteers in the real-world community, as well as participation in an online community and local social media conversations. The community relationships provide initial contributions of valuable resources as well as updates as resource information changes. Because the relationships are ongoing and growing, the knowledge contributed by these relationships continues to grow and evolve as well.

Resources

As demonstrated in the earlier results section, which defined the range of members and resources in the community, the informatics system must be flexible and able to accommodate a wide range of resource types. This flexibility is necessary to include and highlight the diverse organizations, programs, and activities, and tangible resources that provide support in the local community.

Tagging

Because the number of support resources in the local community can become overwhelming, tagging is used to categorize resources by cancer type, by geographical region, and by other strategic boundaries or characteristics. Each individual resource is assigned to one or more tags, which provides additionally flexibility to include a wide range of resources types.

Synthesis

Tagging provides an initial level of filtering for the total list of community-based resources. However, because of the multi-dimensional nature of the cancer survivorship community, there may still be an overwhelming number of tags for users to navigate and interpret. The tags are an unordered collection of words and phrases, without a cohesive flow, structure, or personality.

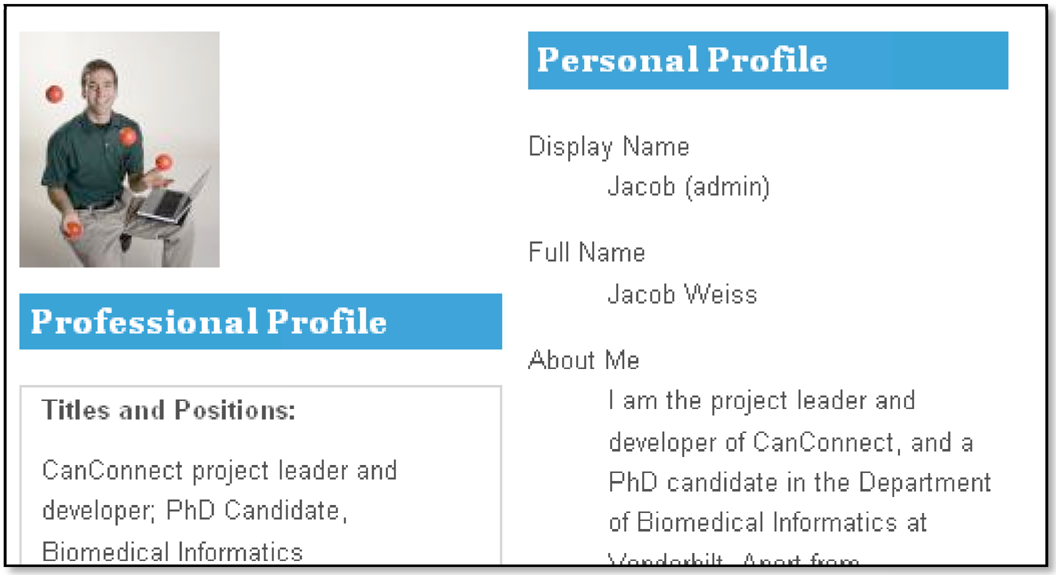
A higher-level synthesis of tags is necessary to provide what one participate termed “windows into the community.” This synthesis aims to present portions of the resources in more manageable pieces. Examples of this synthesis includes visualizing resources and tags geographically on a Google Map, highlighting a different subset of resources each month, text-based collections of tags in paragraph form, and other automated or expert-based approaches.

The synthesis also provides an opportunity to present the information in a more personable and conversational manner, which more closely resembles the valuable roles of patient navigators and social workers. These professionals do not merely connect patients with resources, but they help them navigate, comprehend, and synthesize all of the necessary resources available in the community. This role of synthesizing and navigating can be included in informatics systems in novel ways to increase awareness and understanding of the local community-based resources.

Drupal: A Technology Framework that Supports the Community Resource Synthesis Model

In order to apply the Community Resource Synthesis Model in practice, it is necessary to choose and/or develop a technology framework that can support this model. Drupal[134] is an open-source content management system with components that naturally match the four levels of the informatics model.

Drupal's social networking and role-based access capabilities support the grounding of the system in community relationships (Figure 4.20). Drupal also includes the ability to create custom content types that provide flexibility for the variety of resources types that can be included (Figure 4.21). Tagging capabilities are included in the standard Drupal installation, which allows tags to be applied to all resource types and to a range of other components in the system (Figure 4.22). Finally, Drupal allows developers to create new modules that integrate into the existing social networking, content type, and tagging structures (Figure 4.23). Custom modules provide an opportunity to develop novel approaches to synthesize and visualize the online content through simple and creative interface designs.



Personal Profile

Display Name
Jacob (admin)

Full Name
Jacob Weiss

About Me
I am the project leader and developer of CanConnect, and a PhD candidate in the Department of Biomedical Informatics at Vanderbilt. Apart from

Professional Profile

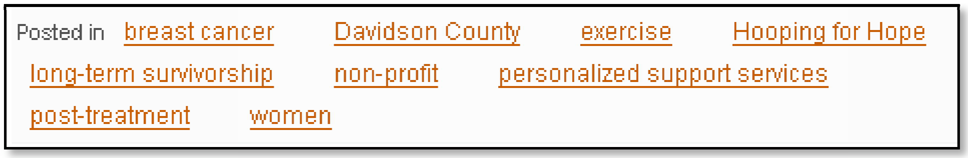
Titles and Positions:

CanConnect project leader and developer; PhD Candidate, Biomedical Informatics

Figure 4.20. Social Networking Profile in Drupal

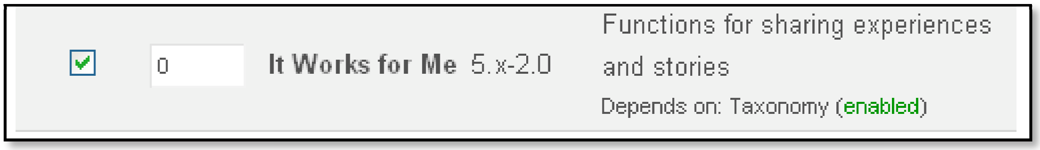
Field	Type
Web Site	Link
Description	Text
Type	Text
Funding Support Offered	Text

Figure 4.21. Custom Content Type in Drupal



Posted in breast cancer Davidson County exercise Hooping for Hope long-term survivorship non-profit personalized support services post-treatment women

Figure 4.22. Tagging in Drupal



☑ 0 **It Works for Me** 5.x-2.0 Functions for sharing experiences and stories
Depends on: Taxonomy (enabled)

Figure 4.23. Custom Module Management in Drupal

While other content management systems or home-grown software also could have been applied to the Community Resource Synthesis Model, Drupal has proven to be a successful choice as the foundation of this informatics application. Informatics researchers and developers can use the design components of the CanConnect online community as a guide to inform future decisions on software frameworks for related online community applications.

Section summary

These results contribute new knowledge to the design of medical informatics systems in several ways. First, the summary of the collaborative design activities complements the Community PARADE methodology as an approach to guide similar community-based informatics design efforts. The emphasis on discovering and synergizing the collaborative relationships in the community is expanded upon in the next section of the results.

Second, the final design components demonstrate how emerging web-based technologies can be used to address six identified opportunities to improve the local cancer survivorship community. The design components were developed through a shared vision of the participants and contribute valuable design strategies for supporting the diverse range of members in the local cancer survivorship community.

Finally, a theoretical model was developed out of the collaborative design to inform the development of medical informatics applications that synthesize a local community's wisdom of community-based support resources. The Community Resource Synthesis Model is especially significant in the area of cancer survivorship, in which there exists a recognized need to better connect patients and providers to these community-based services.

As a whole, these results advance future medical informatics research and applications for improving supportive care and the sense of community in local cancer survivorship communities. As the design components and informatics model are further refined, this informatics-based approach also may translate to other targeted areas of health and community-based initiatives.

Results 4: The Community Discovery Framework: A Relationship-based Approach to Discover and Develop Local Community Partnerships for Informatics Design

Introduction

The previous section described the form and function of the online community created collaboratively by the participants in this study. This live, functioning web site demonstrates a simple, yet significant conclusion of this study: an online community *can* be collaboratively designed to bring together members of the local cancer survivorship community for partnership and support.

The details of the final design do not imply *how* to bring the community together to ensure success in this collaborative effort. A deeper understanding and evaluation of the collaborative design process is necessary to replicate, translate, or expand this approach to other local communities.

The sense of community analysis showed that building collaborative efforts through trust and transparent relationships is essential for successful initiatives in the local cancer survivorship community. While the online community web site is the primary goal in the design process, the relationships in the local community must be nurtured throughout the software design and development. This research analysis explores *how* to discover and build these relationships, and *why* these relationships are essential for community-based, medical informatics initiatives. This analysis resulted in a relationship-based framework for discovering and developing partnerships in the local cancer survivorship community for the design of an online community.

The data for this study comes from the middle Tennessee cancer survivorship community, but the findings may translate to other health conditions (e.g. disabilities), other geographic regions (e.g. east/west Tennessee and other states), or even other local-based communities of interest (e.g. middle Tennessee performing arts). This study seeks to provide full details of the collaborative design process so that researchers and communities in other domains can apply the framework and findings where appropriate.

Summary of Methods

While leading the design sessions and software development, I also conducted a qualitative evaluation of the collaborative design process involving cancer survivors and local professional participants. Because I am the lead on many aspects of the project, I am in the unique position to evaluate the collaborative efforts as a heavily engaged participant observer. A fellow medical informatics student participated in the design sessions and served as a peer debriefer during the analysis, but I conducted the primary data collection and analysis.

Semi-structured field notes were recorded during and after each collaborative design session as well as in the individual feedback meetings with participants. These field notes documented the discussions and responses during the design sessions as well as my own notes and observations about the meetings. In-process analysis was conducted through written theoretical notes, and personal notes of my own reactions and concerns also were recorded during this data collection.

I also recorded field notes at all times of the day, including the morning, afternoon, and evening, as well as during activities such as falling asleep in bed, taking showers, and walking to the library (emailing notes to myself on a cell phone). These written notes provide an extensive log of my observations, experiences, and ideas throughout the collaborative design process.

The field notes from the design sessions and the log of my daily notes were imported as sources in the Nvivo software package for qualitative analysis. I analyzed these notes using grounded theory methodology to discover categories and themes of the collaborative, creative process. The data were iteratively coded and labeled, and these codes were continually arranged and re-arranged in hierarchical categories. This analysis incorporated many aspects of the collaborative process, including relationship building, software development, the creative process, the research process, and the participatory design activities.

Based on these results, the community discovery framework focuses on finding and building trusted and transparent relationships and on the implications for the informatics design process. This focus on community relationships is chosen due to its importance to the process as indicated by the participants. Also this focus contributes new knowledge to the field of medical informatics by analyzing the roles of local community relationships in the development of informatics systems. As discussed in previous chapters, medical informatics can improve software development and participatory design efforts by applying the relationship-building principles of participatory action research and community-based participatory research.

The qualitative evaluation is complemented by a quantitative assessment of the collaborative design process after the final July design session. Twenty of the forty design phase participants completed and returned a twelve-item collaborative function scales survey either at the final group design session or by mail. These scales evaluate aspects of the design process such as leadership, relationship building, conflict management, and other collaborative characteristics.

The Community Discovery Framework for Online/Offline Capacity Building

Overview

The grounded theory analysis of the field note data resulted in a framework for discovering and developing local community relationships in the collaborative design of an online cancer survivorship community. This framework incorporates a combination of real-world and online approaches to relationship-building with community partners.

The community discovery framework describes the process of iteratively finding and engaging community partnerships. Informatics software development models and community-based participatory research models both include initial steps of a needs assessment, defining the community, and identifying key informants. This framework adds to the existing models by bringing real-world community-building principles and strategies into the software development cycle, while also applying informatics-based strategies to a real-world community development process. The community discovery framework contributes to both fields by illustrating the strategies for success in an *integrated* online and real-world approach to building local communities for health and wellness.

Additionally, the details included in the framework serve as a case study for how this approach was applied to the middle Tennessee cancer survivorship community. Specific strategies are illustrated along with feedback and comments from the community members who participated in the collaborative process. This framework focuses on how to bring the diverse members of the community to the table and foster synergy in their collaborative efforts. The community discovery framework does not replace other long-term models for community-building; its purpose is to complement and enhance these established approaches.

Elements of this framework can be seen in current conversations on social media, social networking, search engine optimization, and other areas of emerging web-based technologies. However, it was not previously known how strategies such as community listening and participation can apply to cancer survivorship in a local community. This framework also serves as a case study of how these strategies have been applied to a specific, health-based community context.

Seven Elements of the Community Discovery Framework: Discovery Cycle and Meta-Process

The community discovery framework is presented in two interrelated parts: the discovery cycle to find, understand, contact, and synergize the community members; and the associated meta-process to manage knowledge and relationships, participate in the community, and continue over time. Table 4.5 and Figure 4.24 present these seven elements of the community discovery framework. Each element is expanded upon using the themes and categories identified in the analysis of the field notes.

After each element and its sub-categories are discussed, descriptive statistics of the collaborative functioning scales are presented to complement the qualitative feedback from the participants about the process. Finally, this section of the results concludes with a discussion of how to apply this framework and the implications of the framework for both medical informatics and community-based participatory research.

Table 4.5. Seven Elements of the Community Discovery Cycle and Community Discovery Meta-Process

Discovery Cycle	**Discovery Meta-Process**
Find people and programs	*Manage* knowledge and relationships
Understand what drives the community members	*Participate* and contribute in the community
Contact and engage	*Continue* to follow the pulse of the community
Synergize the community	

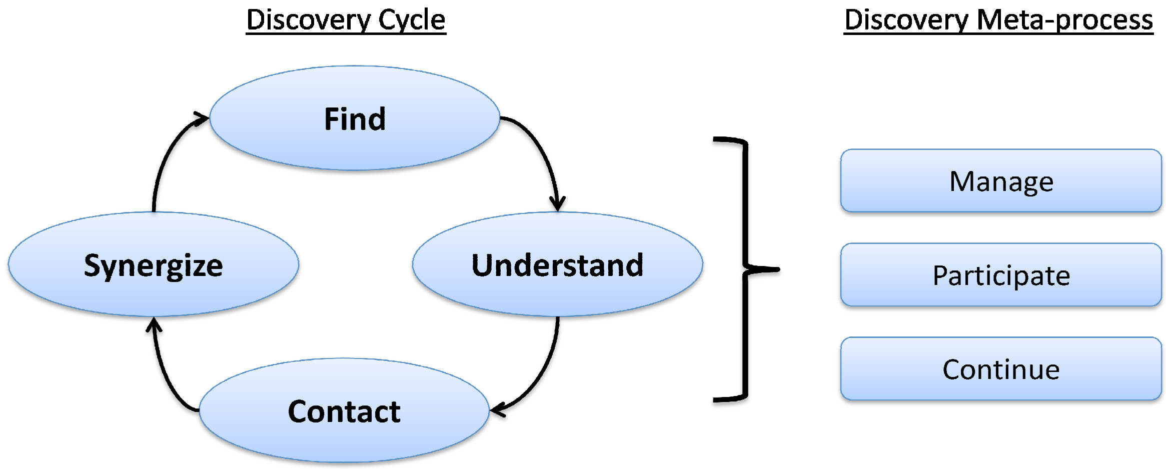


Figure 4.24. Diagram of the Community Discovery Cycle and Community Discovery Meta-Process

1. Discovery Cycle

The four elements of finding, understanding, contacting, and synergizing make up the cyclical process of discovering collaborative partners in the local cancer survivorship community. For each element, themes and examples are provided to illustrate the how the discovery cycle occurred in this design project.

1.1 Find people and programs

The first step of discovery is to find the people, programs, and organizations to include in the collaboration and the online community.

Strategies identified in field notes include where to look, who to find, and how to search. Table 4.6 summarizes the themes and categories of finding people and programs.

Table 4.6. Find People and Programs

Where to look	1. Local Community	*a. Documents and media*
		b. Meetings and events
	2. Online	*a. Archived documents and articles*
		b. Cancer-related web sites
		c. Social media and networking
Who to find	1. Local organizations/programs	
	2. Passionate cancer advocates/ leaders	
	3. Local community leaders	
	4. Collaborators through parallel interests	
How to search	1. Variety of online queries	*a. Cancer topic*
		b. Location
		c. Cancer type
		d. Month
		e. Person's name
		f. Organization name
	2. Iteration	*a. Learn relevant keywords*
		b. Unexpected tangents
		c. Friend of a Friend (FOAF)
		d. Follow-up searches for additional context
	3. Filtering	
	4. Real-world conversations and recommendations	
Challenges to Finding	1. Information out of date	
	2. Information not online	
	3. Information not centralized	
	4. Less information on underserved populations	

1.1.a Where to look

People and programs were found through a variety of sources both in the local community and online.

Local Community

In the local community, potential community partners were found in documents and media, as well as through meetings and events.

Documents and media

Document and media sources include posters and flyers in local cancer organizations, billboard advertisements, local television news stories and interviews, and local papers and magazines.

While many of these sources involve more passive observation, reading daily, weekly, and monthly local publications is a more active search process. Potential contacts were discovered in local publications through featured articles on survivor advocates and local support programs, lists of local grant funders and recipients, paid advertisements, and community event listings. The publication types included local university news magazines, local health magazines, and local newspapers.

Meetings and events

People and programs were discovered by seeing and/or meeting people at local community events such as presentations by local health professionals on relevant topics to cancer survivorship, community celebrations related to cancer, participant lists from local events that target non-profits, local academic conferences and workshops, booths at health fairs/conferences, and local technology-focused interest groups

Finding people at community events relates to the community discovery meta-process element of participation in the local community, which is discussed later in this framework.

Online

Online sources for finding people and programs include archived documents and articles, cancer-related web sites, and social media and networking sites.

Archived documents and articles

Local programs and key individuals were found in online archived documents and articles. These documents included PDF newsletters from local non-profits, local cancer community profiles, conference presenter lists and power point presentations, and online news stories.

The online news stories included archived video coverage on local television station web sites, articles publicizing fundraisers for local non-profits, volunteer/wish lists for local non-profits, letters to the editor, and featured stories.

Cancer-related web sites

Cancer-related web sites include clinical trials web sites for local survivorship/supportive care studies, web sites of local cancer treatment/support organizations, web sites of their national affiliates, lists of their community partners, lists of local support groups, and online resource guides filtered locally by zip code and/or by cancer keywords.

Social media and networking

Browsing and searching popular social media and social networking sites uncovered more people and programs in the local cancer community. These sites included volunteer matching sites (both national and locally developed; Craigslist using 'cancer' keywords); profiles, groups, pages, and events on social networking sites (Facebook, MySpace), text-based social media (blog search, Twitter microblogging), photo/video-based social media (Flickr, YouTube), as well as city-based special interest networks, city guides, and local social media aggregation sites.

As will be described more in the following 'how to search' category, each of these sites was explored using a variety of cancer and city/state based search queries.

1.1.b Who to find

A variety of people, programs, and organizations were found in these sources. Four categories of contacts were discovered using these sources: local organizations/programs, passionate cancer advocates and leaders, general community leaders, and potential collaborators through parallel interests.

Local organizations/programs

This category includes organizations and non-profits that are based in middle Tennessee and also local affiliates of national non-profits. These organizations may be focused solely on cancer support, or cancer support may be one aspect of their support priorities in the community.

Passionate cancer advocates/leaders

This category includes local volunteers who lead cancer-related fundraising and awareness efforts, local cancer survivors who share their story, support group leaders, and cancer support professionals ‘in the trenches’ who know the local cancer community landscape.

Local community leaders

Local community leaders include community foundations that support local non-profits, other non-profit organization leaders, key contributors to other local web sites, and ‘unofficial’ leaders who community members trust and respect.

Collaborators through parallel interests

Potential collaborators were found through parallel interests that could be applied to the online and/or real-world cancer survivorship community. This includes technology experts who also have an interest in cancer, health, or non-profits. Also, my own personal contacts in the community have abilities that can contribute to cancer support and the online community (e.g. student organizations, performing/variety arts, film production, and graphic design).

Potential collaborators also include people and programs that may benefit from the online community or my personal volunteering to help their own community efforts. These types of community partners are described more under the participation element of the community discovery meta-process.

1.1.c How to search

In addition to knowing where to look and who to find, knowing *how* to find these connections is essential to the community discovery process. Throughout this study, I documented the types of queries, keywords, and iterative steps that were used to find people and programs in the local cancer community. I identified four themes in the strategies used to discover the community by searching: a variety of online queries, iteration, filtering, and real-world conversations.

Variety of online queries

A variety of search terms were used in online queries to find people, programs, organizations, and resources for cancer survivorship in middle Tennessee. The types of queries documented in the field notes are:

1. *Cancer topic + location, in multiple combinations:* Cancer topic search terms included cancer, oncology, survivorship, cancer survivors, cancer news, cancer research, cancer nutrition, cancer blog, cancer survivors day, glbt cancer, cancer survivor book, and cancer songs. The location search terms included Tennessee, Tenn, middle Tennessee, Nashville, Clarksville, as well as other local cities and county names.
2. *Cancer type + location:* Search for a specific cancer type (e.g. ovarian cancer) with local terms.
3. *Cancer type + location + month:* Include the month or its abbreviations (e.g. September or Sept) with searches for the cancer awareness type of that month.
4. *Cancer topic + location + social media site name:* Include the names of social media sites (e.g. MySpace) with searches to find relevant public pages on these sites. Also search within the sites' internal search engines.
5. *Person's name+ location or organization:* Search for a person with location terms or specific organization names to discover relevant connections or partnerships they have in the local community.
6. *Person's name + cancer topic:* Search for a person with cancer keywords to discover their associated cancer-related organizations and activities.

7. *Organization name + location:* Search for an organization's name with location terms to find their local events, connections, and partners.

Many of the cancer topic and location terms were based on information found from previous queries (see also the 'iteration' category). Learning the keywords and synonyms for the subject matter (e.g. cancer, oncology, survivors, etc.), and the terms and abbreviations associated with the local area, are valuable aspects of the discovery process. Each type of search found one or more results with new and relevant information. Google was the primary search tool used for this process.

Iteration

These searches were not carried out with a specific search plan determined in advance. Rather, the types of search queries evolved iteratively as more information was discovered. The themes of the iterative process identified in the field notes include the following categories:

1. *Learn relevant keywords:* The content on each newly discovered web site suggests new cancer topics or location keywords to use in subsequent queries. For example, some newspapers use the abbreviation "Tenn", rather than the full name of Tennessee when citing local cities in an article.

2. *Unexpected tangents:* When looking for information on one topic, a result may directly or indirectly inspire ideas for a new direction in which to

explore the community. Being open to actively exploring these tangents leads to finding entire new areas of the cancer survivorship community. For example, after finding several cancer-related music links, I specifically searched for music and local musicians who are cancer survivors, musicians who have written songs about cancer, and musicians who support the local cancer community. Similarly, looking for information on one organization can lead to tangents of other unexpected organizations to include.

3. *Friend of a Friend:* Friend of a Friend iteration refers to finding links to other people and groups from the web site of a previously discovered organization (e.g. lists of community partners or support groups). Friend lists on social networking pages also provide opportunities for this type of discovery. This iterative browsing complements the active searching by finding links from one group to another based on their publicly listed relationships in the community. For this study, I started with a home base of my own university medical center's web site, and iteratively branched out through the internal links to other departments and through external links to the local community organizations.

4. *Follow-up searches for additional context:* Rather than stopping when finding the basic name and contact information for a person or group, I followed up the initial discovery with a series of searches specifically to

find additional information about these people and groups. Searching for a person or group also finds links for upcoming and past events and programs hosted by that organization. This provides a richer understanding of potential community partners, as well as finding the full web site and contact information for groups that are mentioned briefly on another web site or newspaper article. This approach is discussed further in the see the next step of understanding what drives the partners.

Filtering

Another way to find people and resources is by filtering collections of web sites and media and pulling out only the cancer-related information. This is valuable for the initial discovery process as well as for finding new filtered information in the future.

Examples of filtering for the local cancer survivorship community includes finding videos of local patient stories and highlighting the cancer survivor stories, linking to general health resource listings filtered by ‘cancer’ keywords, and creating playlists on YouTube of all videos relevant to cancer in Tennessee.

Real-world conversations and recommendations

In addition to searching for publicly available information online, I also found new potential community partners through conversations and recommendations from the local community members. The key informant interviews, conducted in the Fall before the beginning of the design phase, played a major role in finding these recommendations.

The interview participants suggested key people and types of organizations to contact, and they also described the general programs and resources that they have used or seen used by others. In addition to the main research process, I found new people and programs in the community from friends, colleagues, and acquaintances that knew my area of interest and directed me to relevant people and programs.

1.1.d Challenges to Finding

A main challenge to finding people, programs, and organizations in the community is that the needed information is not readily available. As illustrated by the range of strategies described above, there was no simple, straightforward way to find everyone and everything in the community.

Information out of date

Online descriptions of programs were out of date. Contact information, such as the name of the program coordinator, was not updated when a staff turnover occurred.

Information not online

In some cases, the needed information about a group or program never was listed online. For example, several local cancer support organizations were listed as support resources on a cancer center web site, but their web site links were not included. Additionally, many of the local cancer support and survivorship programs do not have their own web sites.

Information not centralized

Information about the local cancer community is not centralized in a single location or web site. For example, several organizations have their own events calendars (online and in print), and finding all events for a given month or week requires visiting each of these calendars individually. The same is true for news and announcements from the local cancer support organizations.

Less information on underserved populations

Finding information and key professionals that target underserved populations also proved to be difficult. While a few groups and professional target minorities and lower socio-economic populations, I had trouble finding local support professionals that primarily serve men, couples, families, and young adult populations. It is significant to note that while three of the cancer survivors participating in this study were men, all of the professionals participating in the study were women. Because of this one-sided representation, it is especially important to make an effort to engage more men to represent their perspective in the community (as professionals or as patients and family).

1.2 Understand what drives the community members

The second step of discovery, after finding initial information about a person or organization, is to understand what drives and motivates each member of the community, as well as to learn the relevant background or partnership history. Several of the previously presented strategies for finding people and programs overlap with the approaches used to gain a deeper understanding about them. These strategies include iteratively searching for more information on a particular program and using a variety of cancer and location terms to find all relevant information. This information is valuable in order to develop a more complete picture to contact and engage these people appropriately. This element in the discovery cycle places the researcher/developer on the same page as the potential community partners, to the best extent possible, before actively engaging them.

Two themes for developing this understanding were identified in the field notes, the first theme being relatively straightforward, and the second theme being more complex. First, it is necessary to determine the inclusion criteria of the information for the local cancer survivorship community. Secondly, understanding the motivation and potential for collaboration is needed on multiple ecological levels of the local community (from individual passions to community and cultural factors).

Table 4.7 summarizes the themes and categories of understanding what drives the people and programs.

Table 4.7. Understand What Drives the Community Members

Determining inclusion criteria	1. Credibility	
	2. Appropriateness	
	3. Relevance	
Ecological levels of motivation and collaborative potential	1. Individuals	*a. Recognize unofficial roles*
		b. Casting for targeted

		interests
		d. Scheduling
		e. See from their perspective
	2. Community-wide	*a. History of previous collaboration*
		b. Current efforts and strengths
		c. Current gaps
	3. Culture and Society	*a. Regional areas of interest*

1.2.a Determining inclusion criteria

Three categories were identified in the theme of determining inclusion criteria. These categories are: credibility, appropriateness, and relevance for contacting and including in the online community.

Credibility

I was uncertain of the credibility of some discovered people and programs. For example, it was not clear to me the credibility of a local pharmaceutical company that announced a new, successful treatment approach. Knowing how to determine credibility, and/or who to ask for input, is an important ability for finding community partners. The credibility of a newly discovered program was easier to determine when it was recommended by a trusted partner or located at a respected hospital, medical center, or local non-profit.

Appropriateness

A few resources discovered for local cancer support and awareness were not family friendly, and I was not sure how to include them appropriately. One example is a benefit concert that used the word “F**K” in the show title, and another example is a Nashville-based online contest for breast cancer awareness featuring scantily clad women. Including these groups as community partners may be offensive to some people, but not including these community members might also limit a potential collaborative opportunity with an underserved population (young adults).

Relevance

When searching for information and potential participants online, the items found should be relevant to both cancer and to middle Tennessee. Determining the geographical location of people and resources is a key step towards understanding their relevance to the online community. If a person or organization is based in a city in Tennessee that I did not recognize, I attempted to determine its residing county and geographical location. A quick strategy used to determine county name is to search Google for the city’s name along with the words “county, TN”. The county name typically is listed in the first few results. I also viewed the city on a Google map to estimate how close the city is located to Nashville and middle Tennessee. Also, it is important to note that other cities with the same name may be easily mistaken for a local city in search results (e.g. Nashville, Illinois).

Some cancer support services directly focus on cancer patients and survivors, while other organizations offer more ancillary services. Some of these services may be extremely relevant to cancer survivors, while others are less necessary to include. Determining the relevance of a general social service to the cancer community is another challenge for determining who to contact and engage in the online community.

1.2.b Ecological levels of motivation and collaborative potential

Based on the theoretical framework of ecological systems theory, three levels of the local community were identified in which a person's motivation for collaboration can be understood. These ecological levels of the community include: Individual motivations, community-wide motivations, and societal and cultural motivations for collaboration and partnerships.

Individuals

1. *Recognize unofficial roles*

   In addition to their formal job titles, certain people or groups also play key unofficial roles in the community. Several roles identified in the community through the interviews with key informants include connectors, 'cultural brokers', navigators, 'someone who gets it', leaders with integrity, and a neutral 'Switzerland' (the latter being a group role).

Understanding an individual's motivation and potential for collaboration requires recognizing their unofficial roles that they carry out by choice and by passion, rather than by requirement.

2. *Casting for targeted interests*

   Another step of understanding individual motivations is look for opportunities to match a community members' role and interests with specific aspects of the collaboration and online community. In essence, this process involves being a combined 'casting director' and 'talent agent' for the collaboration, with the goal not only to find the best 'actor' for a part, but also to find the most desired parts for the actor. For example, I learned in the initial interviews of one participant's passion and experience with laughter and play therapy and later invited her to contribute additional brainstorming and input when developing the "Hope through Humor" section of the online community.

   In addition to allowing the participants to choose their own areas of interest in the project, I played an active role in suggesting areas of participation based on a deep understanding of peoples' interests and enthusiasm (see the discussion of building on strengths under the 'Synergize' element of community discover for more on this approach).

3. *Scheduling*

   It is important to understand the community members' schedules in order to accurately assess their interest in participating in the collaborative project. I found that individuals who did not return initial emails or attend initial meetings were still interested in the project but their busy schedules were barriers to participating. For example, one social worker participant who missed several design sessions explained that she had trouble getting away from the clinic during the day.

   Understanding each individual's schedule is important for finding ways to engage these members of the community in ways that work with their schedules. The community members each have busy times of the day as well as busy weeks or months during the year. Getting these people to participate in the collaboration, either in group meetings or individually, requires an awareness and understanding of their schedules and logistical concerns.

4. *See from their perspective*

   Especially for a project leader who is not a cancer survivor and who is not a long-standing community professional, understanding the community members requires the ability to 'see from their perspective' as much as possible. Throughout the collaborative process, I took time to write extensive field notes and think deeply about the potential significance of design ideas from the perspective of the participants. Writing these notes was a creative process in which I used my imagination and grounded it in my knowledge about the community members. This mindset is essential for casting and engaging people appropriately, and also for becoming more of a leader ‘who gets it’ by understanding and appreciating the cancer survivorship community on a deeper level.

Community-wide

1. *History of previous collaboration*

   Understanding the history of collaboration in the community helps make it possible to recognize both the positive and negative contexts in which a new collaborative effort is proposed. For example, previous collaborations for cancer awareness and support by the local music industry community suggest directions for including the leaders of these past efforts in this project. Similarly, certain events that were community-wide collaborations in the past are currently held separately by individual organizations. The history of the community’s collaborative successes and failures colors the participants reactions to the proposed collaborative project. Understanding and respecting this history and the key players involved helps address potential barriers and facilitating factors to getting the right groups and individuals involved is this effort.

2. *Current efforts and strengths*

   In addition to understanding the history of successful collaborative efforts in the community, understanding the community's current strengths and successes provides a foundation for new collaborative efforts. Specific strategies include discovering which programs are open to all patients regardless of cancer treatment facility; learning which support programs and organizations are commonly used, praised, or recommended by other community members; and finding similar community-based collaborations and networking efforts with which to partner appropriately.

   The approach to learning about other current collaboration efforts in the local cancer community is especially important in order for this new initiative to not duplicate these efforts unnecessarily, and to find ways to combine efforts that build on each others' strengths. Understanding the community's strengths helps when trying to engage the leaders of these efforts to participate in this new project without feeling a sense of competition.

3. *Current gaps*

   In addition to learning the community strengths on which to build, understanding the gaps in supportive care across the community helps uncover opportunities to improve and people to engage. By interviewing key informants in the community, I learned specific opportunities to improve the community as well as underserved populations to address. I also learned which organization representatives are part of a tight-knit network, and which individuals are more isolated in the community. Understanding the current gaps in connectivity guides the approach to contacting and engaging these people.

Culture and Society

1. *Regional areas of interest*

The regional culture also suggests people and organizations to include in a collaborative effort and online community for cancer survivorship. In middle Tennessee, located in the southeastern United States, aspects of this culture include country music, rodeos, and hunting. Cancer support and awareness groups and events were identified in the local community in each of these areas of interests.

Of special note are the roles of country music, musicians, and the music industry in the Nashville community, known to many as "The Music City." I discovered a variety of ways in which the local music community contributes to cancer survivorship, including benefit concerts and tours, musicians who are cancer survivors, efforts and

> donations by music industry leaders, health care professionals who are also musicians, songs written about or with cancer survivors, and music celebrity fundraising events.
>
> Understanding the motivations and interests in the local community culture opens up opportunities for collaborative partners in the cancer survivorship community.

One participant in the design collaboration explained the value of my initial efforts to understand the community and its members:

> I think the whole thing has been amazing, but I really was impressed with the groundwork you did, the personal interviews, and they weren’t short, and really thinking outside the box of people to involve, like you say, really painting a broad canvas, because I feel like you were really well informed coming into it, and you had already seen connections that could be made, so I was very impressed with that.

1.3 Contact and engage

The third step of the discovery cycle, after finding and understanding the motivations of the community members, is to contact and engage these people to participate in the collaborative design and the online community.

Four themes of contacting and engaging the potential participants were identified. The first two themes are: 1. Create an easy and welcoming atmosphere for people to get involved, and 2. Take initiative to actively invite participation. These themes are balanced between more passive and more active strategies. The next two themes are: 3.

Contact a variety of people inclusively, and 4. Contact each person individually. These themes are balanced between broad participation and personalized interactions.

The balance in these themes illustrates the range of approaches used to contact and bring the participants to the table in this collaborative project. Table 4.8 summarizes the themes and categories of contacting and engaging the participants.

Table 4.8. Contact and Engage

Easy and welcoming atmosphere	1. Schedules and Location
	2. Personality
Take initiative	1. Introductions
	2. Follow-up
	3. Persistence
Inclusive approach	
Personalized approach	1. Personalized communication media
	2. Preparation prior to contact

1.3.a Easy and welcoming atmosphere

The first theme of contacting participants is that I tried to make it easy for the participants to reach me and to make the project open and inviting.

Schedules and Location

My flexible schedule as a graduate student allowed me to schedule the initial key informant interviews and individual feedback meetings at times and locations that worked best for the participant. Some interviews and meetings took place in my own department's building, but most took place in the participants' own offices or at a community support organization's building in which they felt comfortable. The participants expressed appreciation that the group design sessions were held in the welcoming space of this community support organization.

Personality

Part of the welcoming atmosphere came from my own personality and manner in which I approached the participants. I expressed excitement and enthusiasm for this project, as well as a genuine interest in learning more about their efforts and how this project might support them. One participant described that several of the participants first got involved in the project because they liked me and had faith in me, not just because of the concept of the project itself:

> I'll be honest with you Jacob, I think a lot of us weren't real sure that we were ready to commit because we believed in you but we weren't really sure until we could see it and see it living and breathing… We did a lot of this on faith, because we love you, but now its breathing and we get it.

This response illustrates the importance of the project leader's personality and his or her community relationships when proposing a new technology-based initiative in the local cancer survivorship community.

1.3.b Take initiative

In addition to making it easy for the participants to get involved by creating a welcoming environment for the project, I also took initiative to contact and engage the participants. Three components of taking initiative are introductions, follow-up, and persistence.

Introductions

Taking initiative to introduce myself and the project at community events, rather than simply attending events, led to meeting new potential participants. Any time I stumbled across a person or group that might be interested, I introduced myself and the project, and invited them to get involved. This included meeting people at booths at community events/fairs, meeting performers after benefit concerts, and meeting people at events in which I volunteered.

Follow-up

After introducing myself in person, I followed up on email or by phone to connect further about the project. Follow-up also occurred in person, for example when I spoke with one participant, who did not attend the first design session, at a community event and she indicated that she still wanted to participate.

Persistence

Related to follow-up is persistence. The effort of repeated follow-ups with a person is an example of the persistence required to contact and engage busy individuals in the community. For example, I made phone calls and sent additional emails to potential participants after not receiving a reply to my initial emails. Throughout the collaborative design process, I sent group email reminders for each design meeting and individual reminders for those participants who did not RSVP. Rather than feeling bothered, the participants expressed appreciation for the persistent contact, because it helped them stay engaged in the project.

> it's really, really helpful how persistent you were and how easy you made it for those of us who are really busy busy busy, and you just kept calling us back, and I never felt bothered by that. I always was just like 'thank you so much for calling me or emailing me again' and I'm just too busy…

I also identified an attitude in myself that facilitates appropriate persistence in contacting the community members. I recorded my reaction in my personal field notes when making follow-up calls. When I did not receive an initial reply, I chose not to assume that this lack of response meant a lack of interest. I find that it is easy for my initial reaction to a person not responding to a message, in general, to mean that they are not interested in what I what I said. However, my conscious attitude of rejecting this thought and enthusiastically making follow-up calls allowed me to engage several participants who otherwise would not have been involved in this process.

1.3.c Inclusive approach

Taking initiative also relates to the entire process of searching and finding the many people in the community to contact. Seeking to be as inclusive as possible in the collaboration, I contacted both individuals who I knew directly or who were recommended to me, as well as representatives from local cancer support programs that I only recently had discovered on my own. Taking the time to contact and introduce myself to the many groups that I discovered provided an opportunity for more isolated members of the community to get involved in the project.

1.3.d Personalized approach

In addition to contacting and engaging a wide variety of people, I made an effort to make the contact personalized for each individual's needs and interests.

Personalized communication media

As one participant noted, my ability to pick up the phone and make a call, rather than only using email, helped engage the participants that I contacted. Additionally, when I did use email to contact the participants with a standard message or reminder, I sent individual emails addressing each individual by name. Depending on the context of our previous meetings, this also allowed me to include a brief message at the top specifically addressing that individual's level of participation.

Preparation prior to contact

As discussed previously in terms of understanding the individuals and groups found in the community, doing my homework prior to contacting an individual helped me personalize the conversation to match their needs and interests. Searching for more background information on an individual or group helped me understand the context in which they might participate and address any confusion they have about the project. For example, one participant initially did not understand why I wanted to include her, because her organization does not deal directly with patients. Because I knew the background of the organization, I was able to explain why the role of their organization is an important perspective to include. Similarly, I was able to describe how this project might fit in line with their organization's goals. Because the initial vision of the online community was (necessarily) vague, it was not always easy for the potential participants to grasp its relevance to their interests from the initial, basic description.

1.4 Synergize

The fourth step of the discovery cycle, after contacting and initially engaging the community members, is to synergize their participation and vision for the collaborative design process and the online community. While the first three steps bring each participant to the table, this next step of synergy brings the individuals together to create a whole that is greater than the sum of their parts. The first three steps involve *me* discovering and engaging the many parts of the local cancer survivorship community, while the fourth step requires *us* to work together to discover the overall vision for the cancer survivorship community.

I identified themes both of how synergy develops and why synergy is significant for the collaborative design and implementation of the online community. The four themes of how the synergy develops are 1. Build from existing strengths; 2. Support one another; 3. Lead with integrity and transparency; and 4. Sensitively address potential competition. The three themes of why synergy is significant are 1. Willingness to participate; 2. Forming a shared vision; and 3. Making shared decisions.

Table 4.9 summarizes the themes and categories of synergizing.

Table 4.9. Synergize

How synergy develops	b. Build from existing strengths	*a. Incorporate existing interests and expertise*
		b. Incorporate existing enthusiasm and energy
	c. Support one another	*a. Me supporting the participants’ own efforts*
		b. Participants supporting one another
	d. Lead with integrity and transparency	*a. Genuine interest in the community*
		e. Connecting on a personal level
		f. Commitment to continue
		g. Neutrality and avoiding territoriality in affiliations
	h. Sensitively address potential competition	*a. Competition among community members*
		b. Competition between this project and other related community initiatives
Why synergy is significant	1. Willingness to participate	

	2. Forming a shared vision
	3. Making shared decisions

1.4.a How synergy develops

Synergy in the collaborative design process develops through a combination of the group members and the group leader supporting and encouraging one another's abilities and efforts.

Build from existing strengths

1. Incorporate existing interests and expertise

The strategy of 'casting for targeted interests' was described previously in terms of understanding the motivations of each member of the community and how they might like to be involved in this project. I used my understanding of the overall strengths of the community and the strengths of each participant to continue to engage participants in the collaboration. For example, as previously mentioned, one participant used her interest and experience in laughter and play therapy to contribute to the "Hope through Humor" design in the online community. Another participant who leads networking lunches for community health professionals was engaged to discuss targeted aspects of the online community's professional mentorship features. As this participant described, I was able to take key issues from the work that people are doing in the community and lay out a plan.

Similarly, I engaged the cancer survivor participants more for design decisions and feedback that relate to their experiences and expertise. For example, the survivors' provided key input on the privacy levels for survivor-contributed content, desired topics of shared stories, wording/phrasing of text, ease of navigation in the design, and other essential design components.

2. *Incorporate existing enthusiasm and energy*

Throughout the collaborative design process, I noted when participants expressed sparks of enthusiasm and invited these participants to contribute more in individual brainstorming and feedback discussions. Engaging the participants in various levels for different design needs helped to ensure that potential synergistic energy was not left untapped.

The approach of building on existing strengths and energy helps to synergize the cancer survivorship community's existing efforts into key components of this shared collaborative effort.

Support one another

The approach of building on the community's existing strengths also relates to the theme of supporting one another in the collaborative design process. This theme includes aspects of me supporting the participants' own efforts, as well as the participants supporting one another.

1. *Me supporting the participants' own efforts*

In addition to the participants bringing their unique strengths to this collaborative effort, I sought to support the participants' own efforts in the local community.

Volunteering in the community

I personally participated and volunteered for many of the community members' own events throughout the year. One participant said that my desire to be involved in other programs in the community meant a lot to her. It showed that I want to be a team player, that I want to have a vested interest in the community, and that I believe in the community. This approach helped create a synergy between my own efforts for this project and my efforts for the entire community.

Co-learning by the participants

The participants described a variety of ways in which they learned and grew over the course of the collaborative design project. Both cancer survivors and professionals said that they learned about new support programs and organizations in the community. One cancer survivor explained that a rewarding aspect of the project was learning by example how to organize, coordinate, and communicate a big project; he appreciated my approach to listening and accepting feedback and demonstrating that it will be considered. Several professionals also indicated that they learned new approaches to coordinating group efforts by participating in the design sessions.

Additionally, the project's emphasis on internet-based strategies to support the local cancer survivorship community helped the participants think in new ways about their own work and approaches to community networking. One participant explained that this project allowed her to participate in something that they normally do, but in a new context. She said that she gained skills that make her want to do more with their web site for communication. The process gave her insight into what is possible in terms of online strategies for this community. Inspiring the participants to try new approaches and to gain comfort in web-based technologies for cancer support is a key success of this project. This technological co-learning by the participants helps to create synergy among the community's efforts, because each of their own efforts may include more internet-based strategies.

Finally, not to be underestimated is the enjoyment that the community members gained from participating in the collaborative project. One participant described that it was fun to interact and be a part of this project because it is led by a member of the tech-savvy generation "that makes things happen." She described that she enjoyed participating because I had a refreshing sense of idealism, fresh creativity, and confidence to take the risk in doing this project. In one conversation, she said that talking to me on the phone about the project turned her day around when she was having a hard day at work. The participants’ energy and ideals for the community were synergized by the pervasive attitude that working together we *can* accomplish our goals for the project.

2. Participants supporting one another

The participants also supported one another in a variety of ways during the collaborative design project. The participants appreciated that the group design sessions brought people out of the silos and that they had an opportunity to work together. Before and after the design activities, the professional participants shared announcements about their current initiatives and connected with each other to discuss potential partnerships, mentorships, and patient referrals. As one participant explained, it brought her together with people she wants to know about and work with.

The cancer survivor and family participants also supported one another as they described challenging times in their experiences with cancer. The design meeting at times served as an informal support group among the participants, in which I stepped back and allowed them to interact amongst themselves. One survivor shared his contact information with another participant to express his availability if needed. Another survivor said that it helped him out a lot to listen to a fellow survivor’s experiences with cancer research advocacy initiatives.

In both the survivor and professional meetings, rather than leaving immediately after the two hour intensive design sessions, the participants often stayed to chat with one another. Recognizing and encouraging these moments of support for one another in the group meetings helped build relationships and synergy among the participants.

Lead with integrity and transparency

One of the participants in the key informant interviews described her role in the community as a leader “who can be trusted, who has integrity, gets it, and knows what they’re doing.” I took this idea to heart and made a conscious effort to follow her example in my approach to leading the collaborative design project.

1. Genuine interest in the community

As illustrated previously, volunteering for the participants own efforts helped me express my respect and appreciation for their efforts in the community. I was sincere in my participation and genuinely considered myself as working for the community, which is an attitude that came across to the participants. I viewed this effort as *our* project, rather than *my* project. As one participant noted, you can’t do a project like this just barging in on the community; if you have a hidden agenda, it won’t work. This aspect of the project leader’s attitude guided many choices made throughout the collaboration and is a critical element to building trusted relationships and synergy with the community members.

2. *Connecting on a personal level*

Volunteering for community events also allowed the participants to get to know me in a role apart from leading this project. My frequent juggling demonstrations and comments about my juggling interests also provided an opportunity for us to build more well-rounded relationships. The more they knew about my personal interests and career aspirations, the easier it was for me to make clear my sincere intentions for this project.

3. *Commitment to continue*

Along these lines, the participants asked, with some initial concern, what I plan to do after I complete my PhD and graduate. I was able to confidently respond that I am committed to continue this effort in the local community, rather than seeking employment in academic or industry positions elsewhere in the country. I expressed a belief in this project and in the community, which helped to ease their concerns about the longevity of this initiative. One participant noted that at first, people were a little weary of getting involved and sharing information and how it would all be maintained, but I was able to ease people's worries. She said that it was clear that I was trying to find a way to make it happen and be open to the concerns, but find a way to work through them, and people could see that.

4. *Neutrality and avoiding territoriality in affiliations*

I did not feel any sense of territoriality with representatives from programs that potentially compete with my own medical center's programs. I also made a conscious effort to keep the collaboration from being overly dominated by representatives from my own medical center. Likewise, these representatives also expressed the need to keep the project equally represented by other organizations in the community. I openly commented on this strategy with the participants and attempted to be transparent about my motivations for neutrality among the participants.

Sensitively address potential competition

Transparency in the collaboration is especially important to address potential competition among the participating community members, as well as potential competition between this project and other related community initiatives.

1. *Competition among community members*

Openly recognizing areas of potential competition is a strategy used to nurture the synergy and transparency in the collaboration. For example, when the design idea was suggested to include "Donate now" and links to donate to local organizations, the participants quickly shifted away from this topic because funding is an area of competition among local non-profits. I tried to be sensitive to focus on areas of mutual co-operation as opposed to more competitive areas of the community. One participant summed up this approach in the following way:

> I think you were very careful, at least I know you were in conversations with me, and I assume with everybody else, to acknowledge that there are certain things that we are competitive with each other about, but to find that common ground. I remember the conversation we had initially about fundraising, and is this the place to

> fundraise, and we realized very quickly that that would be a place where we step on each other's toes, really quickly, and we were able to set that aside and really focus on the common interests that we could do together. And I think that helped make it more transparent, because we really recognized early on that there are some things that we're going to be competitive, and rather than pretend that that's not the case, let's acknowledge that, and find what we can have in common and work toward together.

Another participant described how the transparency in this collaboration differed from some previous experiences with collaboration in the community:

> …sometimes, we're friends and we kind of do the same thing, but then we can be competitors, depending on where we work or whatever. But regardless of all that, I felt like this was a really transparent collaboration. … so often you want to try to collaborate with people, but people have hidden agendas, or there are people in the back, the higher ups that are running things, so you can't ever come to the table freely and share … I get frustrated when we come together and we all kind of have the same goal, but there's so many little divisive things that keep us from really being able to work together without all of the hidden agendas.

Transparently finding areas of co-operation and common ground is especially important for the design of an online community which provides links to all local organizations. Representatives from one organization must feel comfortable referring patients to the online community without feeling a sense of competition from the patient discovering other support programs and services in the community. As one participant explained, organizations may not want to expose people to the masses, because they don't want to support the competition.

2. *Competition between this project and other related community initiatives*

During the initial process of finding and understanding the programs in the local community, I found several initiatives related to this project. Other organizations have created resources guides for local support resources, and other groups have agendas which include networking and collaboration among local professionals. Early on in this process, I made a conscious choice to always view these organizations as potential partners, rather than as potential competitors. In my field notes, I recorded several situations in which my first reaction was defensive and in fear of competition from another program. By actively taking an approach of partnership over competition with similar programs, I was able to share ideas openly and discuss potential partnership opportunities. As one participant noted, it was my personal and professional approach that made the project work, and always presenting it as 'what can I do for you'. By erring on the side of openness and sharing, these potential competitors also shared openly their ideas for finding ways to partner that are mutually beneficial. I felt that this was one of the hardest attitudes to maintain, but also the most rewarding, both personally and professionally for the success of the collaboration.

However, this does not mean that all other members of the community felt the same way about this project. For example, one community organization representative who participated in the key informant

> interviews did not participate in the collaborative design process. She indicated during the interview that the proposed online community project in certain ways seems to be what they already provide for patients. I was not successful in explaining the opportunity for partnership over competition in this case. Other participants acknowledged the challenge of getting support from certain organizations when trying to start new programs, if they have similar existing programs in the local cancer survivorship community. Throughout the collaborative process I brainstormed alone and with the design participants on possible ways to better approach partnership with such organizations in the future.

1.4.b Why synergy is significant to the collaborative design

Synergy in the collaborative relationships contributes to the community members' willingness to participate in the design and implementation of the online community. Synergy also contributes to the participants' ability to form a shared vision for the online community and make shared decisions about the design.

Willingness to participate

In addition to synergy between me and the participants, the synergy created among the community members is essential for the desire to participate transparently in the proposed online community. Early in the design collaboration, one participant explained that we need to recognize that "as wonderful as the web is, this kind of philosophical commitment to each other has to take place at least initially in person." This philosophical commitment to each other is reached, in part, through the collaborative synergy developed during the group design sessions. The design participants all expressed an interest and commitment to participating in the resulting online community. Their initial involvement built trust in me, trust in each other, and trust in the project, which influenced their desire to help make the online community a success.

Forming a shared vision

Synergy in the collaboration helped the group form a shared vision for the cancer survivorship community and its associated online community. In addition to the group reaching a shared vision for the design together, my role as the project leader and system developer required me to form a shared vision with the participants. I tried hard to see from their perspective, and the participants learned to think about the potential of online communication from my perspective. The synergy in the shared vision came from meeting in the middle, so that the design decisions were mutually understood by all members of the collaboration.

Doing my homework to understand what drives the participants and trying to be a continual learner helped me to see from their perspective as cancer survivors and community professionals. Additionally, I used creative approaches to present the design concepts to the group, such as cartoon storyboards, in order to ease their understanding of technology for the local cancer survivorship community.

Making shared decisions

The synergy among the participants and their faith in the group's shared vision made it possible to conceptualize, develop, and launch the online community in a relatively short period of time. In order to create the multi-faceted online community, many design and priority choices were required. Some choices were complex and needed group discussion, while many other smaller choices were made based on individual feedback from a few participants.

Because of the fast pace of the project, one participant noted if a person missed a meeting, they might have missed a critical decision about the whole system. While I did send meeting reports via email and invited further input, it was suggested that the decisions could be improved through a formal voting process. However, several other participants indicated that they valued the speed in reaching the final product over a complex voting process. These participants said that they felt engaged through the individual follow-up conversations in between the group design sessions.

One participant whose schedule did not permit her to attend any group meetings explained that the idea of trust was important for participating outside of the group meetings. She said that she had faith in me to be able to create the design, and faith in the group to share a common vision. The idea of trust is especially critical in a technology-based collaboration, because rapid software development requires the system developers to quickly build the vision expressed by the participants.

1.5 Summary of the discovery cycle

The four elements of the discovery cycle contain key strategies and approaches to bring the community together for a collaborative design project. As a whole the elements flow together in a natural cyclical progression. The overall process of the community discovery cycle is summarized as follows:

Find people and programs

Finding people and programs requires a triangulation of sources and methods to explore many different aspects of the local community and local-based online conversations. The aim is to find all relevant members of the middle Tennessee cancer survivorship community, including highly-connected community members as well as more isolated groups and individuals. The specific strategies described in this framework are designed to address the challenges of finding all the necessary people to contact and engage in a complex, multi-dimensional community.

Understand what drives the community members

Finding people and programs in the community requires more than simply compiling a list of contact information. In order to most effectively engage the community, one needs to understand what drives and motivates their participation in the community. This understanding comes from fully understanding each community member as a complete person/group, as well as understanding the community and societal context in which they live and work. This learning process serves as preparation for contacting and engaging potential participants. Specific strategies for actively seeking this understanding are described in this framework.

Contact and engage

As the members of the community are found and understood, the next step is to contact and engage each individual appropriately. The process of contacting the community members involves a variety of balanced approaches. First, it is essential to take initiative in reaching out and persistence in following up with potential participants. At the same time, one should be open, flexible, and welcoming so that it is easy for the community members to get involved. Also, while one should inclusively contact a diverse range of people, each individual should be engaged with a personalized approach.

Synergize

Finally, once the community members are contacted and engaged to participate, a synergy must be developed to uncover a powerful, shared vision for the community that builds on the combined strengths of its members. The project leader plays a key role in nurturing the synergy between each participant, and the style of the project can draw the participants into the collaborative effort. Additionally, the community members must have a philosophical commitment to each other to find areas of co-operation as opposed to competition. The process of reaching this synergy and common ground is two-directional; it is based on each person's contributions to the collaboration combined with what they learn from the collaboration. The collaborative effort builds on the existing strengths of the community members, and at the same time the community members learn new approaches to use technology to enhance and improve their own efforts.

As a whole, the four elements work together in an iterative cycle with ambiguous boundaries between each step. For example, the step of understanding a certain community member blends with contacting and engaging that individual based on their strengths. The knowledge discovered from an in-depth understanding of one group helps to uncover related areas of the community to find and include. While partially overlapping, the cycle does flow in a sequential order of finding, understanding, contacting, and synergizing the community members. The final step of synergy occurs with each individual member of the community that is contacted, as well as among the total group that is brought together. In this way, there is both a smaller and larger step of synergy within the cycle.

2. Discovery Meta-Process

The meta-process of discovery in the local cancer survivorship community is made up of three elements: managing knowledge and relationships, participating and contributing, and continuing to follow the pulse of the community. The meta-process elements occur throughout the discovery cycle and provide an overall structure to the cyclical process.

As with the presentation of the discovery cycle, themes and examples are provided to illustrate each element.

2.1 Manage knowledge and relationships

The first element of the discovery meta-process is to manage the knowledge discovered about the people, programs, and organizations in the community. Keeping track of the information found and the people contacted is an essential component to an efficient and effective discovery process. It is easy to forget or neglect this element during the excitement and dynamic exploration of the community discovery cycle. Four themes are identified for managing knowledge and relationships: 1. Efficiency of repeated efforts; 2. Logging of the repeated process; 3. Storing and sharing information; 4. Managing communication in relationships.

In presenting these themes, I also comment on the implications for developing an informatics system for more effective and efficient knowledge and relationship management during the discovery process. This application is envisioned to be web-based and/or integrated as a plug-in for an existing web browser application. As I will discuss further, this application also may be appropriately integrated with the live online community web site.

Table 4.10 summarizes the themes and categories of managing knowledge and relationships.

Table 4.10. Manage Knowledge and Relationships

Efficiency of repeated efforts	1. Iterative Online Browsing 2. Recording notes in real-world activities
Logging of the repeated process	
Storing and sharing information	1. Simultaneous storing and sharing 2. Categorizing information 3. Visualizing information
Managing communication in relationships	

2.1.a Efficiency of repeated efforts

Over the iterative cycles of finding and understanding people and groups, I found it challenging to keep track of the relevant information in an organized manner.

Iterative Online Browsing

A key process to finding relevant information online involves browsing through search results and following a series of iterative threads, tangents, and follow-up search queries. This process required the opening of many browser windows and tabs, out of which I would save pages with useful information. Saving pages included downloading PDFs, bookmarking as a favorite in the browser, and/or recording notes in a word document with the link, quoted text, and my own comments. When I was in a hurry, I would copy the link and type initial notes in a plain text document to follow up at a later time.

Additionally I have bookmarked certain links to check daily, weekly, or monthly. I check these links for new information to continue to keep a pulse on the community (see further discussion of this community discover element later), and many of these sources do not have RSS feeds to access updates in a newsreader.

From this process, I determined a need for an informatics solution to make this repeated, iterative browsing more efficient and easier to manage. This informatics tool should facilitate stepping through threads of iterative search queries and windows, providing a simple interface to save sets of links and the relevant information from each page. While browsing, links can be marked to be revisited for updates on a daily, weekly, or monthly basis. For example, a news story about an organization only requires one view, but a county newspaper's events calendar could be tagged for monthly review of support group listings. In many ways, this aspect of the informatics system could be described as a bookmarking application specifically designed for dynamic community discovery.

Recording notes in real-world activities

In addition to iterative web-based searches, the discovery process also occurs through interactions in the community away from the computer. As described previously in the community discover cycle, the discovery process includes reading stories and advertisements in local papers, meeting people at events, finding information in flyers, along with other activities in the community. In order to keep track of this information, I took physical copies of documents if applicable, and I also recorded quick notes of the information and names to remember. I used my cell phone to text-message or email myself notes with this information along with my initial ideas and comments regarding the information. In some situations, I would record written notes in a paper-based journal.

Based on this process, the informatics tool for community discovery should include the ability for notes and information to be added through email and text-messaging input. Design features can provide natural means to integrate this information with associated information discovered online. The ability to associate online web sites and comments with “external sources” (e.g. physical documents or notes) will help synthesize a complete understanding about certain aspects of the local community. External sources, such as daily newspapers or monthly magazines, also could be marked with review reminders similar to the reminders for online sites that regularly update information.

2.1.b Logging of the repeated process

As part of the repeated efforts in the discovery cycle, I recorded notes on the process to complement the actual information discovered. These notes were used to document the process for the qualitative research analysis, but logging the process also is useful to help manage the efficiency of repeated activities. For example, for regularly updated links the informatics tool should log when the scheduled links are visited in order to provide reminders and prevent unnecessary repeated visits. Similarly, search queries should be logged in such a way that repeated queries over time can be conducted as efficiently as possible. Additionally, the informatics tool can provide streamlined interfaces to conduct searches of common query terms in various combinations (e.g. cancer + Nashville, cancer + Tennessee, oncology + Nashville, oncology + Tennessee).

This functionality would begin to address the challenges I identified in keeping track of which queries found certain types of information. This tool would be valuable for evaluating the best practices of effective search queries and strategies.

2.1.c Storing and sharing information

Another identified need for knowledge management is the approach to simultaneously storing and sharing the information that is discovered. While the information is saved for the purposes of understanding and contacting in the discovery cycle, certain information also has value to share with others in the online community. The cycles of discovering people, programs, and resources for the collaborative process continues into the discovery cycles for the live online community.

Simultaneous storing and sharing

While I initially used unstructured Word documents to record these notes and information, I eventually transitioned into saving the data in the structured fields of the online community's content management framework (Drupal). Using the web-based content management system as part of the discovery cycle streamlined the process of sharing this information with the participants, and ultimately with the broader local community. However, I continued to use the unstructured Word notes to record information and comments that were not intended for public consumption.

In this regard, the informatics tool for discovery should be designed not only to store information, but also to share information as well. This type of storing and sharing follows the general approach of social media sites such as social bookmarking.[132] The ability to record password-protected personal notes alongside public information may facilitate the storing of all relevant information about a program or organization in a single place.

Categorizing information

A major challenge in managing the vast amounts of information discovered about the community is categorizing the data with a systematic organization. My first draft of categorizing the knowledge discovered used a set of static HTML web pages with unordered lists of links. I quickly found that information in the cancer survivorship community often is relevant to multiple categories (e.g. research studies *and* underserved populations). When I transitioned to using the Drupal content management framework, I began tagging the information with multiple keywords. The set of keywords iteratively developed over time as new information was added. The tagging approach to organizing programs and resources is a natural fit for the cancer survivorship community because of the wide range of relevant dimensions (e.g. tagging by cancer type, age-range, geographical location, etc.).

The informatics system for discovery can use a tag-based approach to organize the information found in the community.

Visualizing information

Creating new ways to visualize information facilitated the understanding element of the discovery cycle. Displaying the local organizations on a Google map helped created a deeper understanding of how to engage and contact these organizations. For example, the geographical location may indicate how far a person might have to travel for a meeting. Also, the relative distance between organizations provides additional context about which groups are neighboring and which groups are more isolated from the others. The visualization on the map also illustrates which regions of the community have gaps in available services, for example, by displaying all support groups meeting locations in middle Tennessee. The geographical visualization is especially useful for the discovery process of a community in a specific geographical region, such as middle Tennessee.

The informatics discovery tool should include the ability to visualize the information geographically as well as through other creative approaches that help provide context to the knowledge discovered.

2.1.d Managing communication in relationships

Throughout the discovery cycles, I tracked my history of attempts to contact and follow-up with the participants using an excel spreadsheet. The spreadsheet included the following columns:

1. Contact media used (e.g. email, phone, in person)
2. Contact date

3. Follow up date and media used
4. Their response date
5. My response back
6. Attending next meeting (yes/no)
7. Reminder sent (yes/no)
8. Date and message of my follow-up contact after a meeting
9. Scheduled dates for individual meetings
10. Locations of individual meetings
11. Scheduled meeting completed (yes/no)
12. Additional notes

Additionally, I recorded my contacting/follow-up plans using other methods, including:

1. Written notes of recommended people to contact and their role in the community.
2. Scratch lists in a written document of the next set of people to contact.
3. Saving emails from individuals into an email folder for “People to thank” (at the end of the project).
4. Saving emails from individuals into an email folder for “People to contact” (at some point in the future).
5. Several other email folders relevant to the project (including “Design phase participants” and “Emails to save for methodology”).

A challenge of using a personalized approach to contact the participants is that this process involves a great deal of information to manage about the past, present, and future interactions of each relationship. While my approach worked relatively well, it became clear that an informatics tool could be designed to facilitate this process. Structured input similar to the excel spreadsheet columns could be used, with visualization tools for displaying specific sets of contacts (e.g. ‘people attending a meeting’ or ‘people I am meeting individually this week’). The tool would include calendaring, RSVPs, and reminders. Also, a way to forward key emails to archive would help in saving and organizing email-based communication.

Certain aspects of this functionally may be found in existing contact and customer relationship software. However, much of the needed functionality is specific to this community discovery and collaboration process, which differs from the typical purpose of this software. Furthermore, this functionality should be integrated into the rest of the community discovery informatics tool. This integration, for example, would allow the contact/follow-up history for a relationship to be linked to the relevant discovered knowledge about that person or organization.

2.2 Participate and contribute in the community

The second element of the discovery meta-process describes the general approach of participating and contributing in the community. My participation in both real-world and online activities facilitated the process of finding, understanding, contacting, and synergizing with the participants in the community discovery cycle.

Three themes of this participation were identified: 1. Participate and volunteer in the local community; 2. Participate in online conversations; and 3. Be a connector and matchmaker

Table 4.11 summarizes the themes and categories of participating and contributing in the community.

Table 4.11. Participate and Contribute in the Community

Participate and volunteer in the local community
Participate in online conversations
Be a connector and matchmaker

2.2.a Participate and volunteer in the local community

I participated and volunteered in the community in many capacities throughout this project. Examples of my participation include:

1. Attending local presentations, celebrations, and other events
2. Representing the project at a booth or table in a community event
3. Participating on a local grant review committee
4. Volunteering photography and video production for local events
5. Juggling and entertaining at local events and celebrations

Participating and contributing in these ways allowed me to meet the community members in person and initiate contact more naturally than a cold call or email. I discovered people at neighboring booths, people who presented at meetings, fellow attendees at meetings, and coordinators of local events. Also, by contributing to for the community members' own efforts, their participation in the online community project became a more complete two-way partnership. Participating also added to my general presence in the local cancer survivorship community, which made me more available and approachable for people to get involved with the project.

2.2.b Participate in online conversations

In addition to participating in the real-world, local community, I also discovered community members and resources by participating in the local-based online conversations. This process of online participation includes being a member of local, cancer-related email listservs, being CCed on informal email lists and announcements, as well as registering profiles on social media and social networking sites. My presence and participation in the existing online conversations contributed to an open and welcoming approach of contacting and engaging the community members. Participating online creates additional avenues for people to learn about and participate in this project. Additionally, participating in a range of social media and social networking sites provides key avenues to contribute the knowledge gained from the discovery cycle back to more members of the local community.

2.2.d Be a connector and matchmaker

Over the course of the iterative discovery cycle, I became increasingly knowledgeable about the community members, their interests, and their efforts. Throughout this process, I recognized areas of mutual interest and potential collaboration between community members. In several cases, I suggested and facilitated connections between these individuals that could support each of their own mutual efforts. Not only did this process of matchmaking contribute to the local community, it also served as another way for me to engage and synergize with the community members.

2.3 Continue to follow the pulse of the community

The final element of the community discovery meta-process is to continue to follow the pulse of the community. This element suggests that the community discovery cycle is an iterative and ongoing process, not only part of an initial community analysis or needs assessment.

Three themes for following the pulse of the community were identified: 1. Filtered online media; 2. Community calendars; and 3. Awareness of community changes.

Table 4.12 summarizes the themes and categories for continuing to follow the pulse of the community.

Table 4.12. Continue to Follow the Pulse of the Community

Filtered media	1. Online news
	2. Social media
	3. Advanced Google search
	4. Email
Community calendars	
Awareness of community changes	

2.3.a Filtered media

Certain types of online social media, social networking, and search queries can be used to follow updates of new information in the local cancer survivorship community. This approach extends the previously described use of key search queries in the community discovery cycle. Filtering information by location (middle Tennessee) and by topic (cancer) can be described as a form of online 'listening' to the community conversations.

Examples of the online (and real-world) filtered media that I used in this listening process are:

1. News
    a. Google alerts for 'cancer Nashville', 'cancer Tennessee', and 'cancer Tenn'
    b. Bookmarked local newspapers and TV station web sites
    c. News feeds from local cancer organizations
    d. Browsing local community newspapers and magazines for cancer-related information
    e. Printed newsletters from cancer-related organizations
2. Social media
    a. Bookmarked queries for 'cancer' on the Nashville Craig's List
    b. Bookmarked Twitter search for 'cancer near: Nashville, TN'
    c. RSS feed of YouTube videos tagged with 'cancer Nashville' and 'cancer Tennessee'

    d. Bookmarked blogosphere search for ‘cancer Nashville’ and ‘cancer Tennessee’
    e. Bookmarked local community-based and non-profit blogs
3. Advanced Google search
    a. Bookmarked search for ‘cancer Nashville OR Tennessee OR Tenn’ with the advanced option that limits to changes in the ‘past 24 hours’
4. Email
    a. Local cancer-related and technology-related email listservs
    b. Informal email lists and announcements

I referred to these daily/weekly/monthly bookmarked sites when describing the need for an informatics tool to improve knowledge management. This continuous online listening process is one of the key areas in which such a tool would be helpful.

2.3.b Community calendars

The online queries and bookmarks described above provide strategies for finding local announcement, news stories, and events as they are scheduled. This approach is balanced with knowledge of the regular community events. A general awareness of the annual community calendars provides a context for *expected* updates and announcements. For example, knowledge of the annual events in the local cancer community allowed me to find details for upcoming events even before any information appeared in standard news sources. Similarly, knowing the themes of the national cancer awareness months and weeks provided additional context for expected news and events to discover at different times of the year. Lastly, an awareness of the general local community calendar helps find tangentially relevant news and events (e.g. a women's health fair) in which members of the local cancer community might participate.

2.3.c Awareness of community changes

Several areas of the community were identified that evolve and change over time, which creates a need to continually follow the pulse of the community and update the relevant information. Examples of these temporal aspects of the community include new staff hired, new programs created, existing programs changing, new partnerships and affiliations, funding and associated positions lost, survivor advocates passing away, partnerships lost, and programs ending.

Following the pulse of the local cancer survivorship community involves staying aware of these changes, which are not necessarily announced through the local news media. Again, the constant evolution of the cancer survivorship community is an area in which presence and participation in the real-world community play important roles.

2.4 Summary of the discovery meta-process

Manage knowledge and relationships

The iterative process of the community discovery cycle involves complex sets of information and interpersonal interactions that require careful and efficient management. Based on the evolving approaches documented in this study of the middle Tennessee cancer survivorship community, several knowledge management strategies are described. While not developed currently, an informatics-based knowledge management tool is proposed to facilitate future projects using the community discovery framework.

The knowledge and relationships discovered are valuable to the local community members as well as to the project manager. The knowledge management process and tools should be integrated with the content sharing capabilities of the online community in order to benefit the community as well as the project manager, researchers, and system developers. This integrated approach to knowledge management and online accessibility is a key strategy for the future evolution of the community discovery framework and of the online cancer survivorship community.

Participate and contribute in the community

Participating and contributing to the community is essential for all four elements of the discovery cycle. Participation in the community beyond the context of this collaborative effort facilitates finding new people and programs, understanding what drives them, making introductions in a more personable and informal manner, and creating synergy with each community member’s own efforts. Additionally, being involved in the community and contributing to other efforts helps keep the collaborative design focused on its mission of truly serving the members of the community. Participating and listening to the community makes this new online community initiative a part of the existing conversation in the community, rather than trying to control the conversation.

Continue to follow the pulse of the community

Finally, it is important to remember that the community discovery framework requires a constant and continual effort. The local cancer survivorship community is constantly shifting, evolving, and growing, and the process of discovery in the community occurs piece by piece over time. While there is a necessary role for an intensive, initial start-up phase of community discovery, the discovery cycle should continue beyond the completion of this first phase. Even after the community members synergize as a group, there is a need for continued discovery of new people and new understandings to support continued synergy. Keeping one's ear to the ground at all times requires a passion and desire to follow the community and to constantly explore new directions and collaborative partners to engage.

As a whole, these three meta-process elements play a key role in facilitating and guiding the community discovery cycle. The meta-processes function in the background to complement the four elements of the community discovery cycle, and the cycle elements cannot be fully applied or understood separately from these processes. The three meta-process elements and the four cycle elements all work together to as the overall community discovery framework.

Evaluation of the community discovery framework

The community discovery framework itself resulted from qualitatively evaluating the collaborative design process of an online cancer survivorship community in middle Tennessee.

One measure of success in the collaborative effort is the number and diversity of the community partners involved. A total of 35 professionals from 14 local organizations, as well as 11 cancer survivors and family participated in the project. The diversity of perspectives was considered by the participants to be a unique and impressive cross-section of the local cancer survivorship community. Future studies can evaluate additional measures of the community members who are engaged through the live online community.

Additionally, the participants provided qualitative feedback of what worked well and what could be improved in the overall collaborative process. This feedback was included as part of the qualitative analysis from which the community discovery framework emerged. The participants' feedback is incorporated through illustrative examples in the relevant sections of this framework.

Finally, a quantitative survey of collaboration scales was completed by twenty participants at the end of the final design session. These results complement the qualitative feedback on the success of the collaboration. Table 4.13 shows the mean scores and standard deviation on the twelve-item survey (Appendix P), with choices ranging from 1 (negative) to 7 (positive).

Table 4.13. Internal Collaborative Functioning Scales Mean and Standard Deviation

Scale Item	Mean	Std Dev
Shared Vision	5.8	1.06
Goals and Objectives	6.05	0.94
Responsibilities and Roles	5.5	1.15
Decision Making Procedures	5.6	1.27
Changing Membership	4.75	1.59
Conflict Management	5.85	1.53
Leadership	5.95	1.36
Plans	5.7	1.17
Relationships/Trust	6.15	0.75
Internal Communication	5.8	1.06
External Communication	5.61	1.19
Evaluation	5.76	1.34

In these responses, changing membership was the only item that scored below a 5.0, and all other items were rated highly by the participants.

The participants' expressed desire and commitment to continue to support the growth of the online community also reflects the view of success by the members of the community. As this research only evaluates the initial design phase of the online community, the impact of the online community on the local sense of community, quality of life, and other outcomes will be measured in future studies.

Discussion of the Community Discovery Framework

How to apply this framework

The community discovery framework offers a proactive approach for informatics developers to discover and engage the local community members for a community-based, participatory design process. The overall approach, as well as the specific strategies described, can be used as a guide to situate the informatics initiative into the larger context of the real-world community's existing strengths and efforts. Rather than serving as a checklist of specific people and resources to include, this framework is intended to inspire and recommend interactions, attitudes, and priorities in the collaborative design process. This framework is based in the middle Tennessee cancer survivorship community, but can be adapted and translated to the specific community context in which it is applied.

In addition to supporting the methodology and practice of developing online communities, this framework also contributes to the academic knowledge as a theoretical framework for a collaborative, community-based medical informatics design process. The framework's themes and categories emerged out of a formal, qualitative analysis of in-process field notes and participant feedback.

What is new about this framework

Many aspects of the framework come from community-based participatory research principles such as the focus on the community and building on existing strengths. The steps of defining the community, engaging its members, and reaching a shared vision are not new to real-world community building initiatives. However, the existing literature does not sufficiently address how these principles can be applied to an integrated online/real-world approach to building online environments in local health-related communities.

The focus on technology produced key strategies within each element of the community discovery framework that were not previously described in the literature. Furthermore, the specific organization and focus of these seven elements is a unique framework that complements other existing models for community-building. The overlaps with existing models provide hooks in which to apply the unique aspects of this framework to other community-based initiatives.

The community discovery framework also relates to software development models such as agile software development and community-centered development. However, these models have not fully embraced and incorporated community-based participatory research principles and strategies. The community discovery framework complements, rather than replaces, these software development models so that they can be better applied to building integrated online/real-world collaborative communities.

Also, because this framework is based on the process and insights from a local cancer survivorship community, the findings in each category of the framework contribute new knowledge towards other cancer-focused, community-based initiatives. This framework introduces an entire new area of study for cancer-related research by applying emerging web-based technologies to cancer survivorship and supportive care in local communities.

Implications of the community discovery framework for informatics and community-based participatory research

The community discovery framework involves an integration of emerging informatics technologies with the principles of community-based participatory research. Because of this combined approach, the new perspectives introduced by each field into the other leads to a variety of implications.

This study demonstrates that informatics-based approaches can combine with real-world strategies to discover and engage local community members for a collaborative community-building initiative. More directly, the discovery framework serves as a case study that illustrates the potential for listening and participating in online social media to discover and engage the community in the specific context of cancer survivorship. The role of emerging web-based technologies for health and patient empowerment is a growing interest in medical informatics and the “Health 2.0” industry. The community discovery framework and specific strategies can be applied and expanded upon by researchers and practitioners in these fields.

The strong focus on building relationships and partnerships in the real-world community also has implications for patient-centered informatics initiatives to consider using more community-based principles and approaches. Beyond merely suggesting the use of these principles, this framework provides specific examples of how to bridge the community-based strategies and informatics-based strategies.

The framework is especially significant when a community-based effort is initiated by an informatics researcher/developer, rather than by the members of the local cancer/health community, as was the case with this project. The community discovery framework helps guide the researcher/developer into being an engaged member and leader of the local community. By continually learning about the community and creating synergy among the community members, relationships are built so that a bigger launch of the initiative can be jointly led, supported, and requested by the community members.

The application of this framework to the development of an informatics application also suggests specific implications for improving rapid system design and development. In agile software development, there is a strong focus on the client and including client feedback throughout the development process. In this project, there was no single client, but rather, the diverse community members serve as a type of 'distributed client'. With an inclusive range of participants, I received frequent feedback from different individuals for different design decisions and ideas. By creating a synergy with the community members' own efforts, they expressed a willingness to graciously volunteer their time to this effort.

The synergy of the group in reaching a shared vision for the online community facilitated the prioritizing of all possible design features into a manageable subset to develop. The synergy of the shared vision also allowed for rapid development because decisions could be made without all participants present for group discussion. Similarly, my understanding of the community and the participants' faith in me to share their same vision gave us the confidence for me to make necessary design decisions without constant oversight by the full group.

Lastly, the synergy developed through the community discovery framework nurtured the participants’ willingness to support and promote a wide-scale launch of the completed online community. Our mutual trust and commitment to the local community provides the foundation for the continued success of the project. By participating in the collaborative design, the local community members also became more comfortable and confident with using technology for supporting cancer survivors in their own efforts. This co-learning by the participants further prepares the local community for the technology-based approach of the online cancer survivorship community, by creating additional synergy between this project and other local support initiatives.

Overall, the community discovery framework contributed to the successful, collaborative design of a new online community for cancer survivorship in middle Tennessee. Equally importantly, this framework enhanced the success of the existing efforts and initiatives in the local cancer survivorship community.

CHAPTER V

DISCUSSION AND CONCLUSION

Discussion

This study demonstrates that an online community *can* be created collaboratively by the members of the middle Tennessee cancer survivorship community. Furthermore, the qualitative evaluation illustrates *why* an informatics-based approach is vital for connecting this community as well as *how* to bring the community together for a successful design collaboration effort.

The research methodology combines the principles and cyclical processes of participatory action research, agile software development, and community-centered development into an integrated Community PARADE methodology. The incorporation of community-based participatory research principles, and the emphases on research as well as community action, provide the foundations to this approach. This synergy between the rapid, medical informatics-based design and real-world, community building produces valuable insights and new directions for study and practice in each area.

Review of timeline

Guided by the theoretical frameworks of ecological systems theory and the psychological sense of community, a synthetic review of the literature was conducted on the concept of social support and online support for cancer survivors. This review found that medical informatics research has targeted interpersonal social support in online support groups and online cancer education programs, with limited success. However, emerging web-based social networking applications offer an ideal opportunity to address support for cancer survivors in local communities and social networks. This new informatics-based approach targets the sense of community and social capital as key measures in local cancer survivorship communities.

Grounded in the methodological and theoretical frameworks, this study began in Fall 2007 with interviews and surveys of key informatics in middle Tennessee to better understand and define the local cancer survivorship community. The community's existing strengths and opportunities to improve informed the collaborative design of a new online community for cancer survivorship in middle Tennessee. From December 2007 to July 2008, forty professionals and cancer survivors, family, and friends came together to jointly envision and design this new online community, which was initially launched in June 2008. Throughout this collaborative design process, a qualitative evaluation was conducted through the recording of field notes and feedback from the participants. In addition to this in-process, formative analysis, a final grounded theory evaluation of the data resulted in a new theoretical understanding of cancer survivorship at the local level, as well as a new framework for discovery and synergy in local cancer survivorship communities.

Informatics design implications

The results of this study are presented in four sections, which are summarized here with a special attention to their implications for medical informatics research and practice.

First, the key informant interviews and surveys show that support for cancer survivors extends throughout many aspects of the local community. A synthesized definition and conceptual themes of the local cancer survivorship community identify the local community members, activities, and resources associated with cancer survivorship. The incredibly diverse range of people and programs suggests a natural opportunity for an online community to bring together the inclusive membership in a shared, virtual space, independent of scheduling and geographical limitations. The inclusive definition of the cancer survivorship community suggests a need for flexibility and openness in the user and content types allowed in informatics applications for cancer support. Additionally, the identified individuals and organizations in the cancer survivorship community suggest potential community partners for future community-based informatics efforts.

Second, the local cancer survivorship community has many existing strengths, but also significant challenges and areas to improve its sense of community. The six opportunities to improve identified in this research are 1. Awareness; 2. Connecting; 3. Collaboration & Co-opetition; 4. Community & Survivorship Focus; 5. Knowledge/Relationship Management; and 6. Underserved Populations. Each of these opportunities includes aspects that an informatics-based approach is able to address.

Awareness of local news, events, resources, and people in the cancer survivorship community can be improved through centralized online calendars, news blogs, resource guides, and social networking profiles. The community can be connected through patient-to-patient and professional mentorship match-making databases, trusted recommendations for regional support services referrals, along with real-world efforts to advertise the online community to local clinics and community organizations. An online community can provide space for professional partnering and networking with a focus on mutual areas of co-operation as opposed to competition. The online collaboration must be grounded in a real-world, philosophical commitment to each other to improve all efforts to support cancer survivors in the community. An online community can emphasize survivorship and supportive care issues, which often are overlooked and overshadowed in the general academic and medical approach to cancer care.

Over the course of creating awareness, connections, and collaborations for cancer survivorship, an online community can also serve as a shared archive of the community's knowledge and history. It provides an opportunity to capture, synthesize, and visualize the relevant knowledge and relationships stored in each community member's mental and electronic databases. Additionally, an online community can offer additional visibility and networking opportunities for underserved populations in the cancer survivorship community. An online community can also reach lower socio-economic populations through printed materials and real-world programs that are tied to aspects of the online community.

Third, the launch of CanConnect, the online cancer community connection of middle Tennessee, demonstrates that it is in fact possible to create a functioning informatics system that targets these opportunities in the local community. Additionally, a theoretical model for system design is presented as a guide for further informatics efforts to synthesize the local community's wisdom of cancer support resources. This four-level model grounds the design in community partnerships and emphasizes the importance of synthesizing and visualizing the resources and categories/tags. The open-source Drupal content management system serves as an example of how an informatics software framework can be applied to this model in practice.

Finally, the evaluation of the collaborative design process resulted in the Community Discovery Framework, a relationship-based approach to discover and develop local community partnerships for informatics design. This framework includes four elements of the discovery cycle and three elements of the discovery meta-process. The cycle includes finding, understanding, contacting, and synergizing, while the meta-process elements include managing, participating, and continuing over time. The framework illustrates how an integrated informatics and real-world approach can be applied to discover and synergize the local cancer survivorship community for a collaborative design effort. In addition to theoretical implications for the fields of medical informatics and community-based participatory research, this framework suggests practical strategies that facilitate rapid software development and successful implementations of informatics applications.

Limitations

A limitation of this study is that I was the only primary researcher to conduct the grounded theory analysis of the field notes and participant feedback. In order to address this limitation, I engaged a peer debriefer to provide a second perspective on the analysis. While additional researchers would have offered more interpretations of the process, it is important to note that the ethnographic approach as a participant observer in the process could not have been studied with the same insight if the roles of project manager, software developer, and researcher were separated in this way. Much of the insight about the process came from my own observations and experiences, complemented and confirmed by the feedback from the participants. The methods for trustworthiness described in the methodology chapter address many of the potential limitations of this study in the naturalistic research paradigm.

Many of the strategies and interactions in the collaborative process were based on my own personality, abilities, passion, and previous experiences. Another person in this role would have shaped the collaboration and the final design of the online community differently. This limitation may create a challenge in replicating or translating the community discovery framework to other local communities led by other individuals and groups. To address this limitation, the results of the analysis provide a thick description of the collaboration activities and my own perspective, so that many of the specific aspects that I contributed to the collaboration are made clear. For example, rather than just indicating that my "personal and professional approach" helped the success of the collaboration, the specific characteristics of my approach are presented in structured themes and categories. These details can be used to guide the hiring and/or training policies for these roles in informatics education and community-based programs.

Also, this study was conducted in the middle Tennessee cancer survivorship community, and further research is required to determine how the collaborative process and resulting online community will translate to other local communities. This translation includes cancer survivorship communities in other geographical regions as well as other local-based communities in other areas of health or personal/professional niche interests.

This study would benefit from more active participation by doctors and nurses, in addition to the many community support professionals. Reaching clinicians in hospital-based and private practices would add important perspectives to the collaboration and implementation. Additionally, more depth interviews with cancer survivors, family, and friends would complement the key informant interviews conducted at the beginning of this study. The inclusion of more survivors and clinicians from rural areas of middle Tennessee also would provide valuable insight from individuals who live further from the many Nashville-based resources.

Finally, this evaluation of the collaborative process does not include the official launch activities beyond the design study participants. An evaluation of the use of the online community web site, the associated social media/networking conversations, continued real-world community participation, and other outcome measures have yet to be completed. It is expected that the online community design and the themes of the community discovery framework will evolve through the continuation of this work. Additionally a more in depth analysis of the community discovery framework to determine the relative effectiveness and efficiency of each strategy will be essential to further refine the framework.

Overall, this research represents the beginning phase of a much larger informatics-based initiative for online community building. This study focuses on the initial community discovery and initial software development process. The results presented here eventually can be analyzed in context of a long-term study of the integrated real-world and online cancer survivorship communities.

Conclusion

This results of this study show that the collaborative creation of online tools can bring many members of the local community together for the support of cancer survivors. Despite the potential for competition and territoriality in the cancer survivorship community, this informatics-based approach has demonstrated potential for discovering and synergizing the diverse individuals and organizations involved in this community.

The research has significance in three areas of study: medical informatics, cancer survivorship, and community-based participatory research.

Significance for medical informatics

Future efforts in medical informatics can target supportive care in local communities and include the principles and process of community-based participatory research. Thinking beyond patient-centered approaches to care, informatics can address patients as members of existing social networks and local communities. The sense of community and ecological systems theory are valuable frameworks to guide future informatics design and evaluation. This relationship-centric, community-driven approach to medical informatics and consumer health opens up new directions of study in the field. Additionally, the knowledge and skills required for this type of research and development should be included in informatics training programs and education.

Significance for cancer survivorship

This study presents the first definition of a “local cancer survivorship community” to complement the inclusive definitions of cancer survivor and cancer survivorship research. The formal definition of the cancer survivorship community is an essential step to fully activating the community’s capacity to make improvements in the care and support of cancer survivors and the people who care about them. The sense of community analysis adds knowledge of key strengths as well as six specific areas in which the community can improve its ability to better support cancer survivors. These strengths and opportunities to improve can guide changes in cancer research and policy to reshape the traditional approach to cancer care. The national agenda for cancer care can engage the local community to better address psychosocial support and continuing cancer survivorship. Additionally, the results illustrate the value of informatics-based, social networking approaches for local collaboration and for connecting cancer survivors and providers to community-based support resources.

Significance for community-based participatory research

Beyond the specific context of cancer survivorship, this study serves as a model for including informatics-based frameworks and strategies in community-based participatory research. The seven elements of the community discovery framework can be incorporated into current and future models for local community-building initiatives. This study has demonstrated the framework in the context of cancer survivorship, but the themes and strategies can be translated to other types of local community interests and initiatives. The final design of the online community in this study also can be modeled or directly applied to a variety of local, ‘niche’ communities of interest. The application and study of emerging social networking technologies to impact real-world social change is still in its infancy, and this study contributes to the growing knowledge in this area.

Vision for a nationwide model of an online, local community-based approach to cancer support and survivorship

I envision the growth of a new type of community-based initiative and/or organization whose mission is to bring together local cancer survivors and community partners through a shared vision and innovative online collaboration.

This initiative will seek to increase awareness and participation in local cancer survivorship efforts, foster connections among survivors and professionals, celebrate and recognize community members, and encourage other online cancer-related initiatives. The combined online and real-world role of this initiative is to serve as a neutral, welcoming window into the local cancer survivorship community for all community members and organizations.

This type of effort differs from existing cancer-related programs and non-profits in several ways. The primary emphasis of online strategies for local cancer support is unique. This new type of organization can partner with other local organizations to enhance their existing programs with online components, and it can encourage the community to embrace these approaches. Rather than providing support groups and personalized support services, this effort emphasizes awareness and connecting across the community to facilitate participation in the existing groups and services.

In order to accomplish these efforts, the initiative and its leaders must follow an attitude and principles that foster trust and transparency among the community members. It must be led with integrity and a genuine passion for the local community and for cancer survivorship. As described above, a priority is placed on valuing, supporting, and enhancing existing efforts in the community. By emphasizing support of existing programs, the initiative aims to avoid a sense of competition or territoriality with other local programs. In all cases, a sincere effort should be made to find opportunities for partnership with existing efforts in the community, especially those with related goals of networking and collaboration in the cancer community. For example, the initiative should be closely aligned with state cancer control coalitions to support their networking and survivorship-focused goals.

For these reasons, the focus of the initiative should remain agenda-neutral, so that it can incorporate the agendas of all groups in a non-competitive manner. Because of this requirement, this initiative cannot be carried out fully by existing cancer support organizations, medical centers, or cancer non-profits, because they each have their own existing agendas. A new organization with this specific purpose can be created, or certain existing organizations, such as community foundations, may be able to lead these initiatives locally. A new organization created to accomplish this initiative would be affiliate-based, so that each effort in a local community is led by its own community members. The national component of the organization would serve to train local leaders and provide online and real-world networking opportunities to connect the local communities to one another.

The results of this study illustrate the significance of this type of approach for improving cancer survivorship in local communities. The community discovery framework and online community developed in this study will serve as initial models for achieving this vision on a larger scale.

REFERENCES

---

[1] Cancer survivorship—United States, 1971-2001. MMWR Morb Mortal Wkly Rep 2004;53(24):526-9.

[2] Stanton, A., et al., Promoting adjustment after treatment for cancer. Cancer, 2005. 104(11 Suppl): p. 2608-2613.

[3] Arnold, E. (1999). The cessation of cancer treatment as a crisis. Social Work in Health Care, 29, 21-38.

[4] Lindop, E. and S. Cannon (2001). "Experiences of women with a diagnosis of breast cancer: a clinical pathway approach." Eur J Oncol Nurs 5(2): 91-9.

[5] Lethborg, C.D., Kissane, D., Burns, W.I. (2003). “It’s not the easy part”: the experience of significant others of women with early stage breast cancer, at treatment completion. Soc Work Health Care,37 (1), 63-85.

[6] Maher, E. (1982). Anomic aspects of recovery from cancer. Social Science and Medicine, 16, 907-912.

[7] Helgeson, V. and S. Cohen, Social support and adjustment to cancer: reconciling descriptive, correlational, and intervention research. Health Psychol, 1996. 15(2): p. 135-148.

[8] Cohen, S., Social relationships and health. Am Psychol, 2004. 59(8): p. 676-84.

[9] Kawachi, I. and L.F. Berkman, Social ties and mental health. J Urban Health, 2001. 78(3): p. 458-67.

[10] Eakin E G, Strycker L A. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: patient and provider perspectives. Psychooncology. 2001 Apr;10(2):103–13.10.1002

[11] Institute of Medicine. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: The National Academies Press;2007

[12] Bronfenbrenner, U., 1989. Ecological systems theory. Annals of Child Development 6, pp. 187–249.

[13] Berkman, L.F., et al., From social integration to health: Durkheim in the new millennium. Soc Sci Med, 2000. 51(6): p. 843-57.

[14] Lin, N., X. Ye, and W.M. Ensel, Social support and depressed mood: a structural analysis. J Health Soc Behav, 1999. 40(4): p. 344-59.

---

[15] Patrick K, Intille SS, Zabinski MF. An ecological framework for cancer communication: implications for research. J Med Internet Res. 2005;7(3):e23

[16] Klemm P, Bunnell D, et al. Online cancer support groups: a review of the research literature. Comput Inform Nurs. 2003;21(3): 136-42.

[17] Eysenbach, G, Powell J, et al. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. BMJ. 2004;328(7449): 1166-0.

[18] Eysenbach G. The Impact of the Internet on Cancer Outcomes. CA Cancer J Clin. 2003;53(6): 356-371.

[19] Arnold, Y.; Leimeister, J.M., Krcmar, H.: CoPEP: A Development Process Model for a Community Platform for Cancer Patients. In: Proceedings of the XIth European Conference on Information Systems (ECIS), 2003, Napoli/Naples.

[20] Aziz, N.M., Cancer survivorship research: challenge and opportunity. J Nutr, 2002. 132(11 Suppl): p. 3494S-3503S.

[21] Mullan F (1985) Seasons of survival reflections of a physician with cancer New England Journal of Medicine 313(4), 270-275

[22] About Cancer Survivorship Research: Survivorship Definitions. . [document on the Internet] 2006 [cited 2009 March 20]. Available from: http://cancercontrol.cancer.gov/ocs/definitions.html

[23] Twombly, R. What's in a Name: Who Is a Cancer Survivor? JNCI Journal of the National Cancer Institute 2004 96(19):1414-1415

[24] Building a Bridge of Continued Care for Cancer Survivors. J Oncol Pract. 2006;2(2):77-82.

[25] Hewitt M, Greenfield S, Stovall E (eds): From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC, The National Academies Press, 2005

[26] Sarasohn-Khan J. The wisdom of patients: Health care meets online social media. Oakland, CA:California Healthcare Foundation. [monograph on the Internet]; 2008 April [cited 2008 Sept 12]. Available from: http://www.chcf.org/documents/chronicdisease/HealthCareSocialMedia.pdf

[27] Barrera M, Glasgow RE, McKay HG, Boles SM, Feil EG. Do Internet-based support interventions change perceptions of social support? An experimental trial of approaches for supporting diabetes self-management. Am J Comm Psychol. 2002;30(5):637–654.

[28] Brennan PF, Moore SM, Smyth KA. The effects of a special computer network on caregivers of persons with Alzheimer’s disease. Nursing Research. 1995;44:166–172.

---

[29] Williams P, Barclay L, Schmied V. Defining Social Support in Context: A Necessary Step in Improving Research, Intervention, and Practice. Qual Health Res. 2004;14(7):942-960.

[30] Coiera E. Interaction design theory. Int J Med Inform. 2003;69(2-3): 205-222.

[31] Coiera E. Four rules for the reinvention of health care. BMJ. 2004:328(7449):1197-9.

[32] Levine M, Perkins DD, Perkins DV. Principles of community psychology: Perspectives and Applications. 3rd ed. New York: Oxford University Press; 2005.

[33] House JS, Umberson D, Landis KR. Structures and processes of social support. American Review of Sociology, 1988;14:293-318.

[34] Rook KS. The negative side of social interaction: impact on psychological well-being. J Pers Soc Psychol. 1984;46(5):1097-1108.

[35] Ingram KM, Betz NF, Mindes EJ, Schmitt MM, Smith NG. Unsupportive responses from others concerning a stressful life event: development of the unsupportive social interactions inventory. J Soc Clin Psychol. 2001;20(2):173–207.

[36] Brissett I, Cohen S, Seeman, TE. Measuring social integration and social networks. In: Cohen S, Underwood LG, Gottlieb BH editors. Social support measurement and intervention . New York: Oxford University Press; 2000. p. 53

[37] Perkins DD, Long DA. Neighborhood sense of community and social capital: A multi-level analysis. In: Fisher AT, Sonn CC, Bishop BJ editors. Psychological sense of community: Research, applications, and implications. New York: Kluwer Academic/Plenum Publishers; 2002. p. 291-318.

[38] Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millennium. Soc Sci Med. 2000;51(6):843-57.

[39] McLeroy KR, Norton BL, Kegler MC, Burdine JN, Sumaya CV. Community-based interventions. Am J Public Health. 2003;93(4):529-33.

[40] Meier A, Lyons EJ, Frydman G, Forlenza M, Rimer BK. How cancer survivors provide support on cancer-related internet mailing lists. J Med Internet Res. 2007;14;9(2):e12.

[41] Suler J. Applying social-psychology to online groups and communities. In The Psychology of Cyberspace. [document on the Internet] 1996 [cited 2008 Sept 15]. Available from: http://www-usr.rider.edu/~suler/psycyber/socpsy.html.

[42] Reid, E. Electropolis: Communication and community on Internet Relay Chat. Unpublished honors thesis. Melbourne: University of Melbourne;1991.

---

[43] Bunde M, Suls J, Martin R, Barnett K. Hystersisters online: social support and social comparison among hysterectomy patients on the internet. Ann Behav Med. 2006;31(3):271-8.

[44] Drentea P, Moren-Cross JL. Social capital and social support on the web: the case of an internet mother site. Sociol Health Illn. 2005;27(7):920-43.

[45] Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. Health Serv Res. 2004;39(4 Pt 1):1005–1026.

[46] Baskerville RL. Investigating information systems with action research. Communications of the AIS. 1999;2(3es).

[47] Lorenzi NM, Riley RT. Managing change: an overview. J Am Med Inform Assoc. 2000;7:116 -24.

[48] Kaplan, B. Addressing Organizational Issues into the Evaluation of Medical Systems. J Am Med Inform Assoc, 1997;4(2): 94-101.

[49] Gustafson DH, Hawkins RP, Boberg EW, McTavish F, Owens B, Wise M, et al. CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. Int J Med Inform. 2002;65(3):169-177.

[50] Cummings J, Kiesler SB, Sproull L. Beyond hearing: Where real world and online support meet. Group Dynamics: Theory, Res. Prac. 2002;6(1):78-88.

[51] Wellman B. Computer networks as social networks. Science. 2001;293:2031–2034

[52] Weiss JB, Lorenzi NM. Online Communication and Support for Cancer Patients: A Relationship-centric Design Framework. AMIA Annu Symp Proc. 2005:799–803.

[53] Morris ME. Social Networks as Health Feedback Displays. IEEE Internet Computing. 2005;9(5):29-37.

[54] Pratt W, Unruh K, Civan A, Skeels M. Managing health information in your life. Communications of the Association for Computing Machinery (CACM). 2006;49(1):51-55.

[55] TECC Center of Excellence in Cancer Communication Research UW-Madison. [document on the Internet]. Madison: TECC Center of Excellence in Cancer Communication Research [cited 2008 Sept 16]. Available from: http://chess2.chsra.wisc.edu/tecc/ro1s.htm

[56] Blanchard A, Horan T. Virtual communities and social capital. Social Science Computer Review. 1998;16(3):293-307

---

[57] Schuler D. Community networks: building a new participatory medium, Communications of the ACM. 1994;37(1):38-51.

[58] Hampton K, Wellman B. Neighboring in Netville: How the Internet Supports Community and Social Capital in a Wired Suburb. City and Community. 2003;2(4): 277-311.

[59] Taylor-Powell E, Rossing B, Geran J. Evaluating Collaboratives: Reaching the Potential. Madison, WI: University of Wisconsin–Cooperative Extension. 1998 [cited 2008 Sept 16]. Available from: http://learningstore.uwex.edu/pdf/G3658-8.PDF

[60] Cimprich B, Janz NK, Northouse L, Wren PA, Given B, Given CW. Taking CHARGE: A self-management program for women following breast cancer treatment. Psychooncology. 2005;14(9):704-717.

[61] Marcus AC, Garrett KM, Cella D, Wenzel LB, Brady MJ, Crane LA, et al. Telephone counseling of breast cancer patients after treatment: A description of a randomized clinical trial. Psychooncology. 1998;7(6):470-82.

[62] Feuerstein M. Defining cancer survivorship. Journal of Cancer Survivorship. 2007;1(1):5-7.

[63] Gustafson DH, Hawkins R, Pingree S, McTavish F, Arora NK, Mendenhall J, et al. Effect of computer support on younger women with breast cancer. J Gen Intern Med. 2001;16(7): 435-45.

[64] NCI Cancer Bulletin for June 6, 2006 (HTML) - National Cancer Institute. [document on the Internet]. Bethesda, MD: National Cancer Institute [cited 2008 Sept 16]. Available from: http://www.cancer.gov/ncicancerbulletin/NCI_Cancer_Bulletin_060606/page9

[65] The Cancer Survivors Network, supplying information, resources, chat, stories, discussion forums and support for cancer survivors and caregivers. [document on the Internet]. Atlanta, GA: American Cancer Society, Inc. [cited 2008 Sept 16]. Available from: http://www.acscsn.org/

[66] Jenkins J. Survivorship: finding a new balance. Semin Oncol Nurs. 2006;22(2):117-25.

[67] Koopman C, Hermanson K, Diamond S, Angell K, Spiegel D. Social support, life stress, pain and emotional adjustment to advanced breast cancer. Psychooncology. 1998;7(2):101-11.

[68] Granovetter M. The Strength of Weak Ties. American Journal of Sociology. 1973;78(6):1360-80.

[69] Raveis VH, Pretter S. Existential plight of adult daughters following their mother's breast cancer diagnosis. Psychooncology. 2005;14(1):49-60.

---

[70] Given BA, Given CW, Kozachik S. Family support in advanced cancer. CA Cancer J Clin. 2001;51(4): 213-31.

[71] Mandl KD, Szolovits P, Kohane IS. Public standards and patients' control: how to keep electronic medical records accessible but private. BMJ. 2001;322(7281): 283-7.

[72] Riva A, Mandl KD, Oh DH, Nigrin DJ, Butte A, Szolovits P, et al. The Personal Internetworked Notary and Guardian. Int J Med Inform. 2001; 62(1): 27-40.

[73] Shelby RA, Taylor KL, Kerner JF, Coleman E, Blum D. The role of community-based and philanthropic organizations in meeting cancer patient and caregiver needs. CA Cancer J Clin. 2002;52(4):229-46.

[74] Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). Patient Educ Couns. 2005;57(3): 250-61.

[75] Satterlund MJ, McCaul KD, Sandgren AK. Information gathering over time by breast cancer patients. J Med Internet Res. 2003;5(3):e15.

[76] When Someone You Love Has Completed Treatment. [document on the Internet]. Bethesda, MD: National Cancer Institute [cited 2008 Sept 16]. Available from: http://www.cancer.gov/cancertopics/Facing-Forward-When-Someone-You-Love-Has-Completed-Cancer-Treatment/

[77] CaringBridge: Free online service connecting family and friends [document on the Internet]. Eagan, MN: CaringBridge [cited 2008 Sept 16]. Available from: http://www.caringbridge.org

[78] TLContact,Inc. [document on the Internet]. Chicago, IL: TLContact, Inc. [cited 2008 Sept 16]. Available from: http://www.tlcontactinc.com

[79] Leichti O, Ichikawa T. A digital photography framework enabling affective awareness in home communication. Personal Technologies. 2000;4(1):6-24.

[80] Mynatt E, Rowan J, Craighill S, Jacobs A. Digital family portraits: supporting peace of mind for extended family members. Proc. of CHI ‘01. ACM Press. 2001;333-340.

[81] Farrell J. Wikis, blogs and other community tools in the enterprise. [document on the Internet]. IBM; 2006 Mar 23 [cited 2008 Sept 16]. Available from: http://www-128.ibm.com/developerworks/library/wa-wikiapps.html

[82] Cancer: Stories, support and information-wikiCancer. [document on the Internet] [cited 2008 Sept 16]. Available from: http://www.wikicancer.org/

[83] Welcome to Facebook! [document on the Internet] Palo Alto, CA: Facebook Inc. [cited 2008 Sept 16]. Available from: www.facebook.com

---

[84] Twitter. [document on the Internet] San Francisco, CA: Twitter, Inc. [cited 2008 Sept 16]. Available from: www.twitter.com

[85] Woodgate RL. The importance of being there: perspectives of social support by adolescents with cancer. J Pediatr Oncol Nurs. 2006;23(3):122-34.

[86] Figueiredo MI, Fries E, Ingram KM, The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. Psychooncology. 2004;13(2):96-105.

[87] Klemm P, Reppert K, Visich L. A nontraditional cancer support group. The Internet. Comput Nurs. 1998;16(1): 31-6.

[88] Han HR, Belcher AE. Computer-mediated support group use among parents of children with cancer–an exploratory study. Comput Nurs 2001;19: 27–33.

[89] Kukafka R, Ancker JS, Chan C, Chelico J, Khan S, Mortoti S, et al. Redesigning electronic health record systems to support public health. J Biomed Inform. 2007;40(4):398-409.

[90] MedlinePlus Go Local Index. [document on the Internet] Bethesda, MD: National Library of Medicine [cited 2008 Sept 16]. Available from: http://www.nlm.nih.gov/medlineplus/golocal/

[91] Weiss JB, Lorenzi NM Synthesizing Community Wisdom: A Model for Sharing Cancer-Related Resources through Social Networking and Collaborative Partnerships. Accepted for publication in AMIA Annu Symp Proc. 2008.

[92] Erwin DO, Spatz TS, Stotts RC, Hollenberg JA. Increasing mammography practice by African American women. Cancer Pract. 1999;7(2):78-85.

[93] Coalitions OnLine. [document on the Internet] [cited 2008 August 3]. Available from: http://www.coalitionsonline.org/

[94] Rapkin BD, Massie MJ, Jansky EJ, Lounsbury DW, Murphy PD, Powell S. Developing a partnership model for cancer screening with community-based organizations: the ACCESS breast cancer education and outreach project. Am J Community Psychol. 2006;38(3-4):153-64.

[95] Senathirajah Y, Kukafka R, Guptarak M, Cohall A. Health Information Seeking and Technology Use in Harlem – a Pilot Study using Community-Based Participatory Research. AMIA Annu Symp Proc. 2006: 704–708.

[96] Turner J, Brube J, Meyers J. Developing an optimal match within online communities: an exploration of CMC support communities and traditional support. Journal of Communication. 2001;51(2):231-251

---

[97] Erickson T, Kellogg W. Social Translucence: An Approach to Designing Systems that Mesh with Social Processes. Transactions on Computer-Human Interaction. 2000;7(1): 59-83.

[98] Blanchard A, Markus ML. Sense of Virtual Community–Maintaining the Experience of Belonging. In: Spargue R editor. Proceedings of the 35th Hawaii International Conference on System Sciences. Los Alamitos, CA: IEEE;2002.

[99] Quan-Haase A, Wellman B. How does the Internet affect social capital? In: Huysman M, Wulf V editors. Social Capital and Information Technology. Cambridge, MA: MIT Press; 2002. p. 113-132.

[100] Williams D. On and off the 'net: Scales for social capital in an online era. Journal of Computer-Mediated Communication, 2006;11(2).

[101] The Hugs For Jacey Campaign [document on the Internet]. San Bruno, CA: YouTube; 2006 [cited 2008 Sept 16]. Available from: http://www.youtube.com/watch?v=HZjHTviwDh4

[102] van Uden-Kraan CF, Drossaert CH, Taal E, Shaw BR, Seydel ER, van de Laar MA. Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia. Qual Health Res. 2008;18(3):405-17.

[103] Platner JH, Bennett LM, Millikan R, Barker MD. The partnership between breast cancer advocates and scientists. Environ Mol Mutagen. 2002;39(2-3):102-7..

[104] Zebrack BJ. Cancer survivor identity and quality of life. Cancer Pract. 2000;8(5):238-42.

[105] 2007 Community Program/Research RFP – LIVESTRONG [document on the Internet]. Austin, TX: Lance Armstrong Foundation; 2007 [cited 2008 Sept 16]. Available from: http://www.livestrong.org/site/c.jvKZLbMRIsG/b.2406785/k.F942/2007_Community_ProgramResearch_RFP.htm

[106] Putnam RD. Bowling alone: The collapse and revival of American community. NY: Simon & Schuster; 2000.

[107] Thoits PA. Stress, coping, and social support processes: where are we? What next? J Health Soc Behav. 1995;35:53-79.

[108] McMillan DW, Chavis DM. Sense of community: A definition and theory. Journal of Community Psychology, 1986;14(1): 6-23.

[109] Burnes, B., Kurt Lewin and the Planned Approach to Change: A Re-appraisal. Journal of Management Studies, 2004. 41(6): p. 977-1002.

---

[110] Kaplan B, Shaw NT.Future directions in evaluation research: people, organizational, and social issues. Methods Inf Med. 2004;43(3):215-31

[111] Lincoln, YS, & Guba, EG. (1985). Naturalistic inquiry. Beverly Hills, CA: Sage.

[112] Strauss AL, Corbin J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. 2nd ed. Thousand Oaks, CA: Sage, 1998.

[113] Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health 1998; 19: 173-202

[114] O'Fallon LR, Dearry A. Community based participatory research as a tool to advance environmental health sciences. Environ Health Perspect 2002;110:S155–59.

[115] Susman, G. and R. Evered. (1978) “An Assessment of The Scientific Merits of Action Research,” Administrative Science Quarterly, (23) 4, pp. 582-603.

[116] Fruhling, Ann, Tyser, Kim, deVreede, Gert-Jan,“Experiences with Extreme Programming in Telehealth: Developing and Implementing a Biosecurity Health Care Application,” Thirty-eighth Hawaii International Conference System Sciences, January 2005.

[117] Beck, K., Embracing change with extreme programming. Computer, 1999. 32(10): p. 70-77.

[118] M. Fowler and J. Highsmith, “The Agile Manifesto,” Software Development, Aug. 2001, pp. 28-32.

[119] Skinner HA, Maley O, Norman CD. Developing internet-based eHealth promotion programs: the Spiral Technology Action Research (STAR) model. Health Promot Pract. 2006 Oct;7(4):406-17.

[120] Berg M. Patient care information systems and health care work: A sociotechnical approach (1999) International Journal of Medical Informatics, 55 (2), pp. 87-101.

[121] Foth, Marcus, & Axup, Jeff (2006). Participatory Design and Action Research: Identical Twins or Synergetic Pair? Participatory Design Conference (PDC), Trento, Italy.

[122] Preece, J. (2000). Online communities: Designing Usability, Supporting Sociability. New York: Wiley, New York, NY.

[123] Nielsen J, Curtis B (1995) Applying discount usability engineering. IEEE Software 12:98–100

---

[124] D. Kane, “Finding a Place for Discount Usability Engineering in Agile Development: Throwing Down the Gauntlet,” at the Agile Development Conference 2003,

[125] Andreas Holzinger, Maximilian Errath, Gig Searle, Bettina Thurnher, Wolfgang Slany, "From Extreme Programming and Usability Engineering to Extreme Usability in Software Engineering Education (XP+UE→XU)," compsac, pp. 169-172, 29th Annual International Computer Software and Applications Conference (COMPSAC'05) Volume 2, 2005.

[126] Andrews, D. C. (2002). Audience-Specific Online Community Design. Communications of the ACM, 45(4), 64-68.

[127] Tharp, K. (2004). Individual-centered approach to the design of an online community network. Unpublished PhD, Central Queensland University, Rockhampton, QLD.

[128] Foth, M. (2003, Dec 15-17). Connectivity Does Not Ensure Community: On Social Capital, Networks and Communities of Place. In S. Marshall & W. Taylor (Eds.), Proceedings 5th International Information Technology in Regional Areas (ITiRA) Conference (pp. 31-39). Caloundra, QLD: Central Queensland University Press.

[129] Chipuer, H.M., & Pretty, G.M.H. ~1999!. A review of the Sense of Community Index: Current uses, factor structure, reliability, and further development. Journal of Community Psychology, 27~6!, 643–658.

[130] Long DA, Perkins DD. Confirmatory factor analysis of the Sense of Community Index and development of a Brief SCI. Journal of Community Psychology. 2003; 31(3):279-296.

[131] Welcome to Co-opetition Web site. [document on the Internet] [cited 2009 March 20]. Available from: http://mayet.som.yale.edu/coopetition/

[132] Delicious. [document on the Internet] [cited 2009 March 20]. Available from: http://www.delicious.com

[133] Google Maps. [document on the Internet] [cited 2009 March 20]. Available from: http://maps.google.com

[134] Drupal.org | Community plumbing. [document on the Internet] [cited 2009 March 20]. Available from: www.drupal.org