

ONE-STEP, TWO-STEP, OR MULTI-STEP FLOW: THE ROLE OF INFLUENCERS  
IN INFORMATION PROCESSING AND DISSEMINATION IN  
ONLINE, INTEREST-BASED PUBLICS

by

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## DISSERTATION ABSTRACT

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Doctor of Philosophy

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Title: One-step, Two-step, or Multi-step Flow: The Role of Influencers in Information Processing and Dissemination in Online, Interest-Based Publics

This research examines information flow in online, interest-based networks to determine if existing models of information dissemination are adequate to describe the communication processes that occur in online publics. This study finds that a small number of primary influencers from within online communities are central to information collection, collation, and distribution in online, interest-based networks. This finding is inconsistent with one-step, two-step, and multi-step flow models, which privilege mass media as the central source of information. To more accurately depict online information flow in interest-based networks, this study introduces the radial model of information flow. Furthermore, the results of this study show that communication processes in online publics are best explained using a combination of the transmissive paradigm of communication, on which information flow models are based, and a ritual view of communication.

This research also contributes to the ongoing development of the situational theory of publics by identifying organized publics as a key subgroup of active publics. Organized publics are networks of individuals within active publics who frequently and consistently communicate on a shared interest or concern. Organized publics form active online

communication networks and prepare for advocacy related to a shared interest, making them of particular interest to public relations professionals.

Using a case study approach, this dissertation uses online network analysis and qualitative cluster analysis to study the role of community influencers in information flow and cultural development within the online young adult cancer community. Instead of focusing exclusively on social media as channel for message dissemination, the results of this study indicate that successful relationship building can best be achieved by public relations practitioners who work to develop authentic presences in online communities. This research shows that embracing a participatory model of public relations that actively engages primary influencers in the planning and campaign implementation processes can promote authentic online presences.

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# CHAPTER I

## INTRODUCTION

In summer 2011, I visited the Institute for Health Research's Cancer Communication Research Center (CCRC) at Kaiser Permanente's Denver headquarters, one of five Centers of Excellence in Cancer Communication Research (CECCR), as part of a fellowship for doctoral students interested in cancer communication issues. I spent three days engaging with guest speakers and shadowing professionals. I discussed health communication processes with electronic medical records experts, internal communications representatives, oncologists, primary care providers, web designers, and researchers. During the entire event, however, I never once spoke with someone who discussed health communication practices from a patient's perspective.

Given that the CCRC's primary goal is to "identify and describe optimal communication structures and processes in organizations that facilitate patient-centered communication in cancer care" (Kaiser Permanente, 2011, para. 2), the lack of patient voices during the fellowship was unfortunate, but it was not entirely surprising. Strategic communication research concerning publics is typically presented from a managerial perspective (Karlberg, 1996). The perspectives of key publics are viewed in relation to the position of an organization, rather than as an area of study unto itself. Publics are recognized as forming around particular issues, but their needs and concerns are studied as they apply to the needs of an organization (Moffitt, 1992). Much has been done to study how information and ideas are transmitted from an organization to an interest group, but I have yet to find a comprehensive study that examines the internal communication practices of publics themselves. Although there is value in studying

communication practices from the perspective of the organization, there is also great value in better understanding the communicative actions, practices, and perspectives of organizations' key publics.

Recent advances in communication technologies make the study of issues from the perspective of publics increasingly important. With a minimal amount of technical proficiency, any individual with Internet access and a computer can start a blog, comment on message boards, join social networking sites such as MySpace and Facebook, use microblogging sites such as Twitter, and jump into e-mail lists. The ease with which Internet users can create and publish comments and opinions that can easily be distributed makes it possible for individuals to share information with an entire virtual world of people sharing similar interests. The structure of the social web is shifting the dynamics of message development and dissemination. Such shifts call into question the explanatory power of extant theories of information dissemination and influence.

The earliest models of information flow arose from studies of propaganda techniques and posited a direct influence model (Lasswell, 1938). The one-step flow model of information dissemination, also known as the "magic bullet" or "hypodermic needle" model, proved difficult to validate in media effects research but set the groundwork for subsequent study of information flow and media influences (Bennet & Manheim, 2006).

Katz and Lazarsfeld (1955) developed the two-step flow model to explain the influence of mass media on the general public. According to the model, instead of directly influencing the full audience, media messages are filtered through opinion leaders who interpret and contextualize the content during innumerable small group

interactions. While this theory has been hugely influential in the study of media influence, subsequent testing of the model has shown that the information distribution process and influence of mass media is more complex than the two-step flow model implies (Gitlin, 1978).

Several researchers have posited a multi-step flow of information model, which shows a more complex range of possible interactions than the downward communication flow from more to less attentive persons suggested by the two-step model (Robinson, 1976). More recently, Bennet and Manheim (2006) argued that advances in media technology have led to such differentiation of audiences by interest that messages now simply travel directly from a sender to a receiver in a “one-step flow” process.

The purpose of this study is to test extant models of information flow and determine their role in the formation of publics. The situational theory of publics, the dominant theoretical paradigm in the study of public relations, is used as a framework for this analysis of online, interest-based publics (Grunig, 1997). This study is needed because the public relations industry is in a time of great flux. With new media technologies shifting the roles of audiences, producers, and publics, public relations professionals are finding that building relationships with online influencers can be both time consuming and fraught with potential missteps. By better understanding how online influencers develop and what role they play in disseminating information and influencing others within an online public, public relations practitioners will be better able to work with these wired interest groups. The goal of the study is to find ways public relations practitioners can most effectively build relationships with online, interest-based communities.

## **Background and Context**

Americans are going online in greater percentages and for longer amounts of time than ever before. As of May 2011, a national survey showed that 78% of American adults use the Internet (Pew Research Center, 2011a). These Internet users are not just acting as passive consumers of online data. More than half of American adults and 65% of adult Internet users are active on at least one social networking site, such as MySpace, Facebook, and LinkedIn, that facilitates the exchange of user-generated information (Madden & Zickuhr, 2011). As more social and professional interactions take place through digital interfaces, web-based communities develop around shared interests and purposes (Rheingold, 1993). Through robust communication exchange, interest-based communities can develop shared values, language, and culture (Jenkins, 2006).

There are many examples of online subcultures that develop similar ideas regarding an interest or topic (Jenkins, 2006), and these networks form around a wide range of interests. Just a few examples include an active blogging scene for artisan knitters, numerous wiki sites devoted to expanding the Harry Potter fan fiction genre, and even a number of blogs, fan pages, Twitter feeds, and a dedicated virtual community (PROpenMic) for those interested in public relations pedagogy.

### **Mommy Bloggers**

Some highly networked online, interest-based communities are beginning to flex their collective muscles to promote shared cultural values. The online “mommy bloggers” network, for example, has publically challenged existing representations of motherhood

in Western society (Lopez, 2009). Parents who blog about their children, often with brutal honesty and including both the joyful and difficult moments of motherhood, are “transforming their personal narratives of struggle and challenge into interactive conversations with other mothers, and in so doing, are beginning to expand our notion of motherhood, women bloggers and the mother’s place within the public sphere” (Lopez, 2009, p. 744). By introducing new ideas regarding acceptable mothering, the network of mommy bloggers develops a community with shared language, values, and perceptions that often do not match common notions of parenting (Lopez, 2009).

In recent years, corporate entities have started to recognize the power of influential members of online groups such as the mommy blogging community. In 2008, Procter & Gamble (P&G) provided 15 popular parenting bloggers an all-expense-paid trip to its Cincinnati headquarters to educate them on the company’s product lines and parenting support programs (Neff, 2008). In 2010, P&G sent a popular mommy blogger to the Winter Olympic Games in Vancouver, B.C., Kodak sponsored a mommy blogger’s trip to the Oscars, and G.M. Canada sent mommy bloggers on a road trip to Disney World in a Chevy Traverse (Mendelsohn, 2010). The flood of products and promotions offered to parenting bloggers was part of the impetus for an October 2009 requirement by the Federal Trade Commission that bloggers must disclose any and all endorsements or face fines of up to \$11,000 per post (Ostrow, 2009).

Any corporation that has tangled with a functional web-based interest group likely recognizes the collective power of online networks. In 2008, Johnson & Johnson, the makers of the pain-relieving drug Motrin, enraged the online parenting community by releasing an advertisement that spoke irreverently of “baby wearing” — i.e., carrying a

child in a sling, wrap or any other contraption that keeps a child close to the wearer. The resulting outcry on Twitter, Facebook, YouTube and other social networks caused Johnson & Johnson to pull the offending ad campaign and release a response to the mommy blogging community (Learmonth, 2008).

### **Online Health Communities**

One of the most common reasons people go online is for health information (Pew Research Center, 2011a), and thousands of online communities promote peer-to-peer discussion of shared health issues (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004).

In 2000, the Pew Internet & American Life Project released the first in a series of reports examining how and why individuals access health information online (Fox & Rainie, 2000). It found that 52 million Americans, or about 55% of the adults with Internet access, had used the web to get health information. The researchers dubbed these users “health seekers” and found that a majority of those surveyed went online at least once a month for health information.

More than a decade later, the same researchers released updated information that showed a startling increase in the use of the web as a health resource (Fox, 2011a). In 2010, about 59% of all adults and 80% of adult Internet users reported looking online for health information, the third most popular online activity after checking email and using a search engine (Fox, 2011b). Furthermore, the national survey found that consumers of online health information tend to be highly engaged users. Nearly two-thirds of Internet users look online for information about a specific disease or symptom (Fox, 2011a). Individuals who have faced a serious medical emergency or crisis in the last year and



people who have experienced a significant change in their physical status (pregnancy, weight loss or gain, smoking cessation) are among those most likely to seek out health information online. Adults providing care for loved ones also frequently use the web for health information. Health seekers are actually more likely to be online looking for information for someone else than they are to be searching on their own behalf (Fox, 2011a).

While the vast majority of Internet users turn to the web for health information, some web users exhibit a greater level of engagement with the health information available online. I adopt the term *e-patients*, already in use in both academic and cultural circles, to describe these highly engaged users. Dr. Tom Ferguson, an advocate for participatory medicine who is often credited with coining the term “e-patient,” described the group as follows:

Citizens with health concerns who use the Internet as a health resource, studying up on their own diseases (and those of friends and family members), finding better treatment centers and insisting on better care, providing other patients with invaluable medical assistance and support, and increasingly serving as important collaborators and advisors for their clinicians. (Ferguson, 2007, p. XII)

The Pew Internet & American Life project has completed several surveys on Internet and health behaviors (Fox, 2011c) describing the development of an e-patient movement. There is research available about who e-patients are, what they do online, and what kind of health concerns they face, but I have been unable to find studies that look at how information is distributed and disseminated within e-patient networks.

## Summary

The rise of participatory media is changing the practice of public relations (Wright & Hinson, 2009f). Although evidence suggests that online, interest-based communities can form powerful publics that are able to organize effectively around shared concerns, public relations practitioners in general have not yet been able to utilize social media tools to build mutually beneficial relationships (Taylor & Kent, 2002). Because personal health is one of the most popular reasons individuals access the web and a common shared issue that online communities develop around, this research examines online publics that form around health issues.

Thanks in large part to recent advances in communication technologies, publics are able to develop relationships based on common conditions and interests without the constraints of physical distance and time differences. This dissertation seeks to contribute to the field of public relations by examining the communication practices of these online, interest-based publics with the goal of developing ways public relations practitioners can better build relationships with online communities.

The following section provides an overview of the literature informing this study. The first part reviews the expansion of social media and its relation to Grunig's situational theory of publics (J. E. Grunig, 1975, 1978a, 1978b, 1983, 1987, 1989, 1992, 1997; J.E. Grunig & Hunt, 1984), focusing on the importance of active publics to the practice of public relations. Next, the role of influencers in active publics is discussed in relation to the body of literature on information flow theories and gatekeeping and gatewatching practice. Then, the development of web 2.0 technologies is discussed as it relates to the evolution of public relations practice. Finally, research on the emergence of

interest-based publics focused on issues of health is shared. The literature discussing online publics related to health issues focuses specifically on the young adult cancer community, an active participant in the rising e-patient movement and the community used as a case study in this dissertation.

Following the literature review, the method of study is discussed. This dissertation uses both online network analysis and qualitative cluster analysis to study communication practices of online, interest-based communities. Online network analysis is used to identify primary influencers within an online, interest-based community and cluster analysis is used to develop an in-depth understanding of the communication processes of these primary influencers. The purpose of this study is to illuminate the role of influencers in message dissemination and shared culture creation in online, interest-based communities.

## **CHAPTER II**

### **LITERATURE REVIEW**

#### **The Expansion of Social Media**

The phrase web 2.0 was coined in 1999 in a piece describing the evolution of online communication as a tool that “will fragment into countless permutations with different looks, behaviors, uses, and hardware hosts” (DiNucci, 1999, p.32). DiNucci’s article, published when the online world was nearing the pinnacle of the dot-com bubble that burst in spring 2000, foretold a major shift in web content. The first decade of the new millennium has been marked by the steady proliferation of interactive web applications. Using a multitude of simple platforms, opportunities to publish on broad public communication channels are now available to even novice web users. The term web 2.0 has since come to be used as an umbrella term that refers to web-based programs that are built around user-generated content. Message boards, blogs, wikis, podcasts, and social networking sites are all generally categorized as web 2.0 applications (DiNucci, 1999).

According to a recent Pew Internet & American Life survey (2011b), 75% of adults in the United States and 93% of teens are regular Internet users. Of adult Internet users, 46% regularly use a social networking site with self-publishing capabilities, such as MySpace, Facebook, or LinkedIn. About 19% of Internet users say they use Twitter to regularly share updates about themselves or to see updates about others (“Change in internet access,” 2010), and in 2008 the use of social media overtook pornography as the number-one use of the World Wide Web (Tancer, 2008).

Perhaps because social media are a relatively new development within the Internet infrastructure, there is little established research on how the interactive web influences persuasive communications. In the area of persuasive health communication in particular, researchers have shown interest in the use of social media to spread public health information quickly among hard-to-reach populations (McNab, 2009) and social media as a tool for health education (Creighton, 2010; Lariscy, Reber, & Paek, 2010). There has also been some research into how disparities in access to social media may affect access to public health information (Kontos, Emmons, Puleo, & Viswanath, 2010) and personal health efficacy (Rains, 2008).

Although the research into the interactive web as it specifically relates to health and persuasion is sparse, there is a growing body of research into the ways emerging technologies are more generally affecting public relations practice. The next section discusses the ways interest-based online communities, such as those that form around health issues, can be viewed through the lens of the situational theory of publics, a dominant theory in the study of public relations.

### **The Situational Theory of Publics**

When Grunig and his co-researchers published the Excellence Study in 1986, they set the tone for much of the theory that would be developed in the field of public relations (Sallot, Lyon, Acosta-Alzuru & Jones, 2008). Although the development of theory in public relations has been scattered at best (Greenwood, 2010), excellence theory continues to be recognized by many as the dominant paradigm of public relations research (Botan & Hazleton, 2006; Grunig, Grunig & Dozier, 2006). The situational

theory of publics (J.E. Grunig, 1978, 1978b, 1983, 1987, 1989, 1992, 1997; J.E. Grunig & Hunt, 1984), is an integral aspect of excellence theory and has set the foundation for much of the work in the study of publics (Grunig, Grunig, & Toth, 2007).

The situational theory of publics is founded on the definition of publics popularized by Dewey (1927), which described publics as coming into being in response to issues of import to a particular group. In other words, publics develop around issues that affect the members of that public. The opinion of a public develops through discussion and debate in relation to particular issues (Price, 1992). Public relations theorists and practitioners are particularly interested in publics who mobilize around issues of shared importance to members of a group.

The situational theory of publics (J. E. Grunig, 1975, 1978a, 1978b, 1983, 1987, 1989, 1992, 1997; J.E. Grunig & Hunt, 1984) identifies four different types of publics that develop in response to issues: non-publics, latent publics, aware publics, and active publics. Groups are categorized according to three independent variables: problem recognition, constrain recognition, and level of involvement (Grunig & Hunt, 1984). Public relations practitioners are most concerned with active publics (groups with high problem recognition, low constraint recognition, and high level of involvement) because they are most likely to mobilize and take action in response to an issue (Grunig, 1978a, 1983, 1997; Grunig & Hunt, 1984). Highly active publics engage in shared information seeking and information processing, two forms of communication behavior (Grunig & Hunt, 1984; Grunig & Ipes, 1983). Information processing occurs when individuals take notice of a message and absorb the content (Slater, Chipman, Auld, Keefe, & Kendall, 1992). Information seeking refers to the deliberate search for information on a particular

issue (Grunig, 1989). These active communication processes lead groups to develop organized shared cognitions and engage in behaviors to do something about a situation (Grunig, 1980; Heath, Liao, & Douglas, 1995). Groups that are highly engaged with an issue will often seek information using a variety of channels such as mass media, interpersonal sources, and specialized sources (Heath et al., 1995).

Research has consistently shown that the more active a public, the more active its communication behavior and the more likely individuals will develop shared attitudes and participate in similar behaviors in relation to their common issue (J. E. Grunig & Ipes, 1983). Because active publics seek out many sources of information regarding an issue, their cognitions and behaviors are formed from a composite of the communications from many different information sources and not from a single campaign (J. E. Grunig, 1997). Despite J. E. Grunig's (1997) assertion that active publics develop shared cognitions, the theory has been criticized for making assumptions about the state of consciousness of publics defined by their relationship to issues without addressing the complex nature of the communication practices that lead to the development of a group consciousness (Vasquez & Taylor, 2001).

Members of active publics who believe a particular issue is important to them are most likely to become members of activist groups (J. E. Grunig, 1989). While most activist groups in the past had been largely written off as warranting little attention from organizations because they typically consist of only a small number of highly engaged members, the Internet may well provide a space for activists to gain support for their issue and mobilize in pursuit of a common goal (Coombs, 1998). Even groups with little power or structure can use the Internet as a low-cost way to acquire access to resources

from other activist groups and pressure organizations to instigate change (Coombs, 1998). Hurwitz (1999) argues that “The Internet is an obvious and powerful tool for democratic action because it can help create communities of interests that transcend space, time, and the need for formal introductions” (p. 660). Not only does the web provide space for interest-based communities to form across geographic and cultural boundaries, the nature of web-based communication leaves a virtual record of information that is a veritable goldmine for researchers interested in learning more about the communication practices of interest-based networks.

Several studies in the field of public relations have used the situational theory of publics to study the behaviors of publics in response to issues such as drunk driving (J. E. Grunig & Ipes, 1983), environmental activism (J. E. Grunig, 1989), and earthquake preparedness (Major, 1998). The situational theory of publics positions active publics as information-seeking bodies. Those members who acquire extensive knowledge about the issue of interest become opinion leaders in that area and have the potential to influence information dissemination within the network. The next section discusses the evolution and current research into information flow theory, which examines the role of opinion leaders or “influencers” in the process of information dissemination within a public.

### **One-step Flow, Two-step Flow, Multi-step Flow and One-step Flow**

Media studies as a discipline first came into its own in the 1930s (Bennett, 1982). The United States had experienced only a short period of peace and prosperity after the end of World War I in 1918 and was dealing with the repercussions of a decade-long depression. The country was fast approaching another war with a European superpower,



and morale among the U.S. populace was at an astounding low. The divide between the haves and have-nots was larger than at any other time in this country's history, and citizen discontent was high. Advances in media technology, the proliferation of fairly inexpensive publications, and increasing literacy rates meant that, for the first time, individuals of all economic classes had access to news and information. Movies houses were extremely popular, and, at the end of the decade, the television set was unveiled at the Chicago World's Fair.

The cultural position of the United States during this time period provides context that helps to explain the advent of information flow theories in media studies. Early media researchers were primarily concerned with the direct effects media might have on the general population (Delia, 1987). It was during the early 20<sup>th</sup> century that the term "mass media" came into general use and media studies was developed on the foundation of thought that considered the general population and undifferentiated group subject to media messages (Bennett, 1982). Consumers of mass media (at the time, penny papers, popular movies, entertainment radio) were seen as uneducated publics easily manipulated (Bennett, 1982). In Lasswell's *Propaganda Techniques in the World War* (1938), he found that audiences could be manipulated using various propaganda techniques. While not entirely promoting media as a direct magic bullet or hypodermic needle that had immediate effects on an audience, Lasswell argued that by controlling the media environment and slowly preparing people to accept strange or different ideas, mass media content producers could effectively prepare an audience for calls to action. When Hitler came to power in Germany, Lasswell's thesis appeared to be playing out in the real world

(Bennett, 1982). However, within a few decades media theorists began challenging the one-step propaganda model of media influence.

The two-step flow of mediated information dissemination was introduced by Lazarsfeld (1940) when he challenged a popular and widely held assumption that media messages extended from a content producer directly to the ears (or eyes) of individuals in an audience. Instead, Lazarsfeld argued that influencers actually moderated messages and acted as filters for mass media message dissemination. Lazarsfeld, and later his coauthor Elihu Katz (Katz & Lazarsfeld, 1955), introduced the two-step flow of information theory, proposing that opinion leaders who pay close attention to the mass media add their own thoughts and interpretations to messages before passing them on to their eventual end audiences.

According to Katz and Lazarfeld's two-step flow of information theory (1955), mass media audiences are affected both by the actual information that is distributed as news as well as influencers' interpretation of the news. This serves to move the function of media beyond simply producing and distributing information or entertainment toward the goal of moving the masses toward particular kinds of social objectives (Lazarsfeld, Berelson, & Gaudet, 1944).

Early work studying the two-step flow process focused on the role of interpersonal communication in the interpretation of messages for national political campaigns (Katz & Lazarsfeld, 1955). In these situations, public interest in the issue was high across the vast majority of Americans. Participation in special interest groups by either members of the public or identified opinion leaders was not examined as part of these early studies (Katz & Lazarsfeld, 1955). Katz and Lazarsfeld (1955) found that

opinion leaders acted as influential modifiers of information that was distributed through mass media sources. Their work showed that information distributed through mainstream media, such as fashion trends for a particular season, was sought out by a small subset of the general population who were particularly interested in the topic. These topic-specific influencers then shape public opinion in the topic area by translating and providing context on the topic for the general public (Katz & Lazarsfeld, 1955). Although the presence and influence of opinion leaders has been widely embraced by communication practitioners (Bennett & Manheim, 2006), the role of opinion leader or “influencer” in the communication process has also been widely challenged by academics and communication researchers (Gitlin, 1978).

While some researchers still argue for information disseminations occurring largely through two-step flow processes (Kim, Wyatt & Katz, 1999), the opinions of public relations practitioners vary widely in regards to the recognition and role of important influencers and opinion leaders (Gillin, 2008). Several communications scholars (Bennett & Manheim, 2006; Burt, 1999; Gitlin, 1978; Harik, 1971; Robinson, 1976; Weiman, 1982) have challenged the simplicity of the two-step flow model, which relies heavily on influencers as interpreters and disseminators of information. Many studies testing the two-step flow process have suggested that information actually tends to travel in multi-step flow processes with many different flow directions and iterations (Burt, 1999; Harik, 1971; Robinson, 1976; Weiman, 1982). The multi-step flow model has dominated research in information dissemination for the last four decades (Bennett & Manheim, 2006), but recent advances in communication technologies led Bennett and

Manheim (2006) to posit a one-step flow of information model in which messages travel directly from an organization to its publics.

As discussed earlier, Lasswell's (1938) propaganda model of one-step information flow evolved during a time of rapid change in media technology (Bennett, 1982). However, while Lasswell saw information flowing to a public through mass media, Bennett and Manheim (2006) conceptualized a one-step flow of information developing as a result of highly differentialized media sources. In readdressing the one-step flow of communication theory, Bennett and Manheim (2006) pointed to the evolution of media formats, individual media use habits, and social distribution of media as evidence of a changing media landscape. The technological and media changes over the last 30 years have made it possible for organizations to target their messages to increasingly more specific publics (Bennett & Manheim, 2006). If persuasive communication professionals can adopt narrowcasting to an extent that allows for messages delivered only to interested parties, the direct communication paradigm may be revived and applied in hyper-mediated communication practices (Bennett & Manheim, 2006).

The dominance of multi-step flow models in academic research and the emerging scholarship in one-step flow models have not, however, deterred public relations practitioners from pursuing opinion leaders as part of their communication strategies (Wright & Hinson, 2010). In fact, public relations practitioners indicate that the rise of a social web has led to increased efforts to reach opinion leaders who are active social media users (Wright & Hinson, 2010).

In 2008, researchers surveyed nearly 300 public relations, corporate communications, and marketing professionals as part of a Society for New Communications Research study to determine professional communicators' attitudes toward social media use (Gillin, 2008). The vast majority of respondents reported that social media are a core channel for sharing information. Despite recognizing the importance of social media influencers in online communities, public relations practitioners are still struggling to find effective metrics to conclusively decide whom the most influential players are (Gillin, 2008). Although the study showed no comprehensive agreement among survey respondents as to what the single best criteria is to use when determining who online influencers are, survey participants named traffic numbers for particular websites, quality of content, relevance of content to the organization, and search engine rankings as factors to consider when determining online influencers for particular communities (Gillin, 2008). The most successful online influencers connect to a large network to spread their messages broadly but also recognize the importance of cultivating a smaller, more concentrated network that can be called to action for such campaigns as product boycotts, social responsibility movements, and promotional events (Basille, 2009).

The shifting nature of influence and communication practices as a result of the social web have actually caused some researchers to call for a paradigm shift in media studies (Gauntlett, 2007). The following section discusses the changing state of media studies, particularly in the area of persuasive communication, given the evolution of technologies and the rise of social media use by Internet users.

## Media Studies 2.0

In February 2007, Gauntlett, a professor in the media studies department at the University of Westminster, published an article titled “Media Studies 2.0” on his website, Theory.org.uk. This piece launched much discussion among media scholars regarding the import of new media technologies in the field of media studies. Gauntlett (2009) argues that the power differentials between content producers and content consumers are collapsing. Media Studies 2.0 is concerned with the participatory possibilities of media and seeks to encourage research on how people experience media. Instead of looking primarily at content and messaging, Gauntlett (2009) calls for greater study into the ways individuals work with media technologies and experience hyper-mediated environments. Media 2.0 is concerned with the interaction between new media and societal trends, particularly as it relates to the public as media content producers (Gauntlett, 2009).

The changing role of audience has proven a rich area for professional studies. The book *The Wisdom of Crowds: Why the Many Are Smarter Than the Few and How Collective Wisdom Shapes Business, Economies, Societies and Nations* examines the value of understanding and utilizing public opinion in the online world (Surowiecki, 2004). *Groundswell*, a popular book produced by Forrester Research Center (Li & Bernoff, 2008), examines the changing role of professional communicators as participatory media puts the power of meaning making into the hands of online influencers. Relationships are now forged in virtual spaces, and the role of a public relations person is in flux (Gilpin, 2010, p. 246). The following section examines how changes in media technologies are leading to expansions in the role of public relations practitioners.

## **Social Media and Public Relations**

New technologies are having an enormous impact on the practice of public relations. In a content analysis of the Public Relations Society of America's professional journal *Public Relations Tactics*, researchers found that between April 2008 and March 2009, 59 articles, text boxes, and columns referenced social media (Taylor & Kent, 2010). Of those 59 articles, 39 pieces (about two thirds) made claims about the power of social media and its value as a public relations tool. One way social media have empowered strategic publics is by giving them a dynamic platform through which individuals can communicate and collaborate with a variety of audiences (Wright & Hinson, 2006a & 2007a).

The rising popularity of a social web has created innumerable pathways, through which interest-based networks addressing a nearly endless range of topics can develop and grow (Li & Bernoff, 2008). Audiences are increasingly distrustful of news and advertising messages, relying instead on peers for information and advice (Keller & Berry, 2003). Public relations practitioners are mindful of the potential of new media to communicate with increasingly elusive audiences (Avery, Lariscy, & Sweetser, 2011) but are struggling to find ways to build effective relationships online (Taylor & Kent, 2010).

The rise of participatory websites has created opportunities for people to connect with others who share similar interests. According to the social media and Internet marketing blog Traffikd (2010), there are more than 400 different social media and social networking sites spanning the following categories: arts, bookmarking, cars and auto, connecting with friends, consumer reviews, cooking/food, cultures/foreign language, dating, education/books, event planning, family, fashion/clothing, finance, games,

general networking, health/medical, Internet marketing, link/website sharing, microblogging/IM/mobile, movies, music, news, pets, photo sharing, politics, pop culture, professional, real estate, religious, shopping, social action, sports, technology, teen, travel, video sharing, women, and miscellaneous. Online communities are able to form online around extremely specific interests. For example, the website VampireFreaks.com hosts a social community dedicated to promoting gothic/industrial culture, and the website at EuroGayPolice.com offers support and networking opportunities for lesbian, gay, bisexual, and transgender police officers in Europe. The emergence of communities online that form around precise issues of concern open a valuable opportunity for public relations practitioners looking to connect with publics that are highly engaged in a particular issue.

The online media environment offers a low-cost means for public relations practitioners to bypass mainstream media gatekeepers and engage directly with publics (Gilpin, 2010). Although social media offer some exciting new opportunities for public relations practitioners, the changing nature of communication practices in an increasingly digital environment have led to some difficult transitions for those working in public relations (Solis & Breakenridge, 2009), as the Motrin Moms case presented earlier in this paper attests.

Wright and Hinson (2006a, 2006b, 2007a, 2007b, 2008a, 2008b, 2008c, 2008d, 2008e, 2009a, 2009b, 2009c, 2009d, 2009e, 2009f) recently completed a five-year international, longitudinal study consisting of a series of surveys of public relations professionals to examine the effects social media and other new technologies are having on public relations practice. In 2008, 61% of survey respondents said the emergence of



blogs and social media has changed the way their organizations communicate. In 2009, that figure increased to 73% and then to 85% in 2010. Furthermore, 99% of the 2010 respondents spend part of their day working with some aspects of social media (Wright & Hinson, 2010).

Just because public relations professionals are using social media does not mean they are using it successfully (Kent & Taylor, 2010). Online social media users report that professional communicators damage the authenticity of community interactions. Regular users of the social networking site Facebook, for example, report an almost total lack of interest in engaging with impersonal corporations (Vorvoreanu, 2009). Participants in the Vorvoreanu (2009) study expressed concern that organizations “invade” social networks and “pollute” them (p. 79). Small corporations or organizations that show a clear personal presence in their posts are exceptions to this distaste for corporate or nonprofit communication on social networking sites. According to study participants, the presence of corporations on Facebook clashed with the shared purpose of the community, socializing with friends (Vorvoreanu, 2009).

The engagement with social media has led to a reworking of the concept of gatekeeping as well. Bruns (2005) developed the concept of “gatewatching” to help explain the shift he saw in information flow in online environments. His ideas suggest that perhaps the process of influence online is distinct from traditional understandings of media and interpersonal influence. The following section addresses Bruns’ concept of gatewatching as it applies to public relations research.

## **Gatewatching**

When discussing the process of controlling information, researchers often talk about the concept of “gatekeeping” (Barzilai-Nahon, 2009). In the field of communication, gatekeeping roles are typically attributed to individuals who have control over distribution of content, such as newspaper editors or television producers (White, 1950). Shoemaker (1991, p. 1) described gatekeeping as “the process by which the billions of messages that are available in the world get cut down and transformed into the hundreds of messages that reach a given person on a given day.” Gatekeeping as it relates to journalistic practices happens both in the news production stage — i.e., reporters and editors define newsworthy events — and in the audience response phase — i.e., letters to the editor and other responses through mainstream media are published at the whim of an editorial representative (Gans, 1980).

The model of the World Wide Web functions differently from the traditional editorial process, meaning that editorial gatekeepers can be bypassed by social media users (Bruns, 2005). Unlike newspaper, magazine, radio, or television, the ability to publish is not constrained by space or allotted time. The bandwidth to publish is almost unlimited, both in terms of willing content producers and content space. Given the massive amount of information already distributed online, moderating the vast influx of information available on the web may be more useful than attempting to restrict content creation through traditional gatekeeping methods (Bruns, 2005).

For most newsworthy (and even not so newsworthy) happenings, Internet users can easily access a wide range of news reports and primary source information on the topic. Within interest-based groups, this information is then collected and collated to

provide a manageable presentation of data (Bruns, 2005). The process of collection and collation is described by Bruns (2005) as “gatewatching.” There is still an element of information control in gatewatching, but instead of being enacted by members of the media production and editorial team, the gatewatching process is largely the purview of highly engaged members of online interest-based communities (Bruns, 2005).

Bruns (2005) applied the concept of gatewatchers to the process of news distribution, studying collaborative news sites such as Slashdot, MediaChannel, and Kuro5hin.

Although Bruns conceived of gatewatching as a change in news dissemination, the concept is indicative of the changing nature of information sharing and processing occurring through the interactive web.

To better understand the communication practices of a public that engages in online information and resource development and dissemination, this dissertation takes an in-depth look at a particular online community. The following section describes a highly communicative online public related to cancer issues and examines the research concerning online health-based communities.

### **Studying Online Health Communities**

Online health communication is driven by two forces: the availability and common usage of social media tools and the motivation for those with health concerns to connect with one another (Fox, 2011c). The advent and expansion of social media is changing communication practices in many different fields, but the frequency with which individuals turn to the web for health information makes it a particularly rich area for study (Fox, 2011a).

## **Issues in Participatory Health Communication**

The field of health communication has been dominated by studies based on the transmissive paradigm of communication. The work in this field tends to look to find the most efficient way to segment audiences, create the most effective messages to influence behavior, and determine the best channel for message distribution (Noar, 2006). Like those in other aspects of communications work, public relations professionals in the health care industry have struggled with integrating new technologies into their public relations strategies.

There has been much discussion in mainstream media regarding unreliable health information shared on the web. Despite the participatory nature of the web, a survey (Fox & Rainie, 2000) showed that even individuals who are frequent users of online tools continue to list medical professionals as their most trusted source for health information.

Despite the rise in social media use by health information seekers, public health officials and professional health communicators are still perceived as highly credible sources by most audiences (Avery, 2010). Even when browsing online for health information, Internet users say they view sources such as hospital or non-profit health information sites as more credible than blogs or other forms of more participatory media (Cozma, 2009). Top-down messaging is of enduring interest to both lay consumers of health services and researchers attempting to improve health communications (Glanz, Lewis, & Rimer, 1990), but it is not the only way individuals access health information. The ever-increasing use of new technology to access and share health information (Fox, 2011b) has not only expanded the tools in the professional communicator's toolbox as

some researchers have pointed out (Hallahan, 2008), it has also challenged the role public relations people should play in the communication process.

The web has expanded the role of message producer and has, in some cases, made it difficult for communication professionals to respond and manage crises because of the speed with which information travels online (Hallahan, 2008). Furthermore, people tend to use new media to seek out and associate with others who are similar to themselves (Wang, Walther, Pingree, & Hawkins, 2008), indicating that issue publics are forming virtual ties that may affect traditional relationships among members. The changing nature of public development and interaction can be observed by looking at publics that form around issues of health, one of the most widely discussed topics on the web.

Web users have a variety of health-related content available online that they can use as information sources (Cozma, 2009), and health-based online communities are populated by active and engaged participants (Fox, 2011c). The next section examines the e-patient community, an online collective working to increase support for those dealing with major medical issues.

### **e-Patients: Hunters, Gatherers, Creators, Collaborators**

In a formative whitepaper introducing the e-patient movement, Ferguson (2007) argued that the development of participatory media has led to a period of disruptive science within the medical system. Periods of disruptive science are episodic periods of notable advances in scientific study leading to a paradigm shift an existing societal structure (Kuhn, 1970). e-Patients are driving a healthcare communication revolution through the use of social media (Ferguson, 2007). They are challenging the healthcare

paradigm that solidified during the 19th century as Americans placed increasing faith in a medical institution built on normative scientific assumptions (Ferguson, 2007). The e-patient movement instead extends from a push for greater patient participation in health services.

The Society for Participatory Medicine describes the rise of the e-patient and the more general shift to a participatory medicine paradigm as “a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners” (Society for Participatory Medicine, 2009). The term “e-patient,” although often considered a nod to the use of participatory media to extend medical knowledge, was actually coined by Ferguson (2007) to refer to individuals who are equipped, enabled, empowered, and engaged in their health. The rise of the e-patient, however, is still inexorably tied to the increasing prominence of web-based communication (Ferguson, 2007).

People use the web for many different purposes related to health. Many users gather information in preparation for a doctor visit (Diaz, Griffith, Ng, Reinert., Friedmann, & Moulton, 2002) and to follow up after a doctor appointment (Broom, 2005). It is also increasingly common for individuals to turn to the web as a source of information for self-diagnosis and to find care instructions (Williams, Nicholas, & Hunginton, 2003). The various ways that individuals use the web for health information and communication is defined in large part by the state of their current personal health and the health of loved ones (Cain, Sarasohn-Kahn & Wayne, 2000).

According to a report produced by the California Healthcare Foundation (Cain et al., 2000), e-patients fall into three categories: the well (about 60% of e-patients), the

diagnosed within the past 12 months (about 5% of e-patients), and the chronically ill and their caregivers (about 35% of e-patients). Individuals who are well think about health only occasionally and use the Internet to stay current on general health and wellness information. They are infrequent users of online health resources and may also look up information before or after a doctor visit. e-Patients facing a medical concern or challenge have recently developed or received a diagnosis of a new medical condition. It may be as minor as acne or a urinary tract infection or as major as AIDS/HIV or diabetes. e-Patients search the web extensively for resources and information and reach out to professionals and other patients they find online.

Those with chronic conditions and their caregivers have one or more stable illnesses and use online health resources to manage their illness. They may use Internet resources to keep up to date on their conditions, prepare for doctor visits, or reach out to other patients or caregivers concerned with the same diseases (Cain et al., 2000). Acute e-patients may use the web every day for health purposes, chronics several times a month, and “well” e-patients as infrequently as a few times a year (Fox & Rainie, 2002).

This dissertation uses a case study approach to examine the patterns of links between members of the online, interest-based community that has formed around a particular health issue. By creating a network map that shows the interconnections between various participants in an active online community, this study shows patterns of influence in this online network. Furthermore, by studying the distribution of ideas that lead to shared cognitions within the community, I hope to shed light both on changing models of message dissemination and the evolving role of influencers in public relations.

## **Research Questions**

Because technology is shifting information dissemination channels, models and theories that arose when the technological landscape was dominated by other mediums may lack heuristic value in today's communication environment. This study asks the following research questions:

### **RQ1: How Does Information Flow Through Online, Interest-Based Publics?**

**1a. Who are the influencers in online, interest-based publics?**

**1b. What role do influencers play in online, interest-based publics.**

### **RQ2: What Are the Implications of Information Flow in Online, Interest-Based Networks For Public Relations Practitioners?**

**2a. Is the situational theory of publics adequate to describe public formation in a web 2.0 environment?**



## CHAPTER III

### METHODS

This mixed-methods study uses online social network analysis and rhetorical cluster analysis (Burke, 1967) to explore how communication flows within an online network develop around a single shared concern: cancer in young adults. This study will also seek to illuminate the primary messages that emerge in these information flows. By researching information flows in the online young adult cancer network using a case study approach, this study seeks to expand existing knowledge in online communication practices among interest-based publics.

This research focuses on a specific online community (young adult cancer patients and survivors) in a specific, albeit virtual, space (online) to locate this study in a particular social context (Yin, 1998). The ability to ground research in a particular historical location is a defining characteristic of the case study approach. (Stake, 2005). Given the rapid evolution of emerging media technologies, positioning this study within a particular timeframe provides context for the results as they apply to public relations practice. Although single-case studies often raise concerns about generalizability, the goal of this case study is not to generalize to all online communities but rather to draw conclusions about a situation that may be applicable to other communities with similar characteristics (Yin, 1998).

#### **Case Study: Online Adolescent and Young Adult Cancer Community**

The young adult cancer community is a vocal minority within the larger cancer community, accounting for only a small percentage of new cancer cases diagnosed each

year. A January 2007 *U.S. News and World Report* article dubbed young adult cancer patients “Cancer’s Orphan Generation.” A smattering of researchers have published pieces lamenting the fact that survival rates for young adults with cancer have plateaued (Thomas, Seymour, O’Brien, Sawyer & Ashley, 2006). According to the American Cancer Society (2007), about 1.4 million cases of cancer are diagnosed in the United States each year. Only about 70,000, or roughly 5% of those diagnosed, are between the ages of 20 and 45. More than half of young adult cancer patients report that their information needs are not met by traditional resources (Zebrack, 2009). Haase and Phillips (2004) found that the lack of information sources available to young adults with cancer stem from the tendency for young adults to be lumped in with either pediatric or adult cancer populations.

Young adults with cancer are also in a cultural demographic that tends to be comfortable with online communication and frequent users of web-based resources (Madden & Zickuhr, 2011). There are several online community hubs for young adults dealing with cancer, including PlanetCancer, the I’m too Young for This! Cancer Foundation, and the Livestrong Young Adult Alliance. The young adult cancer community is web-savvy, understudied, and small enough to be a manageable community for study (Stansberry, 2008).

Health concerns, particularly chronic health concerns, are one of the primary issues that drive people to access and share information online (Fox, 2011a). Furthermore, young adults (defined for the purpose of this study as individuals ages 19-40) are among the most wired demographic group (Pew Research Center, 2011a). These

facts, coupled with the availability of information on current young adult cancer bloggers, led to the selection of this population for this study.

### **Social Network Analysis**

Social network analysis can be used to show the web of connections that help define a public. In this online social network analysis, the interlinking nature of web presences is collected and mapped to provide visual representations of the online young adult cancer network. By mapping hyperlink connections between websites, the study first identifies the influencers in online, interest-based publics and provides insight into the communication flow process throughout the network, answering research question 1: How does information flow through online, interest-based publics?

Online networks transcend geographic boundaries. Just as a real-life community consists of more than interactions at a single location, online communities can be created through a variety of sites that allow people to build relationships based on shared traits and interests rather than geographic proximity (Castells, 1996). In social network analysis, the actors within a network are called nodes, and the connections between those actors are called ties, links, or connections. Social network analysis has long been used to map social connections among individuals where the ties or connections refer to interdependencies such as friendship, sexual history, financial relationships, and common interests.

In the analysis of social networks, be they in person or online, researchers discuss social connections in terms of three different types of ties between nodes: strong, weak, and absent. Strong ties describe close friendships and intimate family connections, weak

indicate acquaintanceships such as those between coworkers, and absent ties are social connections that result in no substantial significance, such as a barista at a favorite coffee shop (Granovetter, 1973). Web-based communication tools are particularly well suited to the development of weak ties (Castells, 1996). A preponderance of weak ties has the effect of creating networks where new ideas are frequently introduced and distributed among members, resulting in homogeneous subcultures (Granovetter, 1973).

Homogeneity is the endpoint of the information dissemination process; ideas initially flow into a group from an outside setting because weak ties reach out to groups with diverse views and perspectives. These ideas are then distributed through the weak ties within a network, leading eventually to similar ideologies among network members (Granovetter, 1973). The weak ties that develop through interlinking in online networks can actually lead to the development of similar ways of thinking among members of the web-based community.

To track the information distribution process in an online issue network, I conducted a form of social network analysis to map the hyperlinks between websites. These links represent weak ties among members of the network, but by isolating the most linked-to sites, this process identifies those sites where users are most frequently directed for information. In this way, I used social network analysis to identify probable influencers and trace the sites that influential websites link to. The process diagrams which websites frequently link to influencers' pages, which shows the primary sources of information accessed by influencers. This network mapping process provides a visual representation of the online network of AYAs, which provides direction for the Burkean cluster analysis process discussed later in this chapter.

The Pew Internet & American Life Project has published several studies examining demographic data trends in the blogosphere (“Change in Internet Access,” 2010; Fox, 2011a; Fox & Rainie, 2000; Madden & Zickuhr, 2011), but the exact flow of information through online social networks is largely understudied (Bruns, 2007). The analysis of automated network crawls, which use a starting set of web pages to launch a crawl that iteratively follows hyperlinks to map the interconnected nature of online sites, has added a new dimension to the study of online communication practices in recent years. The process used by network crawlers is similar, although implemented on a much smaller scale, to the process of large search engines such as Google or Yahoo, which use automated crawlers to search and collate content throughout the web. Automated network crawls produce social network data that position websites as individual actors (or nodes) within a network and hyperlinks as the connection between these actors.

Previous social network analyses of social media connections between frequently updated sites such as blogs and news websites have shown that certain “A-list” sites, such as popular blogs or trusted news sources, tend to dominate the network in terms of inbound and outbound links (Herring, Kouper, Paolillo, Scheidt, Tyworth, Welsch et al., 2005). Within online interest-based networks, clusters of highly connected groups of content developers are typically present. These clusters can overlap among interest-based networks; for example, a popular mommy blogger may also be a frequent contributor to cooking or photography social networks. But in general, online interest-based communities have their own systems of primary influencers (Chau & Xu, 2007). The first part of this study uses a network crawl to identify the primary influencers within the online community of those interested in young adult and adolescent cancer issues.

When developing a network crawl, many factors must be considered to ensure rich results. One of the first decisions researchers must make is where to start their crawl to ensure an accurate network map is produced. To develop a map of an issue-based community (in this case, the young adult cancer community) the seed nodes, or websites used as the starting point for the network crawl, must relate directly to the topic of interest. The seed node list for this crawl consisted of the 185 websites listed on the official website for the I'm Too Young for This! Cancer Foundation (<http://stupidcancer.com/>) blogroll. The I'm Too Young for This! Cancer Foundation is the largest support network for AYAs in the United States. The tagline of the I'm Too Young for This! Cancer Foundation is "the voice of young adults," and part of its mission is to find and share resources related to young adult cancer issues. As a site that finds and shares resources and user-created content related to young adults with cancer, the blogroll provided a solid starting point from which to launch a web crawl to develop an AYA network map. Prior to launching the network crawl, all seed nodes were reviewed to confirm that the primary topic of the blog was related to young adult cancer issues. The review determined that all 185 blogs listed on the I'm Too Young for This! blogroll addressed young adult cancer issues. The overwhelming majority of blogs were first-person accounts of cancer experiences written by young adults. For a full list of seed nodes, see Appendix A.

### **IssueCrawler**

IssueCrawler is a publicly available crawler system offered by the Amsterdam-based Govcom Foundation at [www.issuecrawler.net](http://www.issuecrawler.net). The processing power for the tool is

shared among the registered researchers using it, much like early mainframe computers shared processing power at the advent of the Internet. Several studies of web-based networks developed using IssueCrawler have been published in media and communication journals (e.g., Gillam, 2009; Jin & Liu, 2010; McNally, 2005; Zhou, 2009), and the tool is rapidly growing in popularity. As of January 2012, up to five crawls could be run simultaneously on IssueCrawler.

Crawler systems record and follow the hyperlinks from a starting point indicated by the programmer. In this case, the 185 AYA websites listed in Appendix A served as the starting point of the crawl. The crawler gathered the links present on these 185 seed nodes, then searched the pages these links pointed to and identified all outlinks on those pages. IssueCrawler can be programmed to run this process up to three times (known as crawl depth). I ran three crawls with different crawl depths to observe how the major network players changed as further iterations of links were recorded. When a crawl depth is too shallow, there is a risk of overlooking influential nodes, but when a crawl depth is too deep, there is a risk of “network jumping,” which refers to the process of a network crawl derailing toward another strong interest-based group because the network crawl grows too large.

IssueCrawler can also be programmed to perform both “co-link analyses” and “snowball analyses.” When performing a snowball network crawl, IssueCrawler identifies and records all links present in the seed nodes, then all outgoing links present in the web sites linked to by the seed nodes. The number of times this process takes place is dictated by the depth of the crawl. In a co-link analysis, the crawler identifies and records only sites that are linked by at least two of the starting points. This filters out isolated

sites and helps to ensure that crawls at deeper depths maintain ties to the original network. Co-link analyses identify larger and larger neighborhoods of web pages for their linkage patterns, but the iterations of crawls in co-link analyses are more likely to belong to the starting interest-network than are those produced by snowball crawls.

The co-link analysis process produces a record of any site that is linked from at least two of the seed sites. So, for example, when IssueCrawler was programmed to follow two iterations of links, the crawl followed all the co-links presented on the pages found in the first step of this process and recorded the resulting web pages. IssueCrawler reads, records, and follows all links on a web page, including in-text links, sidebar links such as blogrolls, header links, and links to personal social media presences on Twitter and Facebook. Because the overarching theme of the blogs that constitute the seed nodes for this crawl related to young adult cancer experiences, all links from the blogs were deemed appropriate for a crawl looking to build a visual representation of the online young adult cancer community.

A co-link crawl was used because the goal of this crawl was to identify highly influential members of the young adult cancer online interest-based networks. By running a co-link crawl using a large number of seed crawls, this method produced a clear visual representation of the websites involved in young adult cancer issues online.

Graphically plotting the linked web pages is particularly useful in showing clusters of highly connected groups of sites. It can also be helpful in identifying key influencers within online communities. It should be noted that IssueCrawler only shows links between sites and that no prediction is made through the program regarding actual flows of traffic between sites. The existence of links does not guarantee that web users



actually follow that particular path; however, the practice of browsing the web by following interlinking pages is widespread and common among Internet users. Also, because IssueCrawler tracks inbound links, which is one of the most highly weighted criteria in search engine optimization processes, the sites identified by IssueCrawler as dominant nodes within an interest-based network are likely also to be identified as influential by search engines such as Google. Furthermore, traffic is not the only (or even the predominant) indicator of influence within an online interest-based community. The links that young adult cancer bloggers included in their posts, sidebars, blogrolls, etc. show the information sources that are recommended by community members themselves. By tracing the links identified by the content creator sites that make up the seed nodes for the young adult cancer community crawl, IssueCrawler creates a network map that shows the influential participants of an interest-based online community of those communicating about young adult cancer issues.

A network crawl can provide extensive insight into the interlinking nature of online networks, but when looking for influence within networks, further study is needed to accurately track information production and flow. The next section describes how cluster analysis was used to examine the content of sites that the network analysis indicated were major players in the online network.

### **Cluster Analysis**

Burke (1966) has defined man as a symbol-using (and misusing) animal. We build our world through the language with which we describe it. In this sense, language both gives people freedom by allowing for the creation of meaning and limits people by

imprisoning them within the finite words we have with which to create meaning (Burke, 1966). The very act of identifying something with a term is a persuasive act (Burke, 1969). Naming is discriminatory, but it is also necessary to have any kind of collaborative society (Burke, 1969).

Based on Burke's belief that language can produce insight into a rhetor's worldview (Foss, 2004), cluster analysis involves identifying key symbols used by the rhetor or rhetors and charting the symbols that cluster around those key symbols in the text. Quite simply, cluster analysis is the process of looking at what subjects cluster with what. The clusters that emerge in the study of an artifact are generally not known to the rhetor (Foss, 2004). The act of writing is conscious, but the complex interrelationships between key symbols cannot possibly be intentional (Burke, 1967). In this sense, cluster analysis reveals overarching worldview rather than authorial intent.

### **Sampling**

With the goal of understanding and tracking the development of shared cognitions, I analyzed the text of influential websites identified by IssueCrawler using Burkean cluster analysis. Although I originally planned to identify influential websites by a numerical cutoff based on number of inbound links identified by the crawl, preliminary mapping indicates that a handful of websites dominates the field in terms of number of inbound links and influential position within the network. Because the network mapping process identified only five websites as influencers, I addressed the entirety of these influential websites as textual artifacts. Influential sites were identified by their large number of inbound links compared to other sites in the study and position within the

issue network, A cluster analysis was conducted on all aspects of the sites, including “about” sections, bulletin boards, presences on social networking sites, news and updates, blogs, etc.

The free software program SiteSucker was used to download hard copies of the five websites analyzed. This website archive program maintains all links and site formatting, allowing both the written text and website design to be analyzed. All five sites were downloaded on the same day (February 13, 2012), and review of the text was completed using these hardcopies of the websites.

### **Data Analysis**

The cluster analysis process I emulate in this study follows the method used by Foss (1984) in her piece “Women priests in the Episcopal Church: A cluster analysis of establishment rhetoric.” The procedure for conducting a cluster analysis starts with a close reading of the chosen artifact with attention to terms that appear with frequency and intensity, which can mean extreme in size, strength, or depth of feeling (Foss, 2004). The researcher then performs an examination of the words and symbols that cluster around the key symbols identified in the first part of the analysis process. Clustering occurs in several ways. While words may be physically close to the key symbol and perhaps even connected by a conjunction, the clustering effect is not always related to proximity. For example, there may be a cause and effect relation that implies the key term depends upon another phrase (Foss, 2004). Every instance of the identified key terms is examined within the cluster analysis. The key terms, clustering terms, and the overall context of the phrase are charted and reviewed to find patterns in the associations and linkages.

Cluster analysis involves three steps (Foss, 1984). The first is the selection of key terms as described in the previous paragraph. The next step is the examination of each context in which the key terms appear. In this step, the researcher looks for repeated associations and implied meanings to help explain the rhetor's worldview. In the final step of the cluster analysis process, the researcher establishes criteria to help explain the meaning of key terms as presented by the rhetor.

The full content of each of the five influential websites identified in the network analysis were manually reviewed for key terms and subsequent clusters of meaning. While particular attention was paid to language used by the rhetors in this study, visual images that surrounded key terms were also recorded and included in this cluster analysis. Visual elements of a site, such as position of terms on a page or formatting of text or images, can be helpful ways to determine intensity of a term as likely intended by a rhetor.

Through a close reading of the five artifacts I identified four key terms that appeared to be particularly significant to the rhetors. Significance was determined by both frequency of use and intensity of the term. Frequency was measured by number of times the term appeared across the text and intensity was determined by my reading of the texts. Perceived emotional significance of the surrounding text was the primary factor leading to a term being labeled as particularly intense. Using the text search function I found and recorded all instances of the four key terms in the five website used as artifacts. The cluster of terms surrounding the five key terms were recorded and, whenever possible, the original language used by the rhetors is presented in the results when describing clusters of meaning.

To answer the second research question, “What are the implications of information flow in online, interest-based networks for public relations practitioners?” I examined the discourse presented by influential websites in the young adult cancer community. By identifying key terms used across the influential websites and teasing out the context with which these terms are used, this study illuminates the role of online influencers as contributors to online public debate and demonstrating the underlying world view on which that debate is shaped. My personal experience dealing with cancer as a young adult has provided unusual insight into the young adult cancer community. The following section reflects upon my personal relationship to this study.

### **Reflexivity**

I have experienced three major health issues in my life. As a 20-year-old college junior I experienced months of crippling back pain and underwent a series of surgeries to correct a congenital kidney condition. Just a few years later I was diagnosed with Hodgkin’s Disease and experienced six months of chemotherapy and radiation treatments. At 28 I gave birth to my son after a difficult pregnancy. At this stage, I moved from an individual concerned almost exclusively with my own health, to a person entirely responsible for the health decisions affecting my offspring.

Like many other web users, during every stage of my health journey I turned to the web for information, support, and commiseration. Based on personal observation, in the decade since I first found myself a frequent hospital guest, the volume and quality of health information available online has increased exponentially. As a public relations practitioner and a public relations and health communication researcher, this proliferation

of health information on the web is an area of great personal and professional interest. I consider myself an e-patient, although I have not actively participated in the online e-patient community. My strong interest in online health communication stems from my conviction that by applying public relations theories to the study of public health campaigns we will be better able to face health communication challenges. This study contributes both to the development of public relations theory and practice and to the process of professional online health communication.

## CHAPTER IV

### NETWORK CRAWL RESULTS

This section details the process of running network crawls to create visualizations of the online young adult cancer network. IssueCrawler visualizations can provide a wealth of information about network players. On the maps created by network crawls, websites are shown as colored circles and links between websites are shown as arrows. The direction of the arrows represent the linking pattern pointing from the linking site to the linked location. The color of the circles represents the domain type. Sites with a .com domain are represented by the color blue, sites with a .org domain are represented by the color green, and sites with a .gov domain are represented by the color red. The size of the circles in IssueCrawler visualizations indicate the number of inbound links; the larger the circle representing the node, the greater the number of inbound links from sites within the mapped issue network.

The position of the circles on the visualizations, or network maps, indicates relative strength of ties. The websites with the strongest ties to one another are clustered together. IssueCrawler can be programmed to determine strength of ties in several different ways. The visualizations presented in this section all use the concept of degree centrality to determine strength of ties. Degree centrality is defined as the number of links connected to a node.

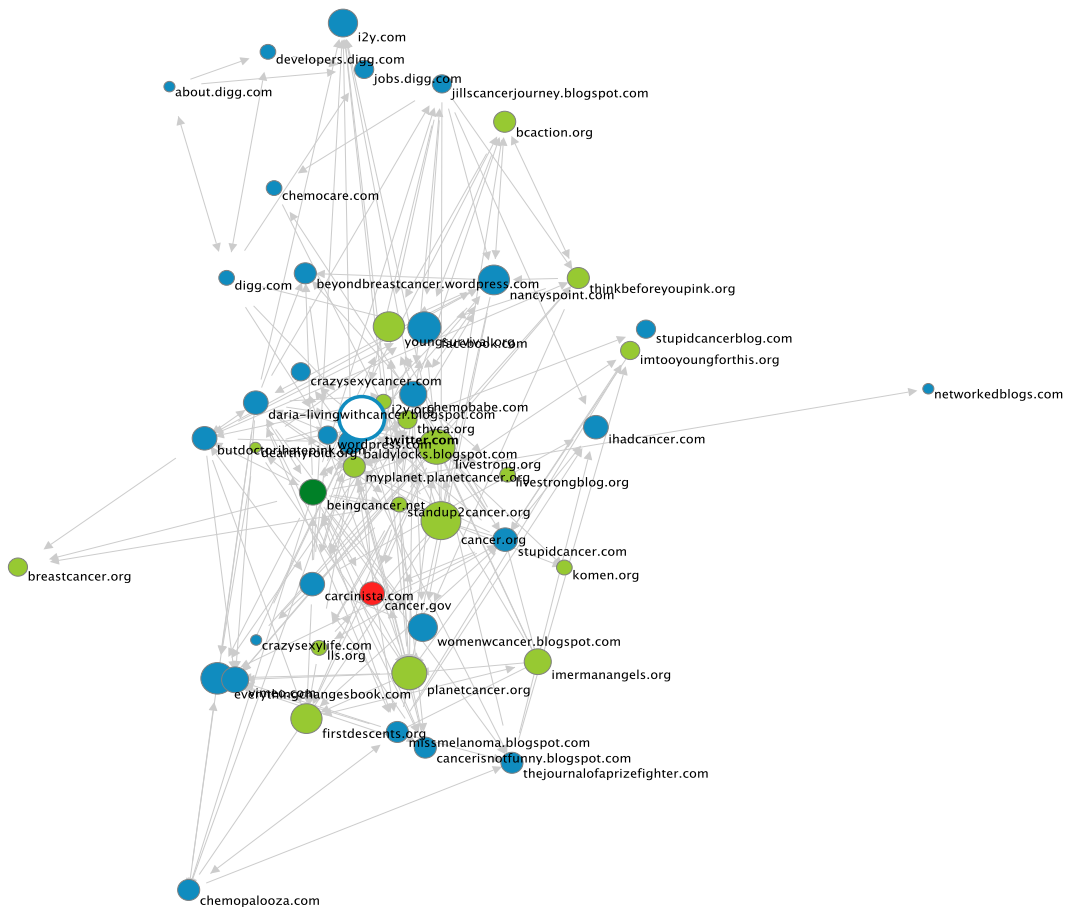
In the case of directed networks such as these, where websites post directional links to other sites, degree centrality is typically defined in two separate measures: indegree and outdegree. Indegree count refers to the number of links coming from other nodes and connecting to the site in question. Outdegree is the number of links that a

network player directs to others. Because I am concerned with the relative influence of websites in the online young adult cancer network, indegree centrality, which is often interpreted as a form of popularity, is the measure used to determine position on the network visualizations presented in this section. Websites on the graphs that are most tightly clustered with one another exhibit the highest measure of indegree centrality, and information that flows through these network players is most likely to be distributed across the full network.

The following network crawls, which show varying crawl depths, were created using the 185 young adult cancer blogs from the I'm Too Young for This blogroll as seed nodes from which to launch the crawl. The three graphs shared in this results section represent co-link analyses with varying depths. As discussed in the methods section, when running a co-link analysis the network crawler identifies and records only sites that are linked by at least two of the starting points.

On January 15, 2012, I ran a co-link network crawl with a depth of one, producing a graph that shows the interconnected links between all sites that are linked by at least two of the seed nodes. The following graph is a visualization of this network:





*Figure 1: Co-link analysis with a crawl depth of one showing the online young adult cancer community. Graph was created using the online link mapping tool IssueCrawler.*

The network that emerges from the network crawl with a depth of one shows a community consisting of a variety of types of websites, including young adult cancer blogs, such as baldylocks.blogspot.com and chemopalooza.com; resource and community development sites for young adults with cancer, such as everythingchangesbook.com, imtooyoungforthis.org, and planetcancer.org; general cancer information sites, such as cancer.org; and social networking sites, such as Twitter and Facebook. The sites that are most centrally located within the network, indicating a great degree of connectivity

among the network nodes, are social networking sites and young adult cancer community development sites.

This visualization shows a network that is closely tied to the original 185 young adult cancer blogs. The websites that emerge in this network represent a broad range of characteristics, including personal cancer musings, resource sites, educational web pages, and social network homepages. It is difficult to identify the key players in the interest-based community using only a single crawl because the resulting sites are so closely tied to the personal interests of the bloggers populating the seed nodes.

Table 1 shows the top 10 sites in the network by number of inbound links. Unlike the graphic visualization of the network map, which shows the interconnectedness of the sites that are linked by at least two of the seed nodes, the following chart shows the total number of inbound links from all the sites recorded during each stage of the crawl:

	<b>Website</b>	<b>Number of Inbound Links</b>
1.	everythingchangesbook.com	3,738
2.	wordpress.com	3,623
3.	beingcancer.net	3,242
4.	imtooyoungforthis.org	3,227
5.	baldylocks.blogspot.com	2,875
6.	I2y.com	2,722
7.	twitter.com	2,573
8.	chemopalooza.com	2,504
9.	facebook.com	2,105
10.	planetcancer.org	2,074

*Table 1:* Top 10 sites by number of inbound links in the network with a crawl depth of one.

The blogging platform Wordpress, microblogging platform Twitter, and popular social network Facebook have a large number of inbound links in this network and are also among the sites with the highest measure of indegree centrality, indicating that community members are conversationalists who create and share content across platforms. Facebook, Twitter, and sites built on the Wordpress platform are among the highest traffic drivers among all websites. In June 2011, Google Ad Planner listed Facebook as the most visited site on the global web, Twitter as the 15<sup>th</sup> most visited site, and Wordpress as the 18<sup>th</sup> most visited site.

To further narrow down the issue network to determine the most influential players in the young adult cancer online community, Table 2 lists the top 10 websites in the network with a crawl depth of one, excluding popular general social networking sites.

	<b>Website</b>	<b>Number of Inbound Links</b>
1.	everythingchangesbook.com	3,738
2.	beingcancer.net	3,242
3.	imtooyoungforthis.org	3,227
4.	baldylocks.blogspot.com	2,875
5.	I2y.com	2,722
6.	chemopalooza.com	2,504
7.	planetcancer.org	2,074
8.	stupidcancerblog.com	2,069
9.	myplanet.planetcancer.org	1,830
10.	imermanangels.org	1,743

*Table 2:* Top 10 sites by number of inbound links in a network with a crawl depth of one, excluding social networking sites.

Web resources designed specifically for young adults dealing with cancer, such as everythingchangesbook.com, PlanetCancer.org, and ImTooYoungForThis.com, are also

central players in this network, joining the general social networking sites as the most linked to and centrally positioned websites in the visualization. The network periphery, which shows blogs with a low measure of indegree centrality, is largely populated by blogs written by individuals dealing with young adult cancer issues. While this style of blog appears to be common among the websites that make up the population of the young adult cancer network, their position at the outskirts of the network indicates that in general, personal blogs may not be the most influential style of web presence in the young adult cancer network.

The results from this initial crawl show the emergence of some possible network influencers, including a few key blogs, such as [chemopalooza.com](http://chemopalooza.com), and young adult cancer support communities, such as [ImTooYoungForThis.org](http://ImTooYoungForThis.org). To more accurately identify influencers, I chose to run another co-link analysis with a slightly deeper crawl depth.

On January 17, 2012, I programmed IssueCrawler to run a co-link analysis with a crawl depth of two iterations (the program's default setting) of links using the same set of seed nodes as the first crawl. The following graph is a visualization of the network that emerged:



*Figure 2:* Co-link analysis with a crawl depth of two showing the online young adult cancer community. Graph was created using the online link mapping tool IssueCrawler.

Running a second iteration of links results in a network showing a dense core of highly interconnected young adult cancer sites and general social networking sites. Many of the individual blogs present on the periphery of the young adult cancer network visualization of a single crawl depth are absent in this deeper crawl. This indicates that the vast majority of personal blogs are not highly influential in the information dissemination process in the online young adult cancer network.

The most centrally located sites in this crawl, which indicates high connectivity within the issue network, are a combination of general social networking sites, such as Twitter and Facebook; young adult cancer support sites, such as [livestrong.org](http://livestrong.org), [stupidcancer.com](http://stupidcancer.com), and [youngsurvival.org](http://youngsurvival.org); and cancer blogs, such as [cancerisnotfunny.blogspot.com](http://cancerisnotfunny.blogspot.com), [butdoctorihatepink.com](http://butdoctorihatepink.com), and [bethlgainer.blogspot.com](http://bethlgainer.blogspot.com).

Table 3 shows the top 10 sites in the young adult cancer network crawl with a depth of two by number of inbound links. Unlike the graphic visualization of the network map, which shows the interconnectedness of only the sites that emerge after the crawl has charted two iterations of links, the following table shows the total inbound links from all the sites recorded during each stage of the crawl:

	<b>Website</b>	<b>Number of Inbound Links</b>
1.	<a href="http://wordpress.com">wordpress.com</a>	3,648
2.	<a href="http://everythingchangesbook.com">everythingchangesbook.com</a>	3,517
3.	<a href="http://beingcancer.net">beingcancer.net</a>	3,432
4.	<a href="http://imtooyoungforthis.org">imtooyoungforthis.org</a>	2,987
5.	<a href="http://l2y.com">l2y.com</a>	2,770
6.	<a href="http://baldylocks.blogspot.com">baldylocks.blogspot.com</a>	2,656
7.	<a href="http://chemopalooza.com">chemopalooza.com</a>	2,599
8.	<a href="http://twitter.com">twitter.com</a>	2,598
9.	<a href="http://facebook.com">facebook.com</a>	2,085
10.	<a href="http://stupidcancerblog.com">stupidcancerblog.com</a>	1,792

*Table 3:* Top 10 sites by number of inbound links in the network with a crawl depth of two.

To further isolate major players in the young adult cancer online community, table four lists the top 10 websites in the network with a crawl depth of two. In the following table, popular general social networking sites Wordpress, Twitter, and Facebook have been removed because they indicate that community members use social

networking sites but do not provide information regarding what websites act as sources of information within the online young adult cancer network:

	<b>Website</b>	<b>Number of Inbound Links</b>
1.	everythingchangesbook.com	3,517
2.	beingcancer.net	3,432
3.	imtooyoungforthis.org	2,987
4.	I2y.com	2,770
5.	baldylocks.blogspot.com	2,656
6.	chemopalooza.com	2,599
7.	stupidcancerblog.com	1,792
8.	planetcancer.org	1,790
9.	livestrong.org	1,660
10.	carcinista.com	1,630

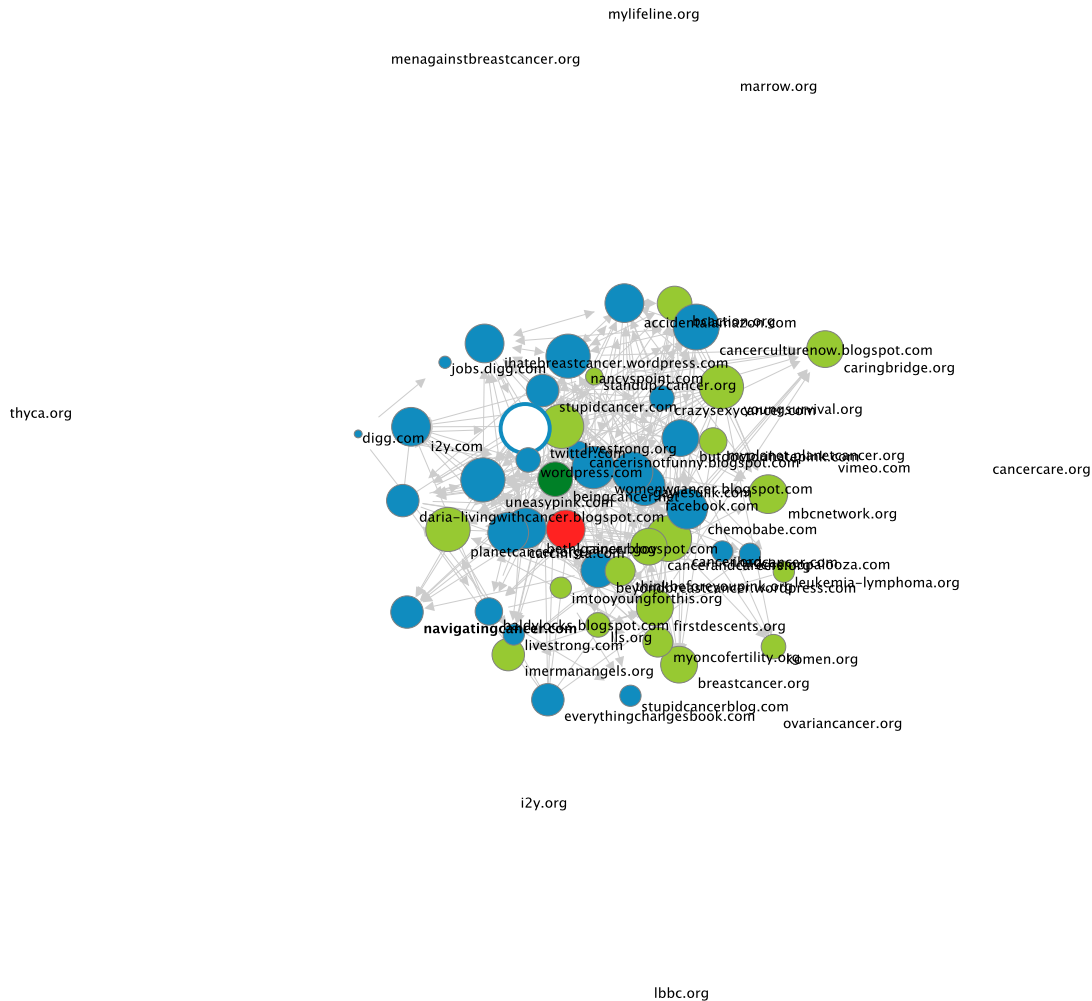
*Table 4:* Top 10 sites by number of inbound links in a network with a crawl depth of two, excluding social networking sites.

Several young adult cancer support sites, such as i2y.org and planetcancer.org, appear on the periphery of this online young adult cancer network visualization, but they are still among the top sites as judged by inbound links within the network. This indicates that these sites are influential sources of information within the online young adult cancer network that tend to link to websites that are not central to this issue network.

Although the network crawl with a depth of two shows a clear online community with marked influencers providing information on young adult cancer care and survivorship, I ran a third network crawl to see if viewing a third iteration of links would further delineate key players in this issue network.

On January 13, 2012, I ran a co-link analysis with a crawl depth of three. This crawl was launched before the network crawl with a depth of two because deeper crawls

can take longer to complete. The following graph is a visualization of the network that emerged:



*Figure 3: Co-link analysis with a crawl depth of three showing the online young adult cancer community. Graph was created using the online link mapping tool IssueCrawler.*

Running the crawl with a depth of three produces an extremely densely connected web of social networking sites, cancer resource and community development sites, and popular cancer blogs. While mapping the first and second iteration of links produced networks with a number of lightly interconnected websites and a highly centralized core,



the network that emerges with this third crawl shows a network that appears to be almost all central core. The diversity in centrality and number of links seen in the networks with crawl depths of one and two are absent in this third network visualization. Instead, this network shows a cluster of some of the highest traffic sites within the cancer community. Because the vast majority of the sites in this visualization show a high measure of indegree centrality, the third network crawl appears to move away from showing the influencers in the young adult cancer community and instead shows the community as a whole without differentiation among influence levels.

Table 5 lists the top 10 websites in the network with a crawl depth of three. While the network map shows the interlinking nature of the sites that emerge after three iterations of links, the table shows the websites with the highest number of inbound links recorded in all stages of the crawl:

	<b>Website</b>	<b>Number of Inbound Links</b>
1.	wordpress.com	4,955
2.	beingcancer.net	3,323
3.	everythingchangesbook.com	3,228
4.	imtooyoungforthis.org	2,879
5.	twitter.com	2,863
6.	cancerculturenow.blogspot.com	2,725
7.	I2y.com	2,718
8.	womenwcancer.blogspot.com	2,632
9.	nancyspoint.com	2,542
10.	baldylocks.blogspot.com	2,483

*Table 5:* Top 10 sites by number of inbound links in the network with a crawl depth of three.

Table 6 again shows the top websites by inbound link found by the network crawl with a depth of three, but in the next table popular general social networking sites Wordpress, Twitter, and Facebook have been removed.

	<b>Website</b>	<b>Number of Inbound Links</b>
1.	beingcancer.net	3,323
2.	everythingchangesbook.com	3,228
3.	imtooyoungforthis.org	2,879
4.	cancerculturenow.blogspot.com	2,725
5.	I2y.com	2,718
6.	womenwcancer.blogspot.com	2,632
7.	nancyspoint.com	2,542
8.	baldylocks.blogspot.com	2,483
9.	chemobabe.com	2,347
10.	carcinista.com	2,295

*Table 6:* Top 10 sites by number of inbound links in a network with a crawl depth of three, excluding social networking sites.

The three network maps show how running crawls of different depths can portray varying levels of online community linkages. For example, while the network crawl with a depth of one shows a diverse network map with nodes of many different sizes, the network crawl with a depth of three shows a far more uniform size and distribution of nodes. The results of the network crawls also show some consistent patterns. For example, in all three crawls, the nodes with the highest number of inbound links tend to be popular blogs by single authors, such as baldylocks.blogspot.com and chemopalooza.com, and sites devoted to building community among young adults dealing with cancer, such as i2y.com and planetcancer.org.

## Summary

The young adult cancer blogger network does not appear to be a densely interconnected network of personal blogs. In fact, the young adult cancer blogs that were used as seed nodes are largely absent from the collection of websites that emerge after the co-link crawls recording two and three iterations of links, which means personal blogs, the type of sites that make up the bulk of the community members, are not the most influential players in this network. The network crawl with a depth of one produced a visualization showing a network with nodes distributed throughout the field. Websites with a high measure of indegree centrality are positioned in the cluster at the center of the network, indicating their popularity within the online young adult cancer network. The network crawl with a depth of two (the default settings for IssueCrawler and the depth most commonly used to graph issue networks) showed the beginnings of a central cluster of highly interconnected sites. This crawl also showed several sites that have low measures of indegree centrality but still show extensive linking from the crawled population. The third network crawl produced a visualization showing the bulk of the network as a dense core of highly interlinked sites.

The next chapter discusses the implications of these results and provides rationale for using the results to identify influencers within the online young adult and adolescent cancer community.

## **CHAPTER V**

### **NETWORK CRAWL DISCUSSION**

Any attempt to define a community and describe the group's actions or processes is rife with challenges. How does one determine who is a member of the community? How are the boundaries of the community defined? Who are the most influential members of a community? How can the community interactions be measured and what do those interactions mean?

Social network analysis can help to illuminate some of the interconnected relationships between community members, but the research method provides only a general view of networks. The results of the network crawls discussed in the previous section enable inferences to be made regarding the construction and interaction processes of the online young adult cancer community, but it is not an exact science, and much is left to researcher interpretation. This section provides an analysis of the young adult cancer community, network maps, and crawl data, which is informed by existing literature on online network development and the young adult cancer community as well as my personal experience as a web-savvy, young adult cancer survivor.

#### **Setting Boundaries**

The boundaries of social networks are dynamic and variable. Few social networks exist as isolated bubbles; instead, individuals must be viewed as existing within many overlapping concentric circles representing various communities. For example, a pediatric oncologist may be a member of the young adult cancer community, a hospital or

clinic community, the larger medical community, and innumerable other iterations of personal and professional networks.

At its most basic, social network analysis is “a means of describing the relationships between and among people” (Berkowitz, 1982). In contrast, this study looks at online interactions and describes the relationships between and among websites instead of people. Much as people hold membership in many different communities, many of the web presences that emerged during the network crawls show overlapping interests. For example, the blog Chemopalooza chronicles an individual’s experience dealing with Hodgkin’s Lymphoma. The content of the website discusses issues of young adult cancer survivorship as well as concerns specific to Hodgkin’s Lymphoma survivorship. Discussion of membership in other interest communities on the websites that appear in the network crawl does not preclude or weaken membership in the online young adult cancer network, but it can make network boundaries difficult to establish.

The network graph showing one iteration of links (Figure 1) consists primarily of websites with the focus of cancer in young adults and online resources for cancer survivors. This network is closely tied to the seed nodes of websites developed by young adult cancer bloggers. Given that the seed nodes were all reviewed to ensure the primary focus was young adult cancer issues, it is unsurprising that a single iteration of links shows a network of sites closely related to young adult cancer issues. Because the nature of blogs, which were the seed nodes, is inherently social, it’s also unsurprising that sites that enable sharing through social media are prominent in the network showing a single iteration of links.

These two types of network members are evident in the three sites that have the largest number of inbound links in the first network crawl. The website with the largest number of inbound links (3,738), everythingchangesbook.com, is the web presence for the book *Everything Changes: The Insider's Guide to Cancer in Your 20's and 30's*, a candid description of young adult cancer experiences. Wordpress.com, the site with the second largest number of inbound links (3,623), is a popular blog publishing platform. The site with the third largest number of inbound links (3,242), beingcancer.net, is a collection of blog posts written by individuals dealing with cancer. While many of the contributors are young adults, the website addresses cancer blogging in general and is not specific to the young adult community.

A crawl with a single iteration of links shows sites that are closely linked to the interests of the seed nodes; in this case, young adult cancer issues, social networking, blogging, and cancer blogging. Given the prominence of websites that address young adult cancer issues as their primary content, as well as the vibrant blogging community focusing on the challenges of dealing with cancer as a young adult, I considered the boundaries of the online young adult cancer community containing only websites where the primary content focus is on issues specific to young adults dealing with cancer. Although this classification does not preclude sites with young adult specific pages, such as the National Cancer Institute's young adult cancer page at <http://www.cancer.gov/cancertopics/aya>, those sites do not emerge as among the most linked to locations in the young adult cancer issue network.

While the first network crawl is helpful in setting the boundaries of the young adult cancer community and showing the interests and issues present in the seed node

population, a crawl of only one iteration of links is too shallow to clearly show influence among network members. A deeper crawl is more effective in isolating those sites that are most influential, as defined by both number of inbound links and high measure of indegree centrality, in the online young adult cancer community.

### **Tracking Influence**

The network crawl with two iterations of links further refines the online young adult cancer network. Whereas several individual blogs were prominent nodes in the network map created after one iteration of links, in this second network map (Figure 2) these personal musings are largely filtered out. Instead, the bulk of the network consists of general social networking sites, which are some of the most frequently linked to locations on the web, and sites that provide resources for young adult cancer patients. In this second network visualization, the resulting nodes are a mix of cancer resource sites, social media sites, and sites with the primary focus on young adults with cancer.

The one-iteration network showed a community largely focused on young adult cancer issues. The two-iteration network showed the sites that were linked to by at least two nodes identified in one iteration network, revealing an online community with more varied topic foci. The visualization of the two-iteration network shows those sites that are highly linked to by the young adult cancer community defined in the single iteration network crawl. The position of the websites within the visualization from the two-iteration network crawl, as well as the number of inbound links recorded for each website, offers insight into relative influence of the network players.

In looking at the total number of inbound links from the network crawl with a depth of two (Table 3), websites focusing on social networking and young adult cancer top the list. Again, because of the popularity of social network sites such as Facebook and Twitter—and the fact that the network crawl only records links to the parent social networking site and not individual profiles—the large number of links to social networking sites are to be expected in blogging communities. The influence of young adult cancer specific sites to the blogging community used as seed nodes, as identified by number of inbound links and indegree centrality, however, is a significant finding. It shows a strong community devoted to the particular issue of cancer in young adults.

Unlike the results of a study of popular mommy bloggers that showed a community network that consisted of social networking sites and extremely popular and high traffic blogs (Stansberry, 2011), the young adult cancer blogs showed a network consisting primarily of social networking sites, young adult cancer resource sites, and general cancer resource sites. While the mommy blogs that were used as seeds nodes produced an issue network that primarily consisted of interlinkings between mommy blogs with high traffic blogs acting as influencers, the online young adult cancer community appears have as its core a relatively small number of young adult cancer community resource sites. These sites can be identified both by their rank in terms of number of inbound links and their position within the network visualizations.

Although the site beingcancer.net is one of the most frequently linked to sites from among the websites recorded in each of the crawl depths, it is a general collection of cancer blogs and not specific to the young adult cancer community. The following young adult cancer sites appear as the most highly linked to locations across all of the young



adult cancer network crawls. For the purpose of this paper, I will refer to these as “common nodes”:

- [everythingchangesbook.com](http://everythingchangesbook.com)
- [i2y.com/imtooyoungforthis.com/stupidcancer.com](http://i2y.com/imtooyoungforthis.com/stupidcancer.com) (all URLs lead to the same web presence)
- [planetcancer.com](http://planetcancer.com)
- [chemopalooza.com](http://chemopalooza.com)
- [baldylocks.blogspot.com](http://baldylocks.blogspot.com)
- [livestrong.org](http://livestrong.org)

The number of inbound links provides guidance regarding those sites that are well regarded by the young adult cancer community, but to determine influence the position of these sites within the issue network must be addressed.

### **Common Node Position in Network Crawl with a Depth of One**

The visualization of the young adult cancer community with a crawl depth of one shows a network closely tied to the young adult cancer community. Most of the websites that appear as nodes in this visualization belong to the young adult cancer online community. The six common nodes listed above are present in the visualization of the network with a depth of one and appear to be well integrated into the network. None of the common nodes stand as isolates, and most are clustered toward the center of the visualization. Their size, indicating number of inbound links from the other nodes in the visualization, tends to be among the larger nodes in the visualization. The blog [chemopalooza.com](http://chemopalooza.com) stands in contrast to these observations. It lies on the edge of the issue network and shows five outbound links and only one inbound link.

### **Common Node Position in Network Crawl with a Depth of Two and Three**

The visualization that emerges after running a crawl with a depth of two shows the majority of common nodes positioned as well integrated members of the issue network. Three of the common nodes, however, fall on the periphery of this issue network; [chemopalooza.com](http://chemopalooza.com), [baldylocks.blogspot.com](http://baldylocks.blogspot.com), and [everythingchangesbook.com](http://everythingchangesbook.com).

The network that emerges after this second crawl is also heavily populated by general cancer resource sites. This indicates that the highly interconnected common nodes ([beingcancer.net](http://beingcancer.net), [i2y.com/imtooyoungforthis.com/stupidcancer.com](http://i2y.com/imtooyoungforthis.com/stupidcancer.com), [planetcancer.com](http://planetcancer.com), and [livestrong.org](http://livestrong.org)) are not only valued resources within the online young adult cancer community, they may also be locations where information is introduced to the young adult cancer network from the larger online cancer community. The common nodes that appear on the edge of the network with few links to the other nodes in the visualization score high in terms of inbound links from the websites tracked in each step of the crawl but do not appear to be as influential in terms of their prominence in the resultant issue network. The crawl with a depth of two provides enough information to conclude that the sites [beingcancer.net](http://beingcancer.net), [i2y.com/imtooyoungforthis.com/stupidcancer.com](http://i2y.com/imtooyoungforthis.com/stupidcancer.com), [planetcancer.com](http://planetcancer.com), and [livestrong.org](http://livestrong.org) are influencers in the online young adult cancer community, but another crawl was needed to determine the role of the sites [chemopalooza.com](http://chemopalooza.com), [baldylocks.blogspot.com](http://baldylocks.blogspot.com), and [everythingchangesbook.com](http://everythingchangesbook.com).

The network crawl with a depth of three produces an issue network visualization consisting of many of the most popular and highly trafficked sites related to cancer on the

web. While the common nodes are present in this network and the sites with the highest number of inbound links remain largely the same as in earlier network crawls, the network itself is more illustrative of a collection of high traffic websites related to cancer instead of those with major influence on the online young adult cancer community. The following common nodes— chemopalooza.com, baldylocks.blogspot.com, i2y.com/imtooyoungforthis.com/stupidcancer.com, planetcancer.com, and livestrong.org—appear as integrated players in this network, indicating that they are influential both within the online young adult cancer community and also may act as representations of that community to the larger online cancer network.

The site everythingchangesbook.com again appears at the periphery of this issue network. This might be explained in part by the fact that the site was not active at the time the crawl was launched. I reviewed content at Everythingchangesbook.com using the Internet archive Way Back Machine available at <http://www.archive.org/web/web.php> to ensure the website was a member of the online young adult cancer community, but the domain is currently invalid and the full website content is unavailable.

### **Summary**

By examining both the most popular sites by number of inbound links and the position of websites within the network visualizations created using the IssueCrawler program, five websites emerged as primary influencers within the online young adult cancer network: chemopalooza.com, baldylocks.blogspot.com, i2y.com/

[imtooyoungforthis.com/stupidcancer.com](http://imtooyoungforthis.com/stupidcancer.com), [planetcancer.com](http://planetcancer.com), and [livestrong.org](http://livestrong.org). These sites were chosen as the focus of the cluster analysis, the results of which appear in the next chapter.

## CHAPTER VI

### CLUSTER ANALYSIS RESULTS

With the goal of understanding the meanings and implications of key terms used by influential members of the online young adult cancer community, I analyzed the texts of five websites, chemopalooza.com, baldylocks.blogspot.com, i2y.com/imtooyoungforthis.com/stupidcancer.com, planetcancer.com, and livestrong.org, using cluster analysis.

#### **Description of Artifact**

The attempt to determine the flow of information among influential members of an online, interest-based public using Burkean cluster analysis is made rather more complicated by the necessity of analyzing documents produced by more than one rhetor. Instead of teasing out the worldview of an individual, in this dissertation I use cluster analysis to develop an understanding of the way meaning is developed by the five influential members of the online young adult cancer community as determined by the network analysis. This analysis does not seek to determine the worldview of a single rhetor but rather find the dominant themes and context espoused by influencers in the online young adult cancer community.

Young adults experience a variety of types of cancer, all with different symptoms, prognoses, and treatments. According to the National Cancer Institute, the most common cancers in the young adult community are lymphoma, leukemia, germ cell tumors (including testicular cancer), melanoma, central nervous system tumors, sarcomas, and breast, cervical, liver, thyroid, and colorectal cancers. The strongest unifying

characteristic among influencers in the community studied, however, is their age, not the type of cancer they experience. Identification as a young adult within a medical community that divides patients into the dichotomy of pediatric and adult care appears to be the unifying factor for this community. While the actual experience of having cancer may differ substantially among members of the young adult cancer community, the experience of being an outlier within the larger cancer community appears to create a strong common bond.

The websites that emerged as influencers through the network analysis process all focus on the experiences young adults go through when dealing with cancer. The resources and information available through the websites cross diagnosis, treatment, gender, ethnicity, and geographic lines, but they all relate to having cancer as a young adult. The following section provides a description of the five websites used as artifacts for the cluster analysis:

### **Chemopalooza.com**

Written by a woman who was diagnosed with Hodgkins Lymphoma in 2007 at the age of 25, this website follows a typical blog format. All posts are written by a single author, and the narrative is written in first person.

The blog posts begin in March 2007, shortly after her diagnosis, and her early posts focus almost exclusively on describing her personal treatment experience. In October 2007, when the author completes her treatment and enters remission, the topic of the blog shifts slightly. While cancer still featured prominently in her writing, the posts in the few months following her remission focused on trying to adjust to life without

fighting cancer. Several posts mention ongoing health concerns and the physical changes, such as weight gain and hair loss, the author faced during this period of time. The author's personal and professional lives also play a prominent role in the blog post-remission as she struggles with dating and returning to work as a cancer survivor. The number of posts dropped dramatically after the author went into remission, moving from more than 20 new posts per month during the author's treatment phase to fewer than 10 a month after remission.

Although Chemopalooza.com is still active, for the last year the author has only posted new content between one and three times a month. Her most recent posts are updates on her health situation (still cancer-free) and commentary pieces on young adult cancer issues and representation in popular culture.

### **Baldylocks.blogspot.com**

This website is a single-authored personal blog written by a woman who was diagnosed with Acute Myelogenous Leukemia on March 31, 2006, at the age of 33. According to the author's profile page on the blog, "I write this chronicle of my life to prove that cancer CAN be beaten, it's NOT like getting over a cold and that life is worth persevering even in the worst of circumstances" (baldylocks.blogspot.com). The author launched the blog in late August 2007, about a year and a half after her initial diagnosis. Although the blog does not chronicle the author's active treatment process, most of her posts touch on ongoing health issues she faces as a result of her treatment.

The author posted most actively in 2007, regularly publishing more than 20 posts a month. Her posting has been irregular over the last four years, but she continues to

actively blog and has posted at least one new post each month. Her posts continue to focus on adjusting to life with ongoing health, social, and emotional challenges she attributes to her cancer experience. The author frequently discusses the intersection of her roles as a mother, artist, friend, and young adult cancer survivor.

**[I2y.com/imtooyoungforthis.com/stupidcancer.com](http://I2y.com/imtooyoungforthis.com/stupidcancer.com)**

The three URLs listed here all lead to the homepage of the I'm Too Young for This Cancer Foundation. With the slogan "the voice of young adults," the I'm Too Young for This Cancer Foundation is a nonprofit organization dedicated to supporting young adults (age 15-40) affected by cancer. The mission of the organization is to build community among those affected by cancer in young adults, improve the quality of life for young adult with cancer, and provide meaningful survivorship.

The I'm Too Young for This Cancer Foundation was founded by Matthew Zachary, a pediatric brain cancer survivor and young adult cancer advocate, in 2004. Zachary was diagnosed with cancer in 1995 at the age of 21. At the time, the web was in its infancy and there were few online resources for individuals dealing with a cancer diagnosis. According to the history statement posted on the I'm Too Young for This website, Zachary developed the organization "to ensure that young adults affected by cancer would have the opportunity to benefit from community and support resources that he and his family only wished they had in 1995."

The I'm Too Young for This website is a clearinghouse of information on young adult cancer issues. These resource pages include lists of young adult cancer bloggers; information on camps, retreats, and excursions for young adults dealing with cancer;



advice for parents of young adults with cancer; books, literature, and movie suggestions; financial resources; cancer advocacy tools; and forums and chatrooms for active patients, survivors, and caregivers. The website also includes information on and links to offline resources provided by the I'm Too Young for This Foundation, such as the weekly Stupid Cancer radio show, the OMG Young Adult Cancer Summit, an annual conference on young adult cancer issues, and Stupid Cancer Boot Camp, which are in-person training events on young adult cancer support and advocacy issues.

### **Planetcancer.com**

Planet Cancer is an online community for young adults dealing with cancer. The website, which offers informational resources as well as a virtual space for those interested in young adult cancer issues in which to interact, takes a particularly irreverent stance on cancer issues. The site features humorous articles and joke items poking fun at everything from chemo-brain to getting used to a prosthetic limb. Heidi Schultz Adams, a cancer survivor who was diagnosed with Ewing's Sarcoma at age 26, and several other young adults dealing with cancer developed Planet Cancer with the goal of connecting young adult cancer patients with others going through similar experiences.

Planet Cancer was acquired by the Lance Armstrong Foundation in 2009. Although Planet Cancer is now a Lance Armstrong Foundation initiative, the community maintains a separate web presence. The Planet Cancer homepage uses frames to divide the site into sections of resources that include recent news stories on young adult cancer issues, a feed of activity on the Planet Cancer forums, Planet Cancer merchandise available for sale, an event calendar, and the Planet Cancer Twitter feed. In addition to

the Planet Cancer online community, the organization hosts weekend retreats, which offer opportunities for recreation and personal exploration to young adults dealing with cancer.

### **Livestrong.org**

Testicular cancer survivor and seven time Tour de France winner Lance Armstrong stepped into the role of cancer spokesperson in 1997, when he established the Lance Armstrong Foundation (LAF). The LAF coined the popular phrase “LIVESTRONG” to embody the spokesperson’s view of cancer. Using plastic yellow bracelets that became an international phenomenon, the LAF launched a successful buzz marketing campaign in 2004, and by the end of 2005, the foundation had sold more than 55 million Livestrong bracelets. The ubiquitous nature of the yellow rubber bracelets shows the foundation’s well-documented success in raising awareness and support through word-of-mouth marketing, and the LAF now expounds its message through a variety of textual and electronic media. Livestrong.org includes seven primary sections: the home page, the cancer support section, the grants and programs section, a section with information about the organization, an area where individuals can make donations, a portal to the LAF store, and a “take action” section, where readers are directed to areas where they can sign up to volunteer for the organization.

The Livestrong website addresses cancer as a whole and is the only site in the cluster analysis that is devoted to cancer patients in general and is not specific to young adult cancer. The LAF has, however, been fundamental in bringing attention to cancer in

young adults, and Lance Armstrong himself, having been diagnosed at age 25, is a young adult cancer survivor.

In addition to first partnering with and later acquiring Planet Cancer, the LAF has funded several research projects with the goal of learning about the needs of young adults with cancer. For example, the LAF founded the Livestrong Young Adult Alliance, a coalition of organizations with the goal to improve the survival rates and quality of life for young adults with cancer. The Young Adult Alliance is a working group consisting of medical professionals, academics, and cancer advocates devoted to improving the cancer experience for young adults. Other LAF foundations and partnerships include Livestrong at School, a cancer awareness program directed at school-age students; the Livestrong Survivorship Centers of Excellence, a survivorship resource group; Fertile Hope, devoted to research and support for cancer patients that face infertility as a result of treatment; and Cancer Transitions, a program to help ease the transition for cancer patients from active treatment to survivorship.

### **Key Terms**

The first step in the cluster analysis process is to do a close reading of the texts to identify terms that appear to have particular importance to the rhetors. I examined the full content of the websites as they read on the date of download (February 13, 2012). During the first close reading of the artifacts I identified the following four key terms based on their intensity and frequency of appearance in the artifacts: “hair,” “death,” “normal,” and “community.” All four terms appeared repeatedly across the five websites identified as influencers in the online young adult cancer community. More so than their frequency,

however, the intensity of their use by rhetors was the impetus for choosing them as key terms for study. They all appear in the texts when the content appears to be expressing extreme depth of feeling.

In cluster analysis, the terms that appear in connection with or close proximity to key terms are recorded and charted. After I identified the clusters that surround key terms, I reviewed the data for patterns and linkages that could be used to chart the worldview of the rhetors. The clusters of ideas and concepts that emerge around these terms are then analyzed to understand the perspective, function, and role of online influencers in the online young adult cancer community. The context of each key term is examined in turn.

## **Hair**

Hair was selected as a key term because of the frequency and intensity of the subject in the artifacts studied. The process of hair falling out during a cancer experience was equated in several instances to the moment of cancer becoming “real.” The topic of hair – both the loss and regrowth – was covered extensively on the blogs studied as well as in personal narratives submitted by cancer survivors to Livestrong.org. Hair loss is even alluded to in the title of baldylocks.blogspot.com, one of the five websites used as artifacts in this dissertation.

In reviewing the text for references to hair, four distinct contexts of the term emerged. The sense of loss as a result of cancer-related alopecia was the most common context in which hair was discussed. Hair loss was also closely related to the realization that one who has cancer is actually sick. Fashion advice on the subject of hair, or to be

more accurate a lack of hair, was present in all of the artifacts, and the subject of hair was frequently discussed in a humorous context. The wordmap depicted in Figure 4 shows the connections and categorizations for the contexts in which the key term “hair” appeared in the texts studied.

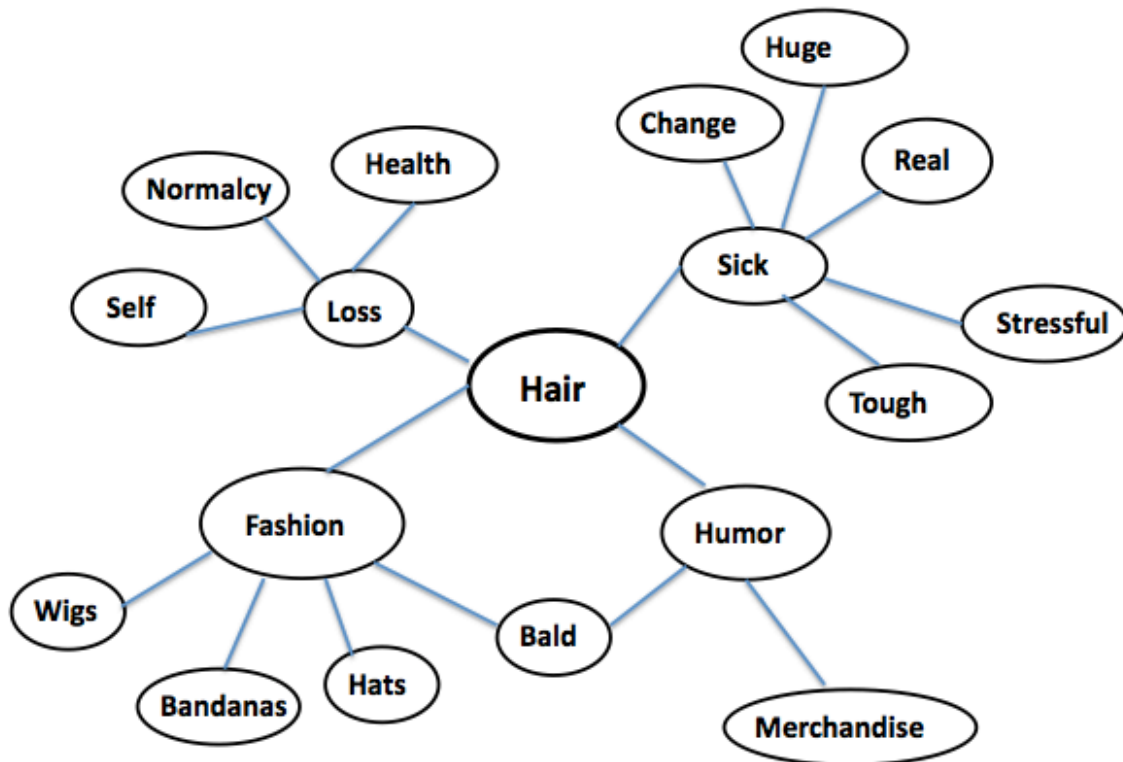


Figure 4: Wordmap showing the context and surrounding terms for the key term “hair” as observed in the artifacts studied.

The most closely connected terms to “hair” in texts of the artifacts were “loss” and “lose.” Chemotherapy, a common treatment for many different types of cancer, is a treatment regime in which cancer patients consume or are injected with drugs. The most common chemotherapy agents attack rapidly dividing cells. Because rapid division and reproduction of cells is a main property of most cancers, chemotherapy is highly effective

at destroying malignancies, but chemotherapeutic drugs also harm cells that divide rapidly under normal circumstances. Alopecia (hair loss) occurs when drugs used as part of the chemotherapy regime attack healthy hair follicles.

**Loss.** References to hair nearly always appeared in close proximity to references to “loss” or “losing.” Occasionally, references to hair loss were made in conjunction with references to losing health or losing normalcy. The loss of hair appears to be related to the larger experience of moving from a healthy state to one of active treatment. The texts describe hair loss as far more than a side effect of cancer. The loss of hair is mentioned in close proximity to discussions of no longer feeling like “my normal self.” The blogger behind the website Baldylocks.blogspot.com wrote, “Cancer causes vanity. I was never much into my looks and didn't even mind when I lost my hair. Now I feel I've lost myself ... I crave to look like myself again.”

The loss of hair appears in the texts in clear conjunction with discussions of losing one of the most basic aspects of normal self—personal health. The process of hair loss is closely associated with the moment when cancer patients accept the reality of cancer and the moment when both the patient and the patient’s supporters recognize that a cancer diagnosis foretells the loss of health. The next section further explores the connection between alopecia and loss of health.

**Sick.** One of the ironies of cancer treatment is that the process of fighting cancer is often more physically uncomfortable than living with cancer. A cancer patient will frequently not feel or look sick until he or she begins treatment. The cause of patients looking and feeling sick is often more a result of the treatment than the disease. As a breast cancer survivor said in an interview published on Livestrong.org, “The biggest

physical issue while I was going through treatment, believe it or not, was my hair falling out. That, to me, was harder than losing my breast, because I looked sick as well as feeling sick.”

The terms “sick” and “change” were frequently found in close proximity to the term “hair.” The process and acceptance of losing hair appeared to be a turning point in a patient’s acceptance of his or her cancer. It is referenced in several locations in the artifacts as one of the most difficult changes in the cancer experience. [Livestrong.org](http://Livestrong.org) includes several interviews with caregivers discussing the challenges they face caring for those with cancer. The following quote is from an interview with a mother describing the experience of helping her daughter come to terms with a recent diagnosis of Hodgkin’s Lymphoma.

“So-and-So said I’m gonna lose my hair. Is that right?” I said, “Well, yeah, probably.” And she just got hysterical. I just looked at her and I thought what can I say? What can I say? And finally I said, “You’re more important than your hair is.” Her hair was long. She calmed down and by bedtime she was saying, “I’m gonna cut my hair short and dye it.” She had adjusted to the fact that things were gonna change.

The author of the blog *Chemopalooza* also adopted hair references as part of her process of entering cancer treatments. One of the blog’s early posts describes the cancer-themed party the author threw for herself shortly after she was diagnosed with Hodgkin’s Lymphoma. Party guests at this event wore colorful wigs to show their support for the author’s upcoming cancer experience. She chose the theme of hair loss for the party that celebrated the change that the cancer diagnosis had brought to her life.

The enormity of losing one’s hair for many cancer patients is evident by the barrage of strong terms that surround references to hair. In personal descriptions of cancer, individuals describe hair loss as “huge,” “big,” “stressful,” “incredibly difficult”

and “tough.” This was found in the descriptions of hair loss provided by both men and women. In fact, one man wrote a poignant story for the Livestrong website of helping his young children come to terms with his recent cancer diagnosis by allowing them to shave his head. Removing his hair made cancer real to this man and his family in a way that the official diagnosis did not.

Given that the topic of hair is so prominent among the musings of those affected by cancer, it is unsurprising that the term also frequently appears in the context of advice and resources for cancer patients and survivors.

**Fashion.** While the blog content and personal reflections on cancer tend to focus on the enormity of losing one’s hair, the topic of hair also frequently appears within the context of resources and advice for cancer patients. The terms “wigs” and “bandana” are frequently found in close proximity to the term “hair” on the websites studied. In addition, images of individuals wearing bandanas and hats appear in close proximity to hair references. Although the term “hair” is found in close proximity to fashion resources, the advice offered to individuals on the cancer resource sites are for those without hair. The authors of both blogs studied discussed the process of their hair growing thin as a result of their cancer treatments, but the terms clustered around “hair” in cancer resource areas referenced fashion accessories appropriate for those who entirely lost their hair.

**Hair humor.** Hair, and loss of hair, is frequent fodder for humor on the websites analyzed in this study. The term “bald” is often found in close proximity to the term “hair” in humorous sections of the artifacts. On the list of young adult cancer blogs published on <http://www.stupidcancer.org>, two blog titles make direct reference to hair loss: Kiss My Bald Head and Redheaded Bald Chic. Although the terms that appear in



close proximity to the key term of “hair” in humorous contexts are similar to the terms that appear in personal reflections (loss, hard, weird, sick), the presentations of the terms is quite different. The bulk of content on Planetcancer.org is presented in a humorous manner, and several of the jokes relate to hair. For example, the site posted the following list in its “Top Ten Lists” section:

**Top Ten Reasons Being Bald Rocks**

10. Topless tanning.
9. No hair in your soup. Or anywhere else, for that matter.
8. No haircuts, no shampoo, no styling - can you say low-maintenance?
7. No lice. Ewww.
6. When on the run from the police, you can hide out in the melon section of the grocery store.
5. Magic Marker skull tattoos.
4. On really hot nights, a cool satin pillowcase is better than sex. Like you're getting any.
3. Low maintenance = more time on your hands = higher blood counts (Yeah, you know what I mean!)
2. You can join the Bald Hall of Fame.
1. Aerodynamics, baby!

Several pieces of cancer merchandise sold online allude to the loss of hair in a humorous way. For example, the Planet Cancer store markets t-shirts printed with the text “Like Animal Planet but with less hair,” and women’s underwear printed with the text “It’s not just my head that’s bald you know....” Also, the writers of the blogs Chemopalooza and Baldylocks both post pictures of themselves wearing bright wigs in primary colors on their profile pages.

The Planet Cancer and I’m Too Young for This websites both state that humor is used to help young adult cancer patients cope with their cancer experience. As the loss of hair is so closely connected to the cancer experience in the texts studied, it is unsurprising that the topic is often the subject of jokes and candid remarks on young adult cancer websites.

**Summary.** For influencers in the young adult cancer community, hair loss is about far more than a change of physical appearance. Losing hair is an enormous shift for a young adult with cancer. The loss of hair is inexorably connected to the idea of what it means to have cancer. When a cancer patient loses his or her hair they can no longer pass as normal without the aid of fashion accessories to help hide the hair loss. Being bald marks young adults as different from their healthy peers. It is a physical manifestation of the isolation young adults face when they transition from their pre-cancer life to being a cancer patient. References to hair often appear in humorous contexts, which is a common coping mechanism young adults use to deal with exceptionally difficult situations.

## **Death**

Like the issue of hair, the topic of death is discussed in a variety of contexts within the artifacts studied. This term was chosen more for the prominence of the discussion related to death than the frequency of the term, however. References to death nearly always presented death as a result of cancer, to the extent that any use of death implied a cancer death. The most prominent context in which death was discussed was examination of the anxiety that concern about death brings. Discussions of death-related anxiety were present across all artifacts but were particularly prominent in the blogs and personal reflections. The concept of death was also widely discussed as it relates to greater appreciation of life and recognition of personal mortality. Eulogies for young adults who had died of cancer were emotionally charged inclusions in several of the artifacts studied. In texts that show examples of public grieving, rhetors frequently invite readers to submit comments, creating a shared grieving process. The final context in

which death was identified as a key term was the use of death statistics to raise the profile of the issue of cancer in young adults.

The wordmap depicted in Figure 5 provides an overview of the various contexts within which the term “death” appeared in the texts.

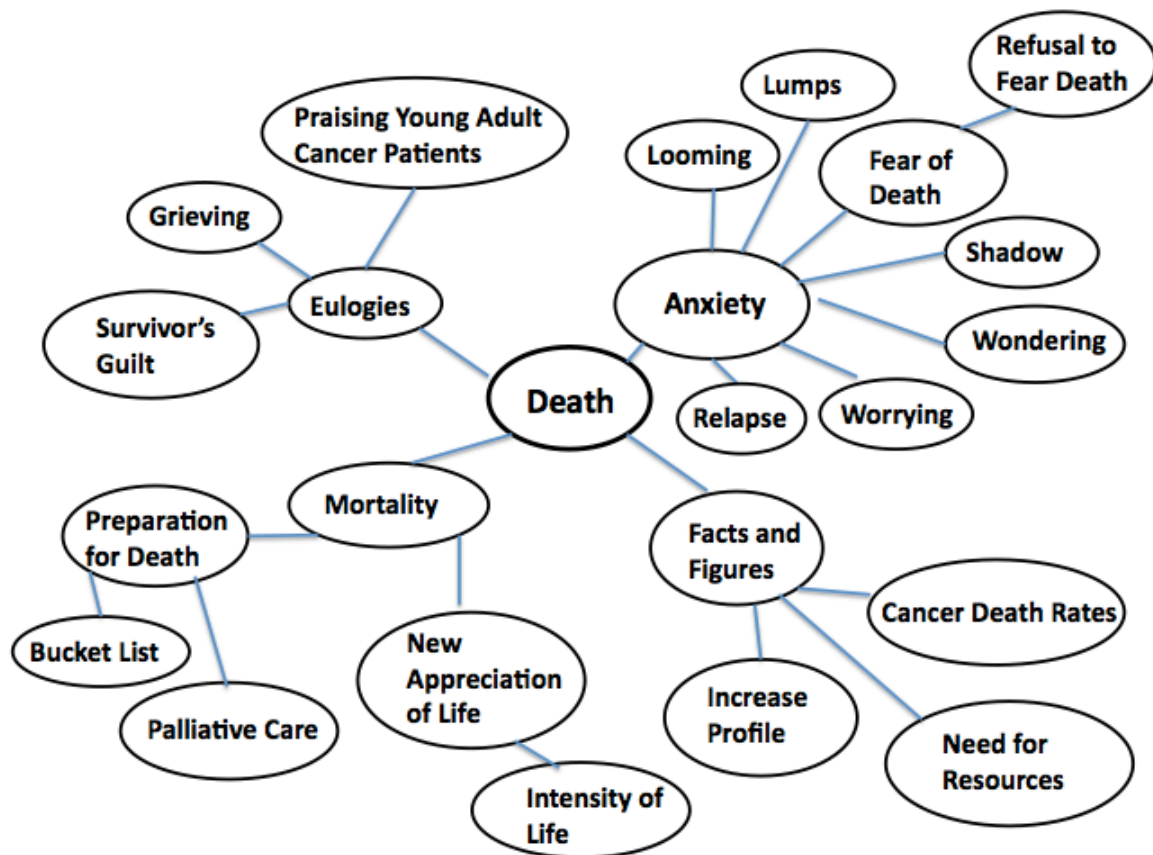


Figure 5: Wordmap showing the context and surrounding terms for the key term “death” as observed in the artifacts studied.

**Anxiety.** By far the term that occurred most frequently in close proximity to references to death and dying was “anxiety.” Dealing with the uncertainty of life appears to take a physical toll on many cancer survivors; several personal accounts published on blogs and the survivor’s story section of Livestrong.org linked concerns about death were linked to anxiety attacks. Death was described in several instances as a “looming

shadow” and a “dark cloud.” Mentions of anxiety surrounding the issue of death tended to appear in personal accounts of individuals who were close to remission or had already completed cancer treatments. Anxiety related to death appears to be a chronic concern even after an initial cancer diagnosis and successful treatment. The following quote comes from a blog post titled “The Fear of Recurrence: Cancer’s Evil Twin,” which was posted October 20, 2011 by a young adult breast cancer survivor on the StupidCancer.com blog.

People think chemo is the worst part of getting cancer, and yes, being bald, bilious, and menopausal was awful. But those physical trials paled in comparison to the mental challenge of managing fear. I would parse every word my oncologist said and obsess over what he meant when he called my cancer aggressive. I would lie awake at night wondering whether the pain in my back came from carrying the stroller or having a tumor. I would read a news story about a celebrity’s death from cancer and wonder if it would happen to me.

The anxiety expressed regarding the topic of death was frequently presented within the context of fear over a cancer relapse or secondary malignancy as a result of initial treatments. The possible return of cancer was so worrying that the rhetors appeared to fear that every bump, lump, or bodily change foretold impending demise.

Conversely, some rhetors expressed an adamant refusal to allow anxiety over death to pervade their lives. Some rhetors, including the authors behind both the Chemopalooza and Baldylocks blogs, acknowledged that thoughts of death caused feelings of anxiety but also detailed their struggle not to be overwhelmed by these thoughts. Overcoming anxiety related to cancer recurrence and death is not an easy process. The language of those asserting dominance over death, anxiety, and cancer is strong and often combative. For example, several of the personal reflection pieces published on Livestrong.org refer to their treatments as “killing” cancer, and visitors to

StupidCancer.com are encouraged to “give cancer the bird,” a reference to a profane hand gesture.

This process of dealing with death issues appears to be made more difficult by the reaction of friends, family, and peers to discussions of death. Several content producers wrote of the relief they felt writing about the issue of death and mentioned that they found it difficult to talk about – and difficult for others to hear. The author of the blog Baldylocks wrote about her struggles to navigate the tricky terrain of other people’s anxiety about death.

I'm not being real if I have to hide what's going on in my life. Yes, there is cancer stuff, but there is other stuff too. I can't ignore what I'm going through to sooth other peoples [sic] anxieties. There's not enough makeup or Spanx in the world to make me look like what they want to see. Maybe I'm too nonchalant about death and the like. Dark humour can be a brilliant thing when you have to stare death down.

Perhaps the grim nature of the subject of death is why the term often appears in humorous contexts. On the Planet Cancer website difficult issues are often discussed through humor. In a *USA Today* article that was reposted on PlanetCancer.org, founder Heidi Adams was quoted as saying, “humor helps many patients cope.” The site touches upon death in its message forums, cancer humor section, and its blog. In one post, on the blog populated by Planet Cancer founder Heidi Adams, the author described her frightening Halloween costume ideas.

I remember Halloween while I was on treatment. It was a banner year in the movies for bald and sick characters. I was trying to decide whether I should be:

- a) Tom Hanks in Philadelphia, dying of AIDS.
- b) a Holocaust survivor from Schindler's List, dying from Nazis.

c) Debra Winger from *Shadowlands*, dying of bone cancer. (Which, by the way, I didn't know until I was trapped in the middle aisle during a sneak preview, not two months after being diagnosed with---yes, bone cancer.)

The anxiety surrounding death, and attempts to overcome this anxiety, appears to be closely tied to ruminations over personal mortality. The next section discusses death as it appears in relation to appreciation of life.

**Mortality.** Mentions of death frequently appear in close proximity to explorations of life. Far from seeing life and death as polar opposites, the rhetors in this study appear to accept that death is a part of life. The acceptance of death that can come with a cancer diagnosis leads to a greater appreciation of life. In ruminations printed on Planet Cancer, founder Heidi Adams wrote, “there is a certain intensity of life when you're constantly faced with evidence of your own mortality, and only those who have come up against this same evidence can understand it.” Several rhetors said that both the large and small pleasures of life are brought into sharper focus after struggling with cancer. A contributor on the StupidCancer.org blog wrote, “After you have been bald and vomiting and fearing death for months, you become remarkably easy to please. There is wisdom in savoring simple pleasures.”

Cancer is frequently referred to as an issue of “life and death.” As printed in a Baldylocks post, “It's hard to focus and regain control of a life where there is no control ... It's ironic that once death is presented, that's when you realize what a farce it all is...and you begin to let it go.” Letting things go by no means implies that young adults dealing with cancer have dropped out of life. The texts showed evidence of several attempts by young adult survivors to take advantage of the time that they do have so they

will be prepared when death comes. Several individuals who posted personal cancer stories on the Lance Armstrong Foundation website referenced “bucket lists,” lists of goals and accomplishments they wanted to achieve before they died. The author of Baldylocks posts a yearly list of goals she calls “The Adventure List,” with entries ranging from the fun (“Dye my hair bright fuchsia”) to the practical (“Pay off My Medication Debts”).

Both Livestrong.org and PlanetCancer.org devote sections of their websites to end-of-life preparation and palliative care resources, and StupidCancer.com links to several resource sites devoted to death and dying. Livestrong addresses practical aspects of the dying process with advice on creating a will, dealing with life insurance, making arrangements for hospice care, and planning for a funeral. Planet Cancer offers advice and support for the more emotional aspects of end-of-life processes and also provides space for young adults to recognize and remember those who have died from cancer.

**Eulogies.** Common across all the artifacts reviewed was the use of the blog format to eulogize young adults who died of cancer. Although there are more than 100 different types of cancer, all with different symptoms, diagnoses, and treatments, any kind of cancer diagnosis appears to be enough to develop empathy across the young adult cancer community. For example, the author of Chemopalooza, a Hodgkin’s disease survivor, wrote a post eulogizing a fellow blogger “cancer pal” who died of colorectal cancer. Regardless of the differences in diagnoses, the text of the post indicated the two bloggers connected over their identity as cancer patients. Cancer in general, and not the specific type of cancer, appears to be the overarching community identifier for young adults in the network studied in this dissertation.

Posts that discussed the death of another member of the young adult cancer community tended to be posted soon after the person passed away. Raw emotion is evident in these posts, as is to be expected when one dies of the same category of ailment a blogger has dealt with, and the content tends to be similar across posts. Personal memories of the subject of the post are shared, and readers are encouraged to respond with their own memories in the comment section. The comments submitted on posts eulogizing young adults who had passed away were without exception positive and tended to include expressions of shared grief and declarations of support for the author.

In eulogy posts, the authors mention the subjects' admirable qualities and lament their passing. A nearly universal aspect in these eulogies that is not always present in traditional remembrances, however, is strong commendations of the subject's strength. In a post written shortly after a friend died of cancer, the author of Chemopalooza printed, "However, I want it to go on the record, she did not lose this fight against cancer! She chose to go home. She died with honor and dignity, keeping her chin up and she went down swinging!"

The influencers in the young adult cancer community appear to adamantly object to the idea that a person "loses" a fight with cancer when they die. The following poem is printed in the "cancerainment" section of the Planet Cancer website:

**A Poem by Paul Cox**

"He lost the battle to  
cancer," you say.  
Cancer's the winner?  
Do you see it that way?  
To die is to lose?  
Is that how it ends?  
So then can you tell me,  
Does anyone win?  
Death comes to all,



So everyone loses?  
Why play the game  
If that's how it is?  
I fail to see it  
That way at all.  
Play the game how you want  
You make the call.  
When it's the end  
Only you and God know  
If you win or lose  
And which way you'll go.  
So don't tell me I lost  
for that is a lie.  
It's how you live  
Not how you die.

Even on the Livestrong website, where combative language dominates the discussion of cancer process (i.e., war on cancer, battling cancer, surviving cancer), I was unable to find the metaphor “lost the battle” used to describe a death from cancer. Instead, the rhetors appeared to contradict the assumption that individuals who died of cancer were in any way weak.

The issue of death from cancer appears to elicit complicated feelings among the rhetors. Although the rhetors wrote extensively of the strength they observed in other cancer patients, they also wrote of the strong feelings of guilt when members of the young adult cancer community die. There were several instances where rhetors wrote of the guilt they felt when a strong cancer patient died. As part of a post celebrating four years of remission after a stem cell transplant, the author of Baldylocks.blogspot.org wrote the following:

I grieved and wondered why I was left while others were gone. I am completely aware that it's survivor guilt but that doesn't do anything to alleviate it. I'm so sorry. To the beautiful people I had the privilege of knowing and sharing that intimate time of our lives with, I'm so sorry that you had to go while I stayed.

The eulogies for those who died of cancer are both a remembrance for an individual and a way to share information about rhetors' personal struggles and the struggles members of the young adult cancer community face. The reality of deaths from cancer is personalized in these online eulogies; the next section discusses how a far less personal presentation of cancer deaths is used to impart the importance of the young adult cancer issue.

**Facts and figures.** The use of statistics regarding cancer deaths among the young adult population is common among the websites studied. Livestrong.org, PlanetCancer.org, and StupidCancer.com all claim that the issue of young adult cancer is understudied and the severity is underestimated by the general public. Concerns over the visibility and resources available for young adults with cancer are expressed on the Planet Cancer welcome page as follows:

Every year, nearly 70,000 young adults between 18 and 40 will be diagnosed with cancer in the U.S., representing nearly 7% of all cancer diagnoses. The young adults served by Planet Cancer are marginalized in a medical infrastructure that does not have a "home" for them, lacking specific resources geared toward their unique needs and issues. Survival rates for this age group have not improved in over 30 years, yet the medical community still doesn't recognize young adults as a specific group in need of unique medical, emotional, and psychosocial tools.

The fact that the survival rate for young adults has not increased in the last 30 years is present on the "about" sections of both Planet Cancer and Livestrong.

StupidCancer.com features a page of cancer statistics with the following introduction:

Most people, when they think of cancer, don't even consider for a moment that it can happen to an 18 year old. Or a 25 year old. Or a 37 year old. But it does. Help us change this stigma and spread the word that our generation deserves better. The public needs to be aware that we exist... and that we matter, too.

Each year:

- 72,000 adolescents and young adults aged 15-39 are diagnosed with cancer.

- That's one every eight minutes.
- 10,000 young adults die annually due to cancer.
- That's one every hour.

The rhetors in this study appear to use information about cancer death rates and general cancer statistics as a way to communicate the importance and serious nature of cancer in young adults.

**Summary.** Death is an extremely powerful concept to those dealing with a life-threatening illness. Bringing up death lends gravitas to the issue of cancer, which is often discussed with humor and levity in the online young adult cancer community. References to death and dying have the effect of magnifying issues of great importance to the young adult cancer community. The anxiety that cancer patients and survivors deal with, their increased appreciation of life, the importance of remembering the dead as strong, and the imperative of raising the profile of cancer in young adults are all issues that come through as important to influencers in the young adult cancer community when combing the texts for references to death.

For a young adult with cancer, coming to terms with death appears to be a process that both isolates and insulates. The process of coming to terms with death is difficult; the rhetors describe it as growing accustomed to living with death looming over them. Being shadowed by death appears to set young adults with cancer apart from their healthy peers but it also appears to create a sense of community with other young adult cancer patients that transcends different diagnoses. The experience of dealing with the fear and anxiety associated with death appears to contribute to the sense of community among individuals affected by cancer during young adulthood.

## Normal

The term normal was chosen for analysis because of the frequency and prominence of its use in the artifacts studied. Used most frequently in blogs and personal reflections, references to normality occur in several different contexts. The overwhelming message that comes through when studying the use of the term in the texts is the repeated assertion that cancer is not normal. Medical terminology refers to abnormal test results as indication of possible malignancies. Individuals who chronicle their cancer experience in blogs or through personal reflections on cancer resource websites refer to their life before cancer as normal, positioning it in opposition to the abnormality of life with cancer.

Figure 6 shows the clustering of terms around the key term “normal”: normality before cancer, normality after cancer, and the assertion that cancer is not normal.

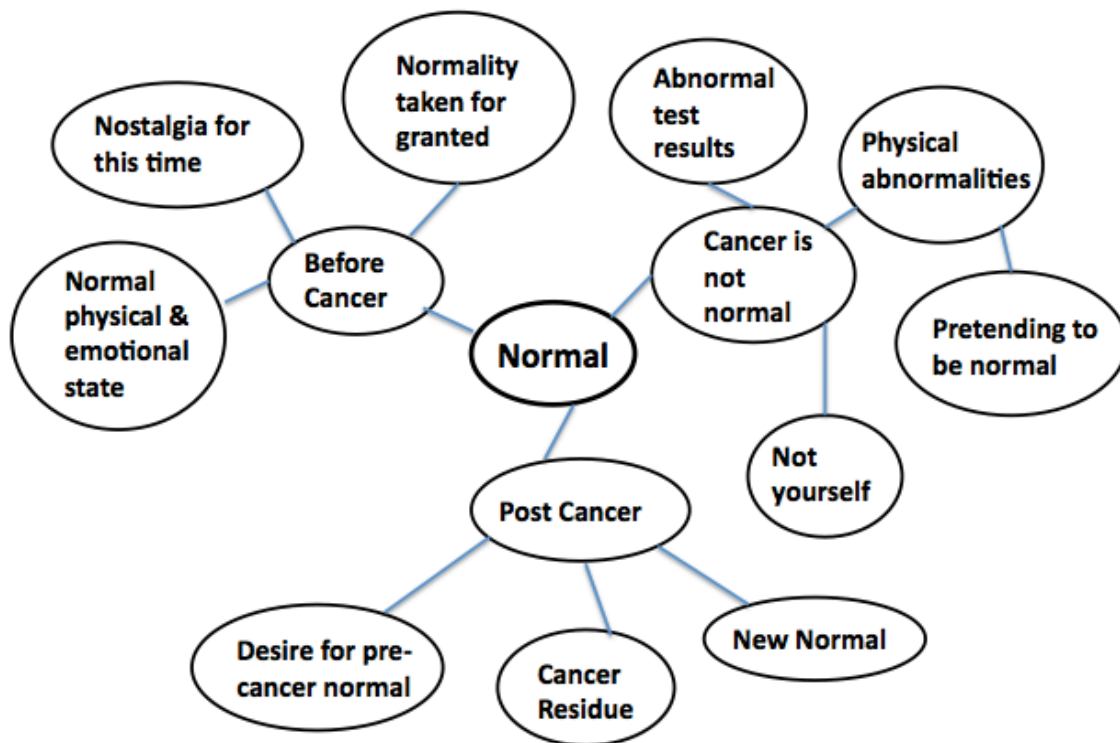


Figure 6: Wordmap showing the context and surrounding terms for the key term “normal” as observed in the artifacts studied.

**Before cancer.** The most common use of the term normal in the artifacts studied was to reference some aspect of life before cancer. The rhetors frequently discuss a longing for the pre-cancer state of normalcy – both physical and emotional. Prior to experiencing cancer the rhetors claim they did not consider their lives normal because there was no comparison to draw with a life that was not normal. They didn't consider their normality at all. It was only after being diagnosed with cancer that normality became a state of being, and during the cancer process they were most certainly not in a normal state anymore.

At several places in the artifacts studied rhetors expressed nostalgia for their pre-cancer normality. The author of Chemopalooza wrote, "I miss being normal and going to work and going out and doing karaoke with everyone. I really hope that I'm done with cancer this summer and done for good!". Not only did this rhetor express a longing for the normalcy of her life before cancer, she also directly related the loss of normality to her cancer experience. On the blog Baldylocks, the author expressed a similar sense of nostalgic remembrance for her pre-cancer life, writing, "All I want is a normal life where I get to do normal things that any other 37 year old would get to do." While these bloggers likely had good and bad days during their time before cancer, the references to pre-cancer normality show a view of all aspects of life before cancer as a vaguely positive "normal."

At several points in the texts rhetors marvel at the physical and emotional conditions that they took for granted prior to having cancer. Over the more than four years of posts reviewed in this study, the author of Chemopalooza shared a litany of

aspects of normality that she took for granted before being diagnosed with cancer. In some cases, the aspects of normality she claimed were taken for granted were broad, such as a desire to “just feel normal again.” Other aspects of normality taken for granted during her pre-cancer state were specific, such as in a series of posts where the author shared that her teeth had become extremely sensitive and her arm veins were bruised and painful. The author said she neither considered nor appreciated the wonder of having normal teeth and normal veins before she began treatment for cancer. As she wrote, “Days when you’re feeling okay are normal days.”

The desire for physical and emotional normality was expressed in several locations throughout the artifacts studied. The author of Baldylocks even created a term for this longing, writing, “I feel normalish today. Normalish in the way that I can vaguely conceptualize what it used to mean to be me.” The experience of having cancer, and the emotional and physical changes that the artifact creators experienced during the treatment process, are compared to the emotional and physical state the artifact creators remember from before their cancer diagnosis. The pre-cancer “normal” emerges as the antithesis to the active cancer state.

**Cancer is not normal.** From the moment of diagnosis, the language of cancer is one of abnormality. Normal test results indicate benign conditions while abnormal results foretell malignancies. The bloggers and website contributors in this study who chronicled their treatment experience adopted the language of medical professionals when discussing treatments and medical evaluations. For example, a “normal” chemotherapy regime would be one in which the nausea is manageable and there are no catastrophic side-effects. The moment of remission is heralded by “normal” x-rays or blood tests,

meaning those that show no evidence of cancer. In referencing a recent medical appointment the author of Baldylocks wrote, “He checks for graft/host in my mouth to see how my body is coping with the transplant. He looked in my mouth and said it looked really good. It in fact looked fairly normal!! Yay! Normal isn't something I hear much these days.” Test results that indicate a reduction in cancer symptoms are referred to as “normal,” but the implications of normality for cancer patients is bigger than that. Cancer begins at the moment a test result comes back as abnormal and it ends when normal test results are obtained.

The abnormality of cancer moves beyond medical diagnoses and extends to personal understandings of self among the rhetors in this study. As written by the author of Chemopalooza, “I must say, I actually looked pretty normal today! Almost like my old self!”. The physical and emotional effects of cancer treatment are abnormal, while not experiencing cancer effects is referred to as being “myself.” In several instances across the blogs and personal reflections included in this study, when the term “normal” was used during and post-cancer treatments it was written inside quotation marks. As quotation marks within text are commonly used to denote irony, putting quotation marks around the term “normal” implies that the normality of cancer is not a true normal at all. The author of Chemopalooza wrote, “I'm really excited about getting back into a routine again, and seeing people, and being ‘normal!’” and on the Stupid Cancer blog a contributor wrote, “Young survivors tend to summon all our strength to sprint through treatment. We are in such a hurry to regain our “normal” lives as soon as the stubble grows back on our heads that we are caught off guard by the intensity of emotions that hit us as soon as we slow down.”

The physical changes that come during cancer treatment are common fodder for blog posts and personal reflections in the artifacts reviewed in this study. Hair loss in particular was used by female content contributors as a barometer of normality. The authors of Chemopalooza and Baldylocks, both female bloggers, wrote extensively of losing and re-growing their hair. Both spoke enthusiastically of their hair growing back after treatments, saying they were starting to “look normal again.”

The techniques used by both men and women to hide the effects of cancer treatment are referred to as “pretending to be normal” or “passing as normal.” Ruminations on wearing a hat or wig to hide hair loss or covering up scars with strategic clothing choices appear in frequent proximity to references of looking “normal.” But as further study of the artifacts show, regaining physical attributes does not lead to a return of normality. The process of moving from active treatment to post-treatment is rife with difficulties.

**Post cancer.** The discussion of life post treatment in the texts studied frequently refers to the concept of a “new normal.” While much of the previous discussion of normality has relied on content produced in the blogs and personal reflections studied, the difficulty creating a new sense of normality after treatment is covered extensively on the cancer resource sites [stupidcancer.com](http://stupidcancer.com), [livestrong.org](http://livestrong.org), and [planetcancer.com](http://planetcancer.com). In an interview with Planet Cancer founder Heidi Adams published on [Livestrong.org](http://Livestrong.org), she discussed the difficulty young adults can face after completing cancer treatments.

Getting back to normal life just doesn't happen overnight. It's a lot of transitioning you have to do in your own head. When you're in treatment, everything is so immediate. It's so life or death, black or white, the big issues. Then you get back into real life and you have to think about things like picking up the dry cleaning. It's hard to make that shift.



When chronicling the cancer treatment process, influencers in the online young adult cancer appeared to expect that their life would go back to normal, as defined by life pre-cancer, after completing treatment. The author of Baldylocks realized that her sense of normal had changed after cancer:

The cancer made me sick and would have killed me. The bone marrow transplant may make me sick and disabled for life (and may kill me). Great choices. I firmly believed that I would get back to "normal" but now I wonder what is normal? What kind of normal can I live with?

The residual effects of cancer and cancer treatment, both physical and emotional, continue after the active treatment process is completed. Several of the rhetors expressed frustration both with their own unmet expectations of normality post cancer and dealing with friends' and families' expectations that the cancer survivor would adopt pre-cancer normality. The following quote from a blog post on Chemopalooza, although lengthy, does an excellent job of describing the post-cancer struggle with normality.

I'm feeling really weird lately. It's so tough to get acclimated to being "normal" -- I'm not normal, and everyone else's lives kept going on while I was out of commission. I feel like I don't fit in with anyone these days, and even though I don't have a date set to go back to work, I'm really scared. I don't know anyone anymore, and I don't want to have to answer lots of questions, like hey you cut your hair short -- nope, it just fell out a bunch more :( But yeah, everyone my age has problems like fighting with their friends, not having enough money, wanted to be promoted, boyfriend/girlfriend stuff -- but me, I'm dealing with fighting for my life, getting poked every 2 weeks for 6 months, losing my hair, having scars that will last a lifetime, and just trying to rebuild my life -- it's definitely tough to relate to everyone.

The Stupid Cancer and Livestrong websites both offer a variety of resources for cancer survivors who have recently completed cancer treatments. Livestrong.org in particular provides a wealth of programs for cancer patients transitioning into a "new

normal.” For example, the organization partnered with the national cancer group the Cancer Support Community to offer a six-week program called *Cancer Transitions: Moving Beyond Treatment* for individuals transitioning from active cancer treatments. On the Livestrong website the program is described as providing “cancer survivors with the information, skills and tools to address exercise, nutrition, emotional health, quality of life and medical management after treatment ends.” Livestrong also partnered with the YMCA to offer a 12-week fitness program “to help young adults in the transitional period between completing their cancer treatment and the shift to feeling physically and emotionally strong enough to attempt to return to their normal life or their ‘new normal.’”

**Summary.** I chose to assign clusters of meaning that relate to the sequence of the cancer experience when analyzing “normal” because the term was so closely tied to the timeline of cancer diagnosis, treatment, and post-treatment survivorship. Foss (2004) writes that the terms selected as key terms are often either “god” or “devil” terms. In this case, “normal” is a god term, an ultimate term that represents the ideal for the rhetors. To be normal is to free of cancer. Even after cancer treatments there is no return to normality because the residue from having cancer remains. Instead, the influencers in this study find they had to develop a “new normal” after they completed treatment. My analysis of the term “normal” in these artifacts showed that cancer is extremely disruptive for young adults. The following comment was published on Planet Cancer in a guest article written by a clinical oncology social worker on the needs of young adult cancer patients:

Young adulthood is not a stage of life in which one normally confronts illness. Cancer disrupts the natural course of development and sets the stage for a period of emotional adjustment that will influence every aspect of life. One crucial aspect of adjustment is the reworking of previously held perceptions of normalcy to fit a scarred sense of health.

In many instances, mentions of no longer being normal were discussed in relation to concerns about isolation from friends and co-workers and complaints about being lonely. The next section, which discusses the key term “community,” further explores the social issues discussed in the online young adult cancer community.

## **Community**

The term community, while not used frequently in the personally reflective pieces and blogs, dominates content on the resource websites [livestrong.org](http://livestrong.org), [stupidcancer.com](http://stupidcancer.com), and [planetcancer.org](http://planetcancer.org). To better understand the context within which the term community is used, I identified clusters discussing different types of communities mentioned in the artifacts. The medical community, cancer community, and support communities for individual cancer patients all appeared as frequent contexts in which discussions of community take place. I also identified a cluster of advocacy-related terms that appear in close connection to references of community.

The wordmap in Figure 7 shows the clusters I identified around the key term “community.”

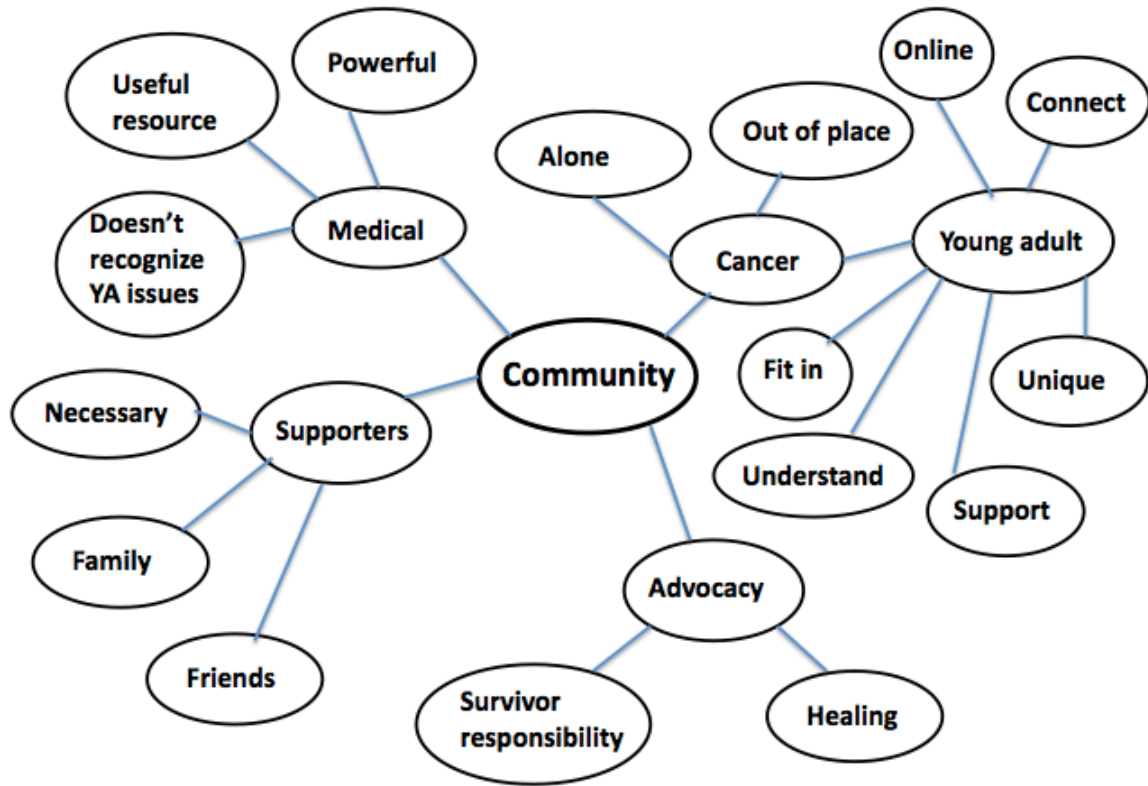


Figure 7: Wordmap showing the context and surrounding terms for the key term “community” as observed in the artifacts studied.

**Cancer.** By far the most frequent context in which the term community appears in the artifacts reviewed in this dissertation is repeated references to the cancer community. The larger cancer community, which encompasses all individuals with cancer, is not portrayed as a welcoming place by the young adult influencers in this study. On the “welcome” page of the Planet Cancer website young adults are described as existing in a “no mans land” within the larger cancer community. In several locations the rhetors report feeling “out of place” in a medical system where patients tend to be divided between pediatric and adult care. In illustration of this, the first paragraph on the Planet Cancer “welcome” page states, “Welcome to Planet Cancer, a community of young

adults with cancer. (You know, that age between "pediatric" and "geriatric," where no one knows whether to give you a lollipop or have a serious talk about your fiber intake.)”

The sense of being “alone” in the general cancer community was evident through all the artifacts studied. Discussion of feeling “alone” and “lonely” during cancer treatments were present in every artifact studied. The following reflection on the cancer experience was printed in a submission on the Livestrong website by a young woman chronicling treatment for non-Hodgkin’s lymphoma: “Even though there can be so many people around you, there was definitely a feeling of loneliness. Thank God that we have the Internet, and I have my support group. But you can't help but feel that you're still going through it alone.” The sense of being alone during cancer stems appears to stem not from a lack of people around a patient, but rather from feeling that one does not fit in either with other cancer patients or with peers outside the cancer community. This sense of isolation is discussed extensively in close proximity to references of a subset of the larger cancer community, the young adult cancer community.

The terms that appear in reference to the young adult cancer community tend to be polar opposite of the terms used in reference to the general cancer community. While according to the rhetors cancer in general is isolating, the young adult cancer community is welcoming. While young adults with cancer are deemed “out of place” in the general cancer community, they “fit in” in the young adult cancer community. Young adults are “alone” in the general cancer community, but the several rhetors describe the young adult cancer community as “my people.” This sense of belonging is artfully communicated in a Haiku published on [planetcancer.org](http://planetcancer.org) that reads, “We are young adults | Bonded by one simple word | But it's not ‘alone.’”

The creation and maintenance of the young adult cancer community appears as a goal of the three cancer resource sites included in this analysis. The mission statements of [livestrong.org](http://livestrong.org), [Planetcancer.org](http://Planetcancer.org), and [stupidcancer.com](http://stupidcancer.com) all include references to “connecting” young adults who are dealing with cancer. The Stupid Cancer organization also appears to work toward building a space for young adults within the larger cancer community by facilitating connections between survivors. The introductory paragraph on a [stupidcancer.com](http://stupidcancer.com) page with links to cancer social networking sites reads, “With over 1.4M young adult cancer survivors in the United States alone, there is simply no reason that anyone should ever feel alone, let alone be disconnected from the national movement.”

The influencers in the young adult cancer community claim to play a deliberate role in facilitating connections among young adults with cancer and the larger cancer community. Planet Cancer, Stupid Cancer, and Livestrong all provide space for both online and face-to-face interactions between young adults with cancer. Planet Cancer hosts weekend retreats several times a year for young adults with cancer and their supporters. Stupid Cancer hosts an annual convention for members of the young adult cancer community called the OMG! Cancer Summit, and Livestrong partners with support communities around the world to provide young adults with opportunities to engage in support groups with other cancer survivors their own age.

Despite the range of in-person programs hosted by the organizations behind the websites in this study, many references to the young adult cancer community found in the artifacts related to entirely online connections. The author of Chemopalooza frequently discussed gifts and messages of support she received from other cancer bloggers, and she

credited the online community with easing her transition from cancer patient to survivor. Several of the websites included in this study offer online spaces for community development and interaction. For example, the Planet Cancer website hosts the “Planet Cancer Community,” which is an online space where young adults with cancer are invited to “share insights, explore our fears, laugh, or even give the finger to cancer with others who just plain get it.” Because the Planet Cancer Community requires registration to read the message boards and view other users, the content of the community was not included in this cluster analysis. Stupid Cancer also hosts a series of message boards where users can post comments and join conversation on a wide range of young adult cancer issues.

Evidence of connecting with other members of the young adult cancer community online was also observed through the pervasive use of social media among the influencers in this study. The homepage of the Planet Cancer website includes a running feed from the official Planet Cancer Twitter account. The right sidebar on [baldylocks.blogspot.org](http://baldylocks.blogspot.org) includes thumbnails of YouTube videos uploaded by the blog’s author. The “contact” page on [Livestrong.org](http://Livestrong.org) shares links to the organization’s Facebook, Twitter, YouTube, Flickr, and MySpace accounts. The Stupid Cancer website features links to the organization’s Twitter, Facebook, and YouTube accounts. Stupid Cancer also produces a popular weekly webcast covering young adult cancer issues, which is archived and available through iTunes.

The rhetors in this study share several reasons why a distinct young adult cancer community is important to develop. The “unique” needs of young adults with a life-threatening illness are mentioned in conjunction with references to the young adult cancer

community. In a blog post on Planet Cancer, website founder Heidi Adams wrote, “See, when 9 out of 10 patients in either a pediatric or medical oncologist's office are under 14 or over 40, respectively, is it any wonder that no one ever thinks of those random young adults as a group or a community? And not just a group, but a group with unique needs, issues and challenges.”

A desire for others who “understand” tends to appear in clusters of terms referencing young adults’ unique position within the larger cancer community. The desire to connect with others who “get it” appears in both the blogs included in the study and in several user-submitted content sections on the young adult cancer resource site. For example, the following poem published on Planet Cancer eloquently explores the need to connect with a young adult cancer community.

It’s like a sad song  
No one understands the words  
but those who sing it  
Here we sing as one  
Let all our voices be heard  
Unique and yet same  
Our community,  
a brotherhood of the strong  
Unbreakable souls  
I found my solace  
in the midst of my sadness  
A calm place to rest

The references to the cancer community in the text are two-fold. The online young adult cancer community influencers claim to be isolated and out of place in the general cancer community. It is through connections with other young adults who are dealing with cancer through a community that largely exists online that these cancer patients’ unique needs for support and understanding are best met.



**Medical.** References to the medical community in the artifacts studied tend to appear in the context of complaints over the lack of mainstream resources and information on issues of importance to the young adult cancer community. The term “community,” when used in reference to the medical infrastructure, is typically used to connote a faceless entity that does not appreciate the concerns of young adults with cancer. The following paragraph, published on Livestrong.org in a section describing the foundation’s partnership with Planet Cancer, is an example of the views espoused by the influencers in the online young adult cancer community.

The young adults served by Planet Cancer are marginalized in a medical infrastructure that does not have a "home" for them, lacking specific resources geared toward their unique needs and issues. Survival rates for this age group have not improved in over 30 years, yet the medical community still doesn't recognize young adults as a specific group in need of unique medical, emotional, and psychosocial tools.

There are also several instances in the text when the rhetors express frustration at the care they receive outside of their oncologists’ offices. On the Baldylocks blog, the author detailed a disastrous experience when she attempted to explain her medical history to the medical professionals at a health clinic. She wrote, “I avoid them because they have no clue what my sentence (Freudian slip there but I’ll leave it) is. I am like some sort of alien science experiment. They don't know what to make of me. Medical professionals don't know what to make of me.”

Influencers in the young adult cancer community show concern regarding the perceived lack of understanding within the medical profession and work toward increasing the profile young adult cancer issues. Readers are frequently urged to advocate for greater recognition for young adult issues. In fact, greater influence in the medical

community is the primary reason Planet Cancer claimed it decided to partner with Livestrong. In a news release announcing the merger, Planet Cancer wrote, “By officially taking on Planet Cancer's programs, they're [Livestrong] magnifying OUR nationally-recognized expertise in YA cancer with their global platform, and we'll combine forces to raise our voices to the medical community and the world at large about this often-overlooked group of patients. You.”

The Livestrong website includes a section on the LIVESTRONG Young Adult Alliance, which is a public-private partnership among medical, scientific, and advocacy organizations with the shared goal of developing a national agenda for adolescent/young adult oncology. The steering committee for the alliance includes medical professionals from top cancer centers around the country and several heads of young adult cancer support organizations. Livestrong.org includes numerous pages on building medical-support community partnerships with the stated goal of “raising the profile of young adult cancer issues” within the powerful medical community.

**Supporters.** Although the online influencers in this study appear concerned regarding the level of recognition among the general medical community regarding young adult cancer issues, individual oncology caregivers are frequently credited with helping young adults through the cancer experience. The young adult influencers in the cancer community may see the general medical community as unconcerned about young adult cancer issues, but individual medical practitioners are frequently the recipients of praise and thanks by the rhetors in this study.

In addition to medical professionals, the different personal accounts in the blogs and user-generated content reviewed in this study showed the rhetors identify a variety of

individuals as imperative in their fight against cancer. For example, the author of Chemopalooza frequently mentioned her parents' role as primary caregivers during treatment, whereas the author of Baldylocks said she largely depended on a loose coalition of friends, family, and professional colleagues throughout her cancer experience. In an interview posted on the Livestrong website, a bone cancer survivor who was diagnosed at age 16 was quoted as saying,

The biggest thing that assisted me with these things [cancer issues] is that I had a great supporting cast around me. Whether it was my nurse practitioner properly preparing me for what I was going to go through, My [sic] family helping me out while I wasn't able to work due to treatment, my employer being understanding of my inability to work, or my parents helping me deal with insurance and bills.

References to a personal support community are present on all of the artifacts included in this study. For example, the Planet Cancer forums have a location for caregivers and supporters to share comments and discuss young adult cancer issues and the Stupid Cancer website provides a series of links that lead to resources and social networking sites for parents, spouses, friends, and children of young adults with cancer. The personal reflections of cancer patients and survivors tend to credit their personal support community as necessary parts of their cancer experience, and the young adult cancer resource websites provide information and support resources to those involved in the care of young adults with cancer.

**Advocacy.** The cancer resource sites included in this study also provide a wealth of materials and support for young adults looking to advocate for cancer issues in their local communities. Livestrong.org in particular encourages community action by young adult cancer survivors. The organization created a community toolkit to show survivors and supporters ways to “take effective action and pursue cancer advocacy in your

nonprofit or community organization.” The extensive community toolkit, which is available in its entirety online at the Livestrong website, provides information on everything from best practices for fundraising to conducting community outreach. In addition, Livestrong.org conducts advocacy and fundraising athletic events such as sponsored runs, triathlons, and distance bike rides. The connection of financial support to cancer advocacy is made clear in this quotation from the Livestrong website: “Getting your community involved to raise funds for Livestrong is a great way to show your support for the fight against cancer.”

Raising money is far from the only reason why cancer survivors engage in advocacy activities. In reviewing the texts, I found several instances where cancer survivors wrote that engaging in cancer advocacy activities was a healing mechanism. It is not just cancer advocacy that the survivors in this study referred to when discussing the use of advocacy activities as an aspect of healing. As a Hodgkin’s disease survivor wrote in a personal reflection piece on Livestrong.org, “I think community involvement is very important, because I think it allows you to channel the energy away from worrying about yourself, but instead, helps you channel it on others, which in turn helps you build your soul.”

For survivors, engaging in community advocacy activities appears to have a downside as well. The author of Chemopalooza was particularly vocal about concerns that other people thought she was not “doing enough” to support young adult cancer causes. In a post detailing all the activities she does to support the cancer community the author wrote, “Ever feel like you're terrible for being a survivor? Like some organizations look down on you for not eating, sleeping and breathing cancer now that you're a

survivor? For not knowing everything happening with every organization? Sometimes that's how I feel.” The author of Baldylocks also wrote that as a survivor she felt a certain responsibility to show support for cancer organizations in general and the young adult cancer community specifically.

The role of advocacy for young adult cancer survivors appears to be a complex issue for the rhetors in this study. While there is value both to the individual and the young adult cancer community in general when cancer survivors engage in advocacy activities, the expectation that advocacy is a survivor’s responsibility can be difficult for young adults handling the transition of moving into survivorhood.

**Summary.** The overarching conclusion that can be drawn from the cluster analysis of the key term “community” is that cancer is not an experience that a young adult goes through on his or her own. The rhetors in this study referenced a broad network of support from family and friends, other cancer patients and survivors, medical professionals, and the general public. The discussions of lack of support for young adults with cancer, such as in references to the general medical community and the broad cancer community, appeared in close proximity to calls for greater recognition of young adult cancer patients’ issues and needs. Given the fact that the current structure of medical care tends to be a dichotomy of pediatric and geriatric support, the rhetors in this study appear to place a great deal of importance on the development and maintenance of a young adult cancer community. Although young adult cancer survivors are outliers in the some communities, the desire for inclusion and support appears to be universal among the influencers in this study.

## Analysis

In this final step of the cluster analysis process, the key terms and their associated clusters are studied for pattern and linkages that can provide insight into the rhetors' worldviews. Examination of the clusters in the five websites used as text in this dissertation, [stupidcancer.com](http://stupidcancer.com), [planetcancer.org](http://planetcancer.org), [livestrong.org](http://livestrong.org), [baldylocks.blogspot.com](http://baldylocks.blogspot.com), and [chemopalooza.com](http://chemopalooza.com), reveal two overarching themes—transition and inclusion.

### Transition

Transition is expressed in many different ways through the clusters identified around the four key terms—hair, death, normal, and community. For example, the transformation cancer patients go through when they lose their hair is a major physical change, but it also involves emotionally coming to terms with the transformation from being healthy to becoming a person with cancer. The clusters of terms surrounding the concept of death deal both with the transition between life and death and the personal transition between fearing death and accepting it as a part of life. Young adults with cancer also transition between several communities as they experience cancer, moving from life as a typical young adult to joining the young adult cancer community, to finding a “new normal” after completing treatment. The struggle with the transition from “normal” life to life with cancer is the overarching concern that comes through in this analysis.

**Hair.** Hair loss is physical and visual proof that a young adult has transitioned from well to sick. The process of mourning the loss of hair detailed by the rhetors in this

study is part of the transition young adults go through when they are diagnosed with cancer. The stressful change of losing one's hair is recognized in the texts as being both a physical change and a transition from the life a cancer patient has always known to the unknown world of oncology wards. The clusters of terms relating to humor and hair loss fashion advice are used in reference to the coping process of dealing with the transition between well and sick, normal and cancer. Losing hair is far more than a physical transition; it is part of the much larger transition that young adults with cancer face. Influencers in the young adult cancer community appear to act as guides for individuals going through this transition. The influential websites in this study offer advice for young adults who experience alopecia, but more than that they provide context for the enormity of hair loss.

The analysis indicates that influencers understand that when young adults lose their hair they lose their normalcy, health, and sense of self. It is a process through which a young adult, in a very visible and physical way, becomes a cancer patient.

**Death.** Science fiction writer Isaac Asimov has been widely quoted as saying, "Life is pleasant. Death is peaceful. It's the transition that's troublesome." In the cluster of terms surrounding the issue of death in the artifacts studied, the transition from life to death is described in much stronger terms than "troublesome." The word "anxiety" was closely connected to the key term death, indicating that the rhetors in this study found the impending transition a difficult concept to accept. The cluster of terms relating to anxiety are overwhelmingly negative and include fear, shadow, relapse, looming, and worry. The transition of death is not easy to come to terms with, and a cancer diagnosis appears to force the young adult to consider the unavoidable reality of the end of life.

The cluster analysis of the artifacts in this study shows another significant transition related to the key term of death—the transition from fearing death to accepting it. The texts reference several methods the rhetors use to ease the move toward acceptance of death, including making bucket lists to ensure they make the most of their lives to praising the strength of other young adults who pass away. This analysis indicates that the acceptance of death is an exceedingly difficult transition for young adult cancer patients to go through. But much as with the transition of hair loss, the primary influencers appear to act as guides for members of the larger community as they experience transitions related to death. Planet Cancer dedicates a section of its online forums to conversations related to death and dying, as well as a section where users can share memories of young adults who have died of cancer. By encouraging communication on the subject of death within the community, the influencers in this study provide a space for members to share support, resources, and concerns related to death and dying.

Burke (1967) argued that an agon analysis, the examination of terms that oppose key terms, can help a critic more accurately discern a rhetor's meaning when using cluster analysis. In the case of the key term death, the cluster of terms related to the state of anxiety surrounding the topic are contradicted by the adamant refusal of the rhetors to fear death. The transition from associating death with anxiety to associating death with strength and acceptance of individuals' morality is clearly a polar shift. The end state of this transition appears to be less a desire to avoid death and more a greater appreciation of life.



**Normal.** When young adults are diagnosed with cancer, they rapidly move from a normality they did not even recognize they had to being a cancer patient, a state that is defined by being inherently not normal. Sontag's (1978) metaphor describing illness as a process of moving from the kingdom of the well to the land of the sick is particularly well suited to the way rhetors described the transition of moving from normal to having cancer. Normal life is that which takes place in the kingdom of the well, whereas the cluster of terms relating to life in the land of the sick refer to an abnormal existence. For young adults in particular, the land of the sick can be a lonely place. They are a distinct minority in oncology wards where the typical patient tends to be far older than members of the young adult community.

Even after completing cancer treatment, the texts in this study show that young adults in the online cancer community face a difficult transition. Despite the rhetor's nostalgia for their "normal" lives before cancer, young adult cancer patients appear to experience a second transition after completing cancer treatments. While no longer a cancer patient, remission does not enable young adults with cancer to go back to their previous lives in the kingdom of the well. Instead they experience another transition, this time from being a cancer patient to the "new normal" of a post cancer existence.

Again in this instance, an agon analysis is helpful in understanding the worldview of the rhetor in relation to the term normal. When normal is discussed in positive terms—such as when rhetors express longing for their pre-cancer "normal hair," "normal teeth," "normal energy," and even "normal self"—the clusters indicate that the rhetors believe good health is normal. When normal is discussed in negative terms, such as when discussing medical test results or the side effects of treatment, the clusters indicate that

the rhetors recognize cancer as the opposite of normal. The impossibility of returning to the old normal indicates that the rhetors do not view cancer as a disease that ever entirely ends.

**Community.** The importance of transition in the young adult cancer experience is clearly present in the clusters of terms identified in close proximity to the key term “community.” The clusters show that rhetors are concerned both with the transition between communities during the young adult cancer experience and with the transition between roles for young adults with cancer within communities. The artifacts chronicle deliberate efforts to create a sense of community for young adults with cancer. Interactions within the young adult cancer community take place largely online, but resource organizations in the young adult cancer community also organize events to facilitate in-person interactions among community members.

The cluster analysis showed that the rhetors see the role of young adult cancer community members changing as they move through the cancer process. During treatment and the transition between health and illness, young adults with cancer largely act as recipients of support and advice from highly active community members and personal supporters. In the later stages of treatment and during survivorship, the role of young adult community members appears to shift from that of resource recipient to the role of cancer advocate. Instead of receiving support, young adult cancer survivors in the latter stages of the cancer experience are encouraged to transition to supporters of young adult cancer issues. The rhetors in this study primarily position cancer advocacy as a healing process, but there is also some indication that the expectation of advocacy work can be unwelcome for some young adults with cancer.

The transitions that young adults with cancer experience appear to act as a sort of credential process. The transitions appear to lead to inclusion in the young adult cancer community. The young adult cancer community may not be a group people hope to join, but once going through the transitions of cancer it appears to create a place where young adults can belong.

### **Inclusion**

The rhetors in this study made frequent reference to facing moments of inclusion and exclusion as young adults with cancer. As young adults transition from being “normal” to having cancer, they find their diagnosis causes them to be excluded from familiar life. The rhetors in this study, however, appear to place enormous emphasis on creating a sense of inclusion for young adults with cancer through the development of a young adult cancer community. An agon analysis of this theme is necessary to fully examine the theme of inclusion. Therefore, references to exclusion are also addressed in this section.

**Hair.** As the process of losing hair during treatment is inexorably tied to the process of accepting the role of cancer patient, the loss of hair heralds the acceptance of inclusion in the cancer community. Because cancer is so closely associated with hair loss, patients who do not lose their hair may even feel excluded from the cancer community. In referencing a series of qualitative interviews with breast cancer patients, Thompson (2009) wrote,

Hair does grow back and from a clinical standpoint it is not a big deal to lose your hair. From a survivor standpoint, it is a sign that you are sick. Survivors may be upset about their hair loss for reasons that go beyond vanity. Perhaps it is a sign to

them that they are really sick, or that they may be dying. Survivors who do not lose their hair may feel less ‘sick’ than those that do.

Thompson’s (2009) findings are consistent with the results of the cluster analysis, which showed strong ties between hair loss and the cancer community. It is a visible and clear symbol that an individual is a cancer patient. The authors of Baldylocks and Chemopalooza both post pictures of themselves wearing unnaturally colored wigs (one is bright blue, the other fuchsia) on the sidebar of their respective homepages. The choice to promote images of themselves wearing what are obviously wigs is a not-so-subtle reference to their attitude toward cancer-related alopecia. In presenting hair loss through images that flaunt, rather than hide, a bald head, the rhetors subvert the notion that cancer should be hidden and broadcast their inclusion in the cancer community.

**Death.** Considering that death is one of the very few things that all living creatures have in common, it’s incredible how isolating the young adults in this study found their concerns over eventual death. An awareness of and desire to discuss death appears to exclude young adult cancer patients from their peers who have not yet experienced major illness. According to the Centers for Disease Control (2009) report on the 10 leading causes of death by age group, young adults are far more likely to die of an unexpected accident, suicide, or homicide rather than illness. When a young adult is diagnosed with cancer, the reality of his or her own mortality, likely not a subject that had previously received much consideration, appears to suddenly move front of mind. Even after completing treatment, when the chances of death from cancer diminish, the influencers in this study indicated that they were still unable to connect with peers who led “normal” lives.

The isolation that young adults with cancer experience because of their preoccupation with death is mitigated by the resources and support networks available within the young adult cancer community. The rhetors in this study provide space for young adults to discuss death and mourn publically. The use of web space to eulogize young adults who die of cancer is indicative of the sense of community that develops between young adults with cancer. The rhetors shared what appeared to be heartfelt expressions of grief for individuals they often knew only remotely or even not at all. The shared experience of being a young adult cancer, regardless of the specific diagnosis, appears to create a powerful sense of inclusion among young adult cancer patients.

**Normal.** The cluster analysis indicated that the rhetors viewed cancer in young adults as the antithesis of normal. When young adults are diagnosed with cancer, they no longer identify as normal. In discussions of the treatment phase of cancer the rhetors express a nostalgic longing to go back to being normal, but upon finishing treatments the rhetors say they found they were excluded from their previous sense of normal. Instead, the rhetors frequently referenced the process of developing a “new normal” during survivorship.

The medical community approaches survivorship care in terms of the three Ps: palliation of ongoing symptoms, prevention of late treatment effects and second cancers, and promotion of ongoing physical health (Ganz, 2011). Rhetors in the young adult cancer community appear to be concerned with the emotional toll of the transition to survivorship, an area they claim is largely ignored by medical providers. Based on the cluster analysis, the rhetors believe a community of support consisting of young adults

with cancer experience is vital during both the cancer treatment and the survivorship process. As it says on the Stupid Cancer website, “Our vision is no survivor alone, ever.”

**Community.** The themes of inclusion and exclusion are tantamount to the discussion of community printed in the artifacts studied. The rhetors appear to see their role as a guide to young adults with cancer who find themselves moving between communities of support. Young adults with cancer report feeling isolated from friends and peers in the normal (i.e., pre-cancer) lives, yet struggle to find community support in oncology wards where young adults are a rare sight.

Through repeated mentions of the lack of support available for young adults with cancer in the medical community, the rhetors in this study argue that young adults justifiably feel excluded from the general cancer community. The cluster analysis indicates that the young adult cancer community grew out the exclusion of young adults in the general cancer community. The founders of both Planet Cancer and Stupid Cancer both write extensively throughout their respective sites on the isolation they felt as young adult cancer patients going through treatment in traditional oncology wards. The following excerpt is from the “welcome” page on the Planet Cancer website:

Planet Cancer was founded by young adults in their twenties; either in the midst of or barely out of treatment for cancer. Not only had they endured the incredible indignity of a cancer diagnosis in what should have been the best years of health, they had also all suffered from an immense void in services and support for young cancer patients. The majority of the other patients they encountered were separated by mental, emotional and physical lifetimes. As young adults with cancer, they felt that they had fallen through the cracks, and they wanted to reach out to others having the same experience.

The prominence of inclusion in this case study, particularly as it relates to creating a community inclusive and welcoming of all young adults with cancer, appears to stem

from the experiences of exclusion the rhetors in this study reported during their own cancer journeys. The young adult cancer community appeared to form as a groundswell movement to fill a need for support and resources that was not being met by the medical infrastructure. The rhetoric of inclusion prominent in the artifacts is born out of the repeated exclusions young adults with cancer experience during their transition from normality to cancer patient and finally to the new normal of survivorship.

### **Summary**

The goal of a cluster analysis is to enable a researcher to discern rhetors' worldview. The results of this study show that influencers in the young adult cancer community view the cancer experience as a series of transitions. The process of transition can be extremely isolating for young adults facing a life-threatening illness at an age when serious health issues are rare. They leave familiar communities and are thrust into oncology wards where their age sets them apart from other patients. Primary influencers in the young adult cancer community combat the isolation they themselves experienced by facilitating the development of a vibrant young adult cancer community. The dominant theme of inclusion is viewed as a solution to mitigate the emotional turmoil young adults with cancer face as they navigate cancer transitions. The rhetors in this study appear to believe that a vibrant, inclusive community of young adults with cancer is the best way to combat the fear, isolation, and resource deprivation associated with the transition from normal to cancer.

## CHAPTER VII

### DISCUSSION

This section synthesizes results outlined in Chapters 5 and 6 by responding to the research questions and discussing findings that emerged from the analysis of the online network mapping and qualitative cluster analysis data presented earlier in this dissertation. The online network analysis research provided data on information flows and the role of influencers in the online, interest-based network that has formed around young adult cancer issues. The qualitative cluster analysis of the content of these influential websites clarifies these findings and reveals the underlying worldview of influencers regarding the needs and concerns of community members. Having experienced cancer myself as a young adult, the analysis is also informed by my position as a six-year young adult cancer survivor. The analysis suggests a number of theoretical implications for the study of influencers in active publics and the practice of relationship building with online publics.

#### **RQ1: How Does Information Flow Through Online, Interest-Based Publics?**

*A small number of influencers from within online interest-based publics play a significant role in information dissemination.*

#### **Information Flow Theory**

This study uses the framework of information flow theory to determine the position and role of influencers in online, interest-based networks. This dissertation was conceived in response to a Bennett and Manheim (2006) article that argued for a return to



a direct-effects model of communication in online communication. One of the few pieces to address the role of influencers in online networks (Bennett & Manheim, 2006), the article posits that web-based communication channels have led to the development of a one-step flow of communication from organizations to publics. Bennett and Manheim (2006) argued that because online communication allows for precise targeting of audience members, organizations are able to affordably and efficiently communicate directly with members of their key publics, effectively eliminating the role of influencer. Instead of broadcasting information to a broad audience, the distribution of content through the one-step flow of communication relies on narrowcasting, which refers to the dissemination of information to niche segments of the population. Using the assumption that two-step flow is the dominant paradigm in communication theory, Bennett and Manheim (2006) refer to one-step communication as a “new paradigm” (p. 228) of communication flow theory.

Contrary to Bennett and Manheim’s (2006) theoretical musings, results of the online network analysis of the young adult cancer community show that a small number of influencers are instrumental in the communication flow of online networks. Information does not appear to flow directly from a producer to a consumer. Instead, the online network analysis of the young adult cancer community clearly shows that active members of interest-based communities primarily reference content from a few influential websites.

Although the results of this study directly dispute Bennet and Manheim’s (2006) claim of one-step information flows in online communities, this study does not fully support traditional notions of either two-step (Katz & Lazarsfeld, 1955; Lazarsfeld,

Berelson, & Gaudet, 1944) or multi-step flow theory (Robinson, 1976). Lazarsfeld, Berelson, and Gaudet (1944) claimed in their explanation of two-step flow theory that "ideas often flow from radio and print to opinion leaders and from these to the less active sections of the population" (p. 151). In two-step flow theory, opinion leaders use primarily interpersonal communication channels to influence individuals who are inactive or marginally active in a particular issue (Lazarsfeld, Berelson & Gaudet, 1944). The development of an interactive web, however, has facilitated the use of multimedia channels to distribute information across a network, exponentially expanding an influencer's potential sphere of influence.

The multi-step flow of information theory (Burt, 1999; Harik, 1971; Robinson, 1976; Weiman, 1982) claims that information flows occur in many different directions and through several iterations of influencers. The rise of social media appears to support the findings of multi-step flow researchers, who argue for the social nature of information dissemination. Instead of relying on traditional mass media entertainment and news resources for information, web users can collect and redistribute information from many different sources including organizational websites, published research, and content from other social media users. On a large scale, the belief in a simple top-down information dissemination system where information flows only from mainstream media content producers to audience members is unsustainable in the currently interactive media environment. Within online, interest-based communities, however, there does appear to be a single group that act as the primary source of information within the network. Instead of mass media though, primary influencers are the dominant source of information in interest-based online communities.

The overarching problem in attempting to apply the one-step, two-step, or multi-step flow model of information dissemination to the communication practices of members of online communities is the inherent assumption in these models that traditional mass media resources are the primary source of information. Within interest-based communities, where members are highly engaged with a topic, media appear to be only one of several sources of information that are introduced and disseminated through the community. This research shows that a core group of primary influencers who act as conduits within the network are more influential in developing shared attitudes and cognitions among members of active publics online than traditional mass media sources are.

With the advent of participatory media, tools that enable web-based mass communication are now widely available, and technology savvy influencers are able to spread information to other web users through an array of social media tools. The network analysis shows that influencers continue to play an important role in communication flows, even in web-based information dissemination, but the role of these influencers in online information flow has changed as communication technologies have advanced. Instead of passing information to an audience through interpersonal communication, online influencers are able to use web-based mass communication channels to distribute contextualized content through a wide network of links. Because modern online opinion leaders have access to mass distribution of messages, they have the tools to exhibit influence within networks of likeminded individuals.

The web facilitates the development of communities and networks that form around psychographic rather than demographic features (Castells, 1996). The

searchability of the web, coupled with the open-access publishing platforms readily available online, facilitate connections between people with different and sometimes obscure interests (Anderson, 2006). Existing models of information flow are not adequate to describe the information dissemination patterns that exist in these interest-based communities that form online. Interest-based communities are heavily influenced by a few key members who act as lynchpins of information dissemination and cultural development. Because influencers dominate communication channels for information dissemination among members of interest-based networks, their power as opinion leaders is of vital concern to those in the field of persuasive communication.

### **Radial Model of Communication Flow**

The online communication patterns of the interest-based community addressed in this study show that a few primary influencers act as essential connecting elements of the network. Key influencers appear to play two primary communication roles within online, interest-based communities. Their first role is of information conduits. Primary influencers collect information from a wide range of sources across the web, organize and collate it, and distribute that information to the community. Because primary influencers are also densely linked to websites outside of the community, they appear to play a prominent role in distributing information developed within the interest-based network to outside websites and users. The second role primary influencers play is one of shared culture creation. In the process of collecting, collating, and redistributing information to the interest-based community, primary influencers contextualize content to adhere to

communities' shared culture. In doing so, primary influencers lead the meaning-making process within interest-based communities.

Figure 8 shows a model of information flow I developed to better explain the communication patterns analyzed in the young adult cancer network. The research in this dissertation showed that influencers, not mainstream mass media sources such as television, newspapers, and radio, are the dominant meaning-makers in online, interest-based communities. Titled the “radial model of communication flow,” the figure offers an alternative way to conceptualize the interactive communication patterns in online, interest-based publics.

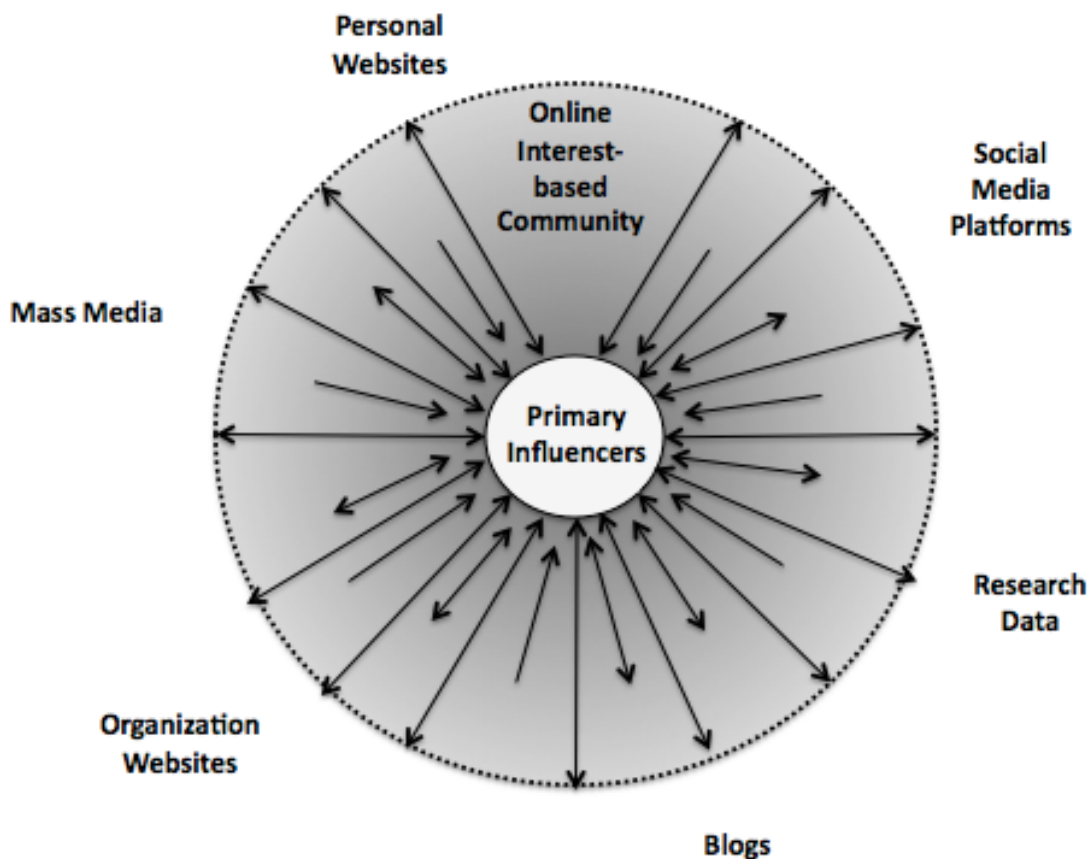


Figure 8: Radial model of communication flow in online, interest-based networks.

The radial model of communication flow positions community influencers at the center of the interest network. These influencers exhibit both inbound and outbound links to websites outside of the online community, such as social networking sites, nonprofit and corporate organizational websites, personal blogs and websites, traditional news publication sites, and primary source research reports such as published surveys and case studies. The primary influencers in this study are also highly interconnected within other web users identified as members of the young adult cancer community, although primarily through inbound links. The radial shading that emanates from primary influencers to the edge of the community represents the flow of influence within online interest-based communities.

Based on the nature of links identified in the online network analysis, primary influencers in online, interest-based networks appear to actively seek out and redistribute information from across the web to the interest-based community. This finding supports the notion that highly engaged publics seek out issue-specific information from a variety of sources (Heath et al., 1995). The influencers in active publics appear to act as key sources of information for members of the online community, with information flowing primarily through influencers to community members. Instead of the top-down communication process assumed by existing models of communication flow, information in online networks appears to flow into and across communities from many different sources, and primary influencers appear to act as both content filters and communication facilitators.

The radial model of information flow seeks to describe information flow in communities that form around a particular shared interest. This study does not attempt to

apply the radial model to information dissemination and processing in more general domains. This study does not invalidate existing models of information flow in all instances; instead this research shows a need to adjust information flow models when looking at online, interest-based communities. Online, interest-based communities, however, are of great interest to public relations and other persuasive communication professionals and it behooves researchers and practitioners in these fields to better understand their communication patterns. The central position of a few key influencers in online, interest-based networks is significant for public relations practitioners looking to engage active publics through the web. The role of primary influencers as collectors, curators, and distributors of information will be examined in greater detail in the next section.

## **Summary**

The network analysis of the young adult cancer community showed that a small number of primary influencers within the young adult cancer network are densely linked with both community members and general resource and cancer information sites. The radial model of communication flow shows the central role of influencers in directing and sharing information within online interest-based networks. The two-step flow model of information dissemination similarly positions opinion leaders as particularly influential within communities, but the radial model of information dissemination refines two-step flow to account for the decrease in prominence of traditional mass media messaging, such as content from newspapers, magazine, television, and radio, in online, interest-based networks. Instead of receiving and modifying information from traditional mass media

sources, online influencers appear to access and share information from a wide range of available sources, positioning them as central to the group information dissemination process.

### **RQ1a. Who Are the Influencers in Online, Interest-Based Publics?**

*Influencers in online, interest-based publics are established members of those publics.*

As the radial model of communication flow shows, primary influencers are the hubs of communication activity within interest communities. Primary influencers in online, interest-based publics are a small number of website managers and content creators who act as central producers, curators, and disseminators of information within the network. The unifying characteristic of primary influencers in online, interest-based communities is that they identify as full members, or insiders, of the group that they influence.

#### **Influencers as Insiders**

The network analysis of the online young adult cancer community showed that five websites were highly influential within the interest network. These websites are chemopalooza.com and baldylocks.blogspot.com, which are personal blogs written by young adult cancer survivors; planetcancer.org and stupidcancer.com, which are young adult cancer resource and community sites; and livestrong.org, a general cancer resource site with extensive content dedicated to young adult cancer issues. Although the personal blog websites are quite different from the cancer resource sites in terms of their layout,



design, and tone, the five websites used as artifacts in this study appear to play many of the same roles.

The blog sites use first person narrative to describe the cancer experience of the individual author. The cancer resource sites also share personal cancer experiences, often through printed interviews and by publishing user-submitted accounts of dealing with cancer as a young adult. Both the blogs and the cancer resource sites offer vetted tips, informational resources, and advice for those dealing with cancer as a young adult. While the cancer resource sites tend to organize these resources by topic, the blog sites tend to provide links to resources as they relate to specific post topics. Also, both the blog and the cancer resource websites provide space for interaction and communication between users. On the blogs, this tends to occur through the comments sections of posts, while on the cancer resource sites conversation tends to flourish on bulletin boards and chat spaces. The last major similarity between the blog and resource sites I discovered over the course of this study relates to the prominence of a site leader from within the young adult cancer community on each of the prominent websites. For two blogs, which essentially chronicle a personal experience, the site leader is obviously the blog author. Each of the cancer resource sites, however, also share the personal experience of a single site leader who dealt with cancer as a young adult.

Early studies of information flow processes found that opinion leaders tend to be similar to those they influence in age, occupation, political beliefs, and other social identifiers (Lazarsfeld et al., 1948). The information in this study indicates that the experience of cancer as a young adult supersedes other similarities, such as economic class, education, and sexual orientation among group members. Despite the fact that there

are more than 100 different types of cancer, the social construct of cancer in general appears to be the dominant identifier for this community. Although the treatment experience of a breast cancer patient will be entirely different than that of a testicular cancer patient, this research indicates that the shared diagnosis of “cancer” is enough to bond people with different diagnoses. The identity as a young adult cancer patient, regardless of diagnosis, treatment process, or prognosis, is a strong linkage for members of the interest-based community in this study.

The most prominent shared feature of these influencers is that the content of each of the websites focuses predominantly on young adult cancer issues. Instead of a mainstream news publication playing the role of distributor and mediator of information, influencers from within the interest-based community appear as both collectors of and sources for information on the core issue that bonds the online public.

The five websites in this study were identified as highly influential because of the large number of inbound links they receive from other members of the young adult cancer community. Based on these findings and previous research into interest-based networks, influence in online environments appears to be determined primarily by community support. In line with early research on two-step flow, “the opinion leader is influential at certain times and with respect to certain substantive areas by virtue of the fact that he is ‘empowered’ to be so by other members of his group” (Katz, 1957, p. 68).

The influencers in this study are experiential cancer experts. Formal opinion leaders, such as medical practitioners and representatives of health organizations, gain expertise through formal training and credentialing processes. Online influencers in the young adult cancer community are trained and credentialed through informal processes,

but that is no way diminishes their role as experts within the young adult cancer network. Instead, this research suggests that that experiential expertise is valued above credential expertise within the community. The cluster analysis showed that young adult cancer patients valued their relationship with individual medical professionals, but viewed the medical community in general as largely ignorant of young adult cancer issues and concerns. The participatory nature of online communication appears to facilitate the development of powerful informal opinion leaders who are extremely influential within web-based communities.

The results of the cluster analysis performed using the influential websites as artifacts lends credence to the conclusion that influential members of the young adult cancer community are influential primarily because members of the interest-based public recognize them as such. Instead of undergoing a more traditional credentialing process such as collecting degrees or assuming job titles, online influencers are considered authentic because of their community presence and participation. The research demonstrates that community members seem to perceive experience as a young adult cancer survivor as a required credential for influencers within the online young adult cancer community.

### **Opinion Leaders of Opinion Leaders**

This research found that primary influencers in online networks play a more active role in information flow than that normally attributed in two-step or multi-step flow theories. The role of primary influencers does, however, appear to share many characteristics with Katz's (1957) definition of high level opinion leaders who exist

within networks of influence. The primary influencers in online active publics appear to act much as “opinion leaders of opinion leaders” (Katz, 1957, p. 73) do in organized publics.

Members of interest-based communities are already engaged in an issue and therefore are likely to act as influencers to peers from outside the community (Lazarsfeld et al., 1948). The primary influencers in an online community act as higher-level opinion leaders within the community. Katz and Lazarsfeld (1955) produced a profile in the 1955 Decatur study of decision-making in marketing, fashions, movie-going and public affairs that addressed the role of opinion leaders of opinion leaders and found that primary influencers were unique across the following key dimensions: “(1) the personification of certain values (who one is); (2) competence (what one knows); and (3) strategic social location (whom one knows), which defines who is inside or outside a group” (Katz, 1957, p. 73). These characteristics of high-level opinion leaders are commonly used to demonstrate official credentialing in formal opinion leaders, but this study indicates that even through informal credentialing processes primary influencers exert a great deal of authority in online, interest based networks. The findings of this dissertation indicate that informal opinion leaders are replacing, or at the very least heavily supplementing, formal opinion leaders as influencers in active publics. The following sections discuss these dimensions in relation to the young adult cancer community case study.

**Personification of values and competence.** The rhetors behind each of the websites identified as primary influencers in the young adult cancer community claim to understand young adult cancer issues because they have experienced them. Even the organizational websites Planet Cancer, Livestrong, and Stupid Cancer feature prominent

cancer survivors who personify the values of the young adult cancer community. The blog Chemopalooza is written by a woman who was treated for Hodgkin's disease in her early 20s, and Baldylocks is written by a woman who was diagnosed with Acute Myelogenous Leukemia when she was 33 years old. Heidi Adams, the founder and executive director of Planet Cancer, experienced cancer when she was diagnosed with Ewing's sarcoma at age 26, and the Stupid Cancer organization was founded by Matthew Zachary, who was diagnosed with pediatric brain cancer when he was 21. The founder and spokesperson of Livestrong, cycling legend Lance Armstrong, was diagnosed with stage three testicular cancer at the age of 25.

Given the nature of their websites, the authors of Chemopalooza and Baldylocks are hyper present in the content and texts. Visitors to those sites read about the authors' experiences as much as they read about young adult cancer issues. It is significant, however, that the young adult cancer resource sites also prominently feature leaders with young adult cancer experience. Adams, Zachary, and Armstrong all maintain very visible presences on their respective websites. Livestrong.org, planetcancer.org, and stupidcancer.com all dedicate sections of the website to sharing the experiences of young adults with cancer through personal reflection pieces submitted by users. The results suggest that those who are most influential to members of the young adult cancer community are not medical professionals, news organizations, online medical sites such as WebMD, or cancer advocacy groups; they are actually members of the community themselves.

**Competence.** The cluster analysis showed that the young adult cancer community is repeatedly referenced as being "unique." The rhetors in this study imply that for

individuals to “know what it’s like” they must have experienced cancer as a young adult. The transitions young adults with cancer experience provide them a store of knowledge that can only be gained through experience. The young adult cancer community is inclusive in the sense that any young adult with any kind of cancer diagnosis is eagerly welcomed; but it is exclusive of anyone who has not experienced cancer. The cluster analysis indicated that the rhetors believe the only way to gain the knowledge necessary to participate as a member of the young adult cancer community is to experience cancer—any kind of cancer—first hand.

**Strategic social location.** Primary influencers in the online, young adult cancer community are highly networked, both within the community and with information sources outside the community. This is evidenced both by the online network analysis, which showed primary influencers as central to network communication processes, and the cluster analysis, which showed that primary influencers value inter-community and extra-community relationship building. The cluster of terms related to the key term “community” indicate that the rhetors view the young adult community as a necessarily separate construct within the general cancer community. Several of the primary influencers provide space on their websites to facilitate connections among young adults with cancer. The rhetors appear to believe the connections among young adults with cancer are vital to building a vibrant young adult cancer community.

Primary influencers also encourage members of the young adult cancer community to act as advocates to people outside the community. By providing advocacy resources and advice, primary influencers in the young adult cancer community prepare community members to disseminate information outside the network. Not only do

primary influencers facilitate networking within the online, interest-based community, they also enable members to build strategic connections with groups outside of the community.

### **Summary**

The primary influencers in online, interest-based communities appear to hold the role of opinion leaders of opinion leaders. This conclusion is based on research showing that primary influencers within the online young adult cancer community exhibit the personification of certain values, competence, and strategic social location indicative of opinion leaders of opinion leaders (Katz, 1957). This research indicates that influencers in online, interest-based communities are first and foremost members of the community. Membership in the online young adult cancer community is restricted to those who have experienced cancer. Primary influencers appear to believe that competence in the topic of cancer in young adults can only be gained through experience. In other online interest groups, earning credibility as a member of a group is not a medical distinction but still likely involves showing one understands and appreciates the needs and concerns of the group. Primary influencers act as network hubs for members of the interest-based community, as well as conduits to external communities. Part of the role of primary influencers appears to be to prepare community members to advocate on behalf of the group to people outside of the interest-based network.

### **RQ1b. What Role Do Influencers Play in Online, Interest-Based Publics?**

*Influencers in online, interest-based publics are critical to community building.*

The role of communication is at the very core of community development, and as highly active communicators, primary influencers are critical to the community development process. As Burke (1969), whose thought informs the cluster analysis process, wrote, “Rhetoric is essential in bridging the divisions of society” (p. 211). The results of this dissertation demonstrate that primary influencers in online, interest-based communities are highly networked, sharing information over a massive web of links and connections. They are at the center of the communication, and therefore the community building and shared meaning-making processes, of online, interest-based publics.

### **Communication As Culture**

Communication is commonly understood through the metaphor of transmission; messages are assumed to move from one person to another like a ball being passed back and forth (Carey, 2009). But the results of this research indicate that the transmissive process alone is not enough to explain the communication processes that take place in online, interest-based networks. This is why I used both online network analysis and qualitative cluster analysis to study the online young adult cancer community. While network analysis is helpful in showing information dissemination processes, the cluster analysis illuminated the meaning-making process occurring within the online community. The results of the cluster analysis show that primary influencers play the role of meaning-makers in interest-based publics, leading to a shared culture within the community.

According to Carey (2009), “a ritual view of communication is directed not toward the extension of messages in space but toward the maintenance of society in time; not the act of imparting information but the representation of shared beliefs” (p. 15).



Within the communication as ritual model, communication is a culture building practice to construct and maintain meaning within communities. The study of communication within publics is inextricably tied to understandings of culture, because without communication there is no shared meaning. Burke (1969) described communication as a ritual process through which cultural norms can be reinforced and challenged. Primary influencers do more than simply modify messages from a monolithic mass media entity; they are central to the meaning-making process happening within interest-based communities. Influencers define and redefine the shared cognitions within a public.

### **Influencers' Role in Developing Shared Cognitions**

A Burkean cluster analysis was used to examine the texts in this dissertation because the method is particularly well suited to determining, comparing, and examining rhetors' worldviews (Foss, 2004). The research in this dissertation showed that existing models of information flow, a strain of research entrenched in the dominant paradigm of media as transmission, does not fully describe the information processes within the online young adult cancer communities. To provide a full picture of communication processes in online, interest-based networks, the process of communication must be understood through a rhetorical model.

Without clear geospatial boundaries, online communities appear to depend on shared cultural constructions regarding a particular interest or topic to develop a cohesive community structure. Communication within the young adult cancer community is both a way to distribute information and a process of contextualization of the cancer experience. As about 7,000 young adults are diagnosed with cancer each year; the online young adult

cancer community has a constant influx of new members. The primary influencers identified in this study appear to act as guides for new members, introducing them to tone, meanings, values, and concerns of the young adult cancer community.

Among primary influencers within the young adult cancer network, the key terms “hair,” “death,” “normal,” and “community” shoulder an enormous burden of multiple meanings. Hair loss, for example, is at a very basic level a common side effect from chemotherapy treatment, but it is also a physical manifestation of the transition young adults experience as they leave their normal life behind and fully engage as a cancer patient. Through their frequent discussions of hair and resources designed to help patients cope with hair loss, primary influencers espouse the idea that mourning the loss of hair is a thoughtful process of accepting illness and not a result of petty vanity.

The cluster analysis of key terms used by influencers in the young adult cancer community shows the power of influencers to create shared dominant meanings within an interest-community, as well as challenge perceived understandings. Burke (1966, 1967, 1969) claims that language and shared use of symbols is the primary way that meaning is created within a network. For example, the cluster analysis of the term “normal” showed that cancer is often referenced as the antithesis of normal, which can be incredibly isolating for young adults. Influencers in the young adult cancer community, however, tout the presence of a strong and supportive community of young adults with cancer. They subvert the assumption that cancer cannot also be normal and reference the development of a “new normal” for young adults who have experienced cancer. The use of language, such as the author of baldylocks.blogspot.org coining the phrase “normalish,” is one way the primary influencers in this study develop shared meaning,

but there are other ways the online influencers in the young adult cancer community shape network culture.

The cluster analysis shows that primary influencers often use humor when discussing the cancer experience. Irreverent discussions of cancer, which dominate the virtual young adult cancer community (Stansberry, 2008), are in direct contrast to the historically acceptable way of talking about the disease. The influencers in this study appear to recognize that cancer has customarily been spoken of in reverent tones befitting its stature as a feared and vile illness. When actually going through the treatment and survivorship process, however, the rhetors appear to share the belief that it is acceptable and even healthy to use cancer humor. The extensive use of humor by the primary influencers in this study sets a tone for acceptable cancer discussion throughout the community.

The recognition of hair loss as a powerful transition instead of a physical change, and the use of humor to broach the subject of cancer, are examples of ways shared meaning within the young adult cancer community sets the community apart. By refusing to adhere to the norms concerning cancer, the young adult cancer community exhibits evidence of a distinctive culture that exists separate from the general cancer community. While traditional communities have public locations like coffee shops, schools, town halls, and libraries where members can gather, engage in conversation, and strengthen community bonds, online communities are largely reliant on virtual spaces for community building. Primary influencers provide space for and facilitate community discussion and interaction around a shared interest. This function is particularly important in online communities because without geospatial ties, online networks rely on

maintaining consistent communication around a shared interest for community development.

### **Influencers as Boundary Spanners**

The transmissive paradigm and the ritual view of communication are often presented as mutually exclusive (Carey, 2009). The research in this study shows, however, that the transmissive and ritual views can be applied in tandem to describe communication practices in online, interest-based networks. Information flow and cultural meaning-making both contribute to understanding the role of influencers as boundary spanners.

The dense connectivity of primary influencers within the young adult cancer community indicates they play a major role in developing a shared network culture. Their connectivity with websites on the periphery and outside of the young adult cancer community indicates that these same influencers also introduce ideas into the community and distribute the group's shared culture outside of the community. Primary influencers in interest-based online communities appear to play a boundary-spanning role, collecting and distributing information within the community and exporting it from the community. This process, which was first identified through the online network analysis research, can be further understood through a close look at the cluster analysis of the key term "community."

The primary influencers in the young adult cancer community reference distinct community boundaries. The texts position the young adult cancer community as a separate entity from the larger cancer community, and young adults with cancer

frequently discuss the segregation of cancer, which isolates them from their pre-cancer social networks. Yet the analysis of the term “community” indicates that the rhetors support opening boundaries between communities. The Livestrong website, for example, provides cancer advocacy resource kits to encourage young adults with cancer to share their unique cancer experiences with groups from outside the cancer community. The organizations behind the websites [planetcancer.com](http://planetcancer.com), [stupidcancer.org](http://stupidcancer.org), and [livestrong.org](http://livestrong.org) all show evidence of supporting strong community development among young adult cancer survivors, but they also encourage members to engage outside that community with the general cancer community, larger medical community, and personal social networks.

The finding that online influencers act as boundary spanners in web-based communities is particularly relevant to the practice of public relations because boundary spanning has traditionally been one of the roles played by public relations practitioners. This research suggests that primary influencers are supplementing or perhaps even supplanting public relations professionals in online, interest-based networks. The journalism industry has found it difficult to stay relevant and profitable in Web 2.0 environments, but the public relations profession has largely seen social media as a channel to extend its reach. The results of this study, however, indicate that the public relations industry may face similar competition from citizen practitioners.

Primary influencers in online communities are far more than message disseminators; they facilitate relationship building among community members and with groups outside of the interest-based network. The transmissive model of communication on its own does not translate well to the interconnected nature of online communication

practices. As the hubs of communication within online interest-based networks, primary influencers are key to the construction of shared meanings within the community.

**RQ2: What Are the Implications of Information Flow in Online, Interest-Based Networks for Public Relations Practitioners?**

*To effectively build relationships in online, interest-based publics, public relations practitioners must exude authenticity.*

The results from this dissertation show that primary influencers in online, interest-based networks define the criteria for inclusion within a community. The finding that primary influencers in the young adult cancer community are also credentialed members of the community is highly significant to the practice of relationship building with members of online, interest-based networks. Primary influencers in online networks are both instrumental to the development of shared culture and conduits between the community and outside information sources. Just distributing content through social media, even if the platform used is highly specific to a target audience, is not enough for public relations practitioners looking to build relationships with key publics. The process of communication is not just transmissive; it is ritual as well.

The author of Chemopalooza dedicated a full post to explaining why public relations pitches were not welcome. In the post she wrote,

***Good News:*** If you're dealing with the hodge and you've got questions for me, I'm happy to help! If you just want to tell me my blog inspired you or helped you through a difficult time - email me, I'd love to hear that!

***Bad News:*** But... if you want me to help your client, I probably don't have the time or interest to help.

This rhetor used her blog to send a clear message that the approaches used by public relations practitioners are both unwelcome and unsuccessful. Public relations practitioners cannot expect to jump into an established community and contribute content. Instead, public relations practitioners must work to learn the shared community culture and develop trust and rapport with primary influencers within communities of interest.

Individuals who blog about young adult cancer issues have a huge array of online information sources they could reference as valuable influencers. But instead of singling out news sources that cover cancer issues, nonprofit healthcare organizations, medical practitioners, research journals, corporate websites, or government health data, members of the online young adult community in this study identified a handful of primary influencers who actively work toward the development and maintenance of the interest-based network. For public relations practitioners to gain influence in active online publics, they must consider the position and values of the primary influencers.

### **Influencers as Gatewatchers**

To understand how to most effectively develop relationships with primary influencers in online communities it is helpful to examine how influencers interact with organizations outside of the interest-based network. This study shows that influencers in online communities perform a gatewatching function, in which they find, collect, collate, and redistribute information throughout the network. Bruns (2005) developed the concept of gatewatcher to describe the information collection and redistribution role played by highly engaged web users. Gatewatchers are individuals who sort through the millions of

messages available in our hypermediated world and organize and redistribute what they consider to be relevant and valuable messages to a particular group (Bruns, 2005).

Both the online network analysis and the cluster analysis discussed in this dissertation show evidence that primary influencers in the online young adult cancer community play a gatewatching role. The online network analysis showed that primary community influencers are densely interlinked with members of the interest-network, indicating that they are valued sources of information for members of the online young adult cancer community. They are also interlinked with sites on the periphery of and outside the community, indicating that they play a gatewatching function, acting as channels for information into and out of the community.

Results of the cluster analysis support the finding that primary influencers act as information leaders within interest-based networks. All of the websites identified as highly influential within the online young adult cancer community publish content and links from outside the network. The cancer resource organizations, Planet Cancer, Stupid Cancer, and Livestrong, also provide space for members of the community to share information and resources from across the web through discussion boards and shared blogs. This indicates that primary influencers both act as gatewatchers themselves and provide web space for community members to participate in the information collection and distribution process.

Primary influencers are largely responsible for collecting and distributing information produced by those not involved in the network. Public relations practitioners looking to influence people engaged in a particular issue or interest will find primary influencers instrumental in affecting attitudes among interest-based community members.



These findings emphasize the need for public relations practitioners to identify and build mutually beneficial relationships with influencers in online, interest-based communities.

### **Authenticity in Social Media**

Public relations professionals judge strength of influence in online networks by the number of connections influencers have within a network, their participation level, and frequency of postings (Gillin, 2008). These processes are in line with the technique used in this study to first identify online influencers, namely number of inbound links from the interest network and network centrality, both measures of strategic social location within the online young adult cancer community. But the identity and role of primary influencers in interest-based networks extends far beyond a simple measure of connections and communication frequency. Primary influencers define the perimeters of a community (Katz, 1957). They are instrumental in developing shared culture within interest-based communities and facilitate communication among members. First and foremost though, primary influencers engage the community because they are members of the community themselves.

Individuals who are active in online publics appear to value authenticity in online communications. Authenticity is subjective and contextual and claims of authenticity, therefore, depend on the shared values of a community (McLeod, 1999). This can create difficulties for public relations practitioners attempting to engage a community without understanding their shared sense of the authentic. As Molleda (2009, p. 95) writes, “authenticity claims must capture the experiences, aspirations, and expectations of the

involved segment of society that organizations aim to engage; otherwise, a clash a values and beliefs may occur and the strategic communication efforts may be lost.”

The vast majority of public relations professionals indicate that social media have enhanced public relations practice (Wright & Hinson, 2009f), but there is little empirical evidence showing that social media in public relations is actually an effective tool for relationship-building between organizations and publics (Taylor & Kent, 2010).

Vorvoreanu (2009) suggests that public relations professionals must first understand and acknowledge an interest-based community’s understanding of authenticity within the network before attempting to participate in communication activities. When professional communication activities clash with the needs and purpose of an online public, it is highly unlikely that they will be successful at building meaningful relationships within the community.

### **Public Relations Practitioners as Community Evangelists**

One way that public relations departments are attempting to earn authenticity in online communities is by hiring existing online influencers to advocate on their behalf in interest-based networks.

Several corporations have invested in “evangelists” who have been hired to act as advocates for an organization or product in the last decade. Yahoo, Microsoft, Sun Microsystems, and Dell have all employed individuals who hold some variation on the title “technology evangelist.” For example, Jeff Barr started working for Amazon in 2002 as a software developer and currently works as Amazon’s Web Services evangelist. Barr builds relationships with entrepreneurs and software developers through speaking events

and informational communication pieces. He is also the main author of the Amazon Web Services blog at [aws.typepad.com](http://aws.typepad.com), which has become an extraordinarily popular source for developer news and information. The process of hiring experts like Barr in their respective fields to act as evangelists for a particular product or service, already popular in the area of technology, is extending beyond just high tech industries. Brian Solis, principal of the new media marketing group FutureWorks, has argued for a change in the public relations profession to better address the type of communication that works well in Web environments.

In reference to the role of influencer within web-based communities, Solis posed the questions, “what if PR actually used and believed in the products or services they represented?” and “what if PR became the people participating in online communities among the very people they were trying to reach?” (Solis & Breakenridge, 2009, p. 34). This dissertation supports Solis’ thesis that online communication practices are leading to a need for greater authenticity in public relations practice.

My research suggests that the most effective way for public relations practitioners to build relationships within online, interest-based communities is to join and become authentic members of online interest-based communities. This participatory view of public relations privileges authentic interactions in social media communications. Because true authenticity is not always an option—most public relations professionals are not young adult cancer survivors for example—the public relations industry must make a sincere effort to exhibit authenticity in online communications.

Some public relations organizations that hire individuals who are already influential in online communities of interest are essentially buying authenticity. In public

like the online young adult cancer community, authenticity is earned through a shared health experience. While hiring a young adult survivor to participate in social media on an organization's behalf is one way public relations professionals can earn credibility within a network, assuming the representative adheres to the community's shared values and culture, it is not always possible or profitable to pursue authenticity this way.

When true authenticity is not an option for public relations professionals, exuding authenticity by showing an understanding and respect for the group's concerns and needs is a way to build rapport within interest-based communities. For example, this study showed that lack of visibility for young adult cancer is a major shared concern in the young adult cancer community and members of the group are advised to advocate on their own behalf. A public relations practitioner who designed a campaign around working with the group for greater visibility of young adult cancer issues would likely be received quite favorably. A campaign designed to educate young adult survivors on the importance of diet and exercise to prevent a recurrence would likely be a much more difficult sell. Although survivorship care is an issue of concern within the young adult cancer community, it is not a primary cultural issue. Furthermore, the cluster analysis indicated that young adults in the cancer community tend to respond favorably to opportunities for involvement in community issues but are suspicious of information and advice coming from outside their network.

One way to ensure social media public relations campaigns exude authenticity is to engage primary influencers in the public relations planning and campaign implementation processes. This research indicates that a participatory model of public relations, one which facilitates partnerships between online influencers and practitioners,

could be an effective means to build relationships through social media. Kent and Taylor (2002) wrote that privileging dialog with publics it is both a both an ethical and practical imperative for public relations professionals. The findings of this study support the assertion by Kent and Taylor (1998) that dialogic communication is particularly important in building relationships through the web. The results of this study show that individual influencers are extremely important to the communication and meaning-making processes in online, interest-based networks and building interpersonal relationships are a key component of dialogic public relations practice. For productive dialog in public relations members of publics must be central to practice, not “others” to be addressed (Pearce & Pearce, 1998).

By viewing publics as active participants in public relations campaigns rather than passive recipients of persuasive communication messages, public relations practitioners facilitate the expression of voices typically marginalized in communication practice (Dutta-Bergman, 2005). Given the concern evident in the young adult cancer community regarding their lack of a voice in the larger medical and general cancer community, influencers in the interest-based public would likely respond positively to participating in public relations campaigns.

Participating in, or at least showing a sincere concern for, an interest-based public’s unique culture is vital to online relationship building, but engaging cultural leaders in campaign development is a way to ensure authentic presences online. This research shows that public relations practice must adjust to prioritize authenticity in online communication practices.

## **RQ2a. Is the Situational Theory of Publics Adequate to Describe Public Formation in a Web 2.0 Environment?**

*The situational theory of publics should be modified to include a subcategory of active publics called organized publics.*

Based on the densely interconnected nature of the online young adult cancer community, and on the efforts of influencers in the community to mobilize members of the network toward advocacy on behalf of young adult cancer issues, the online young adult cancer network mapped in this study appears to exhibit many of the characteristics that define active publics as outlined by Grunig (1978a, 1983, 1997; Grunig & Hunt, 1984). Based on the cluster analysis, members of the young adult cancer community appear highly engaged with the issue of cancer in young adults, they collaborate to overcome constraints, and they view lack of resources for young adults with cancer as a problem. The network analysis indicated that members of the online young adult cancer community access a variety of sources for information seeking purposes, but not all members of the public engage in information seeking and processing to the same extent. Members of the young adult cancer community appear to rely on a few influential members to facilitate communication processes across the network. The question of information flow then becomes, what is the role of these primary influencers in information dissemination within engaged, organized, interest-based online communities.

### **Organized Publics**

Dewey (1927) stated that publics arise when individuals face, recognize, and organize to address a similar problem. In simple terms, issues give rise to publics. The

core definition of publics that is instrumental to the situational theory of publics merits additional study given the nature of online interest-based communities. The analysis of the young adult cancer community presented in this dissertation indicates that online publics can and do communicate and organize around shared concerns or interests. Issues may cause a public to respond, but my research shows that interest-based communities that exhibit characteristics of active publics exist before a particular issue arises.

The following is a hypothetical example to illustrate this point: A major pharmaceutical company decides to increase the price of an anti-nausea drug frequently used to treat chemotherapy patients. The young adult population is likely to be uninsured or underinsured, so this is an issue they are likely to mobilize around. Using the tenets of the situational theory of publics, the pharmaceutical company may well be able to predict that the price increase could give rise to an active public of young adult cancer patients. The fact that a highly engaged community of young adults with cancer already exists through a densely interconnected web of online resources, however, will likely affect the speed and efficiency with which the community can respond to the price increase. Also, because a number of young adult cancer patients already participate in a well-defined community dedicated to young adult cancer issues, the public already has established relationships with media, government, and donor representatives. As it currently stands, the situational theory of publics does not account for publics that organize around general interests prior to the development of specific issues of interest to that community.

Based on the findings in this dissertation, I recommend the situational theory of publics be modified to include organized publics as a subset of active publics. Organized publics are groups of individuals who frequently and consistently communicate on the

subject or share a particular interest or concern. While active publics are likely to develop shared cognitions, organized publics address new issues with previously established shared cognitions and a common culture. While members of activist publics are aware of a problem and mobilize despite existing constraints, organized publics have already set the groundwork to mobilize by addressing potential constraints. Organized publics are characterized by a core group of primary influencers who promote ongoing communication within the interest-based community. Organized publics are of particular concern to public relations practitioners because they can mobilize more quickly and effectively than traditional active publics around issues of concern.

The young adult cancer community exemplifies the process of addressing constraints by training members of the network to advocate effectively when the need arises. Several of the primary influencers in the online young adult cancer community post downloadable guides for community activism on their webpages, and the organizations Planet Cancer and Livestrong host daylong seminars at locations across the country to teach young adults with cancer about advocating on behalf of the community. The members of the online young adult cancer community not only have the potential to become activists, they have easy access to advocacy information and tools through the primary influencers.

### **Activists in Organized Publics**

The rise of online interest-based networks makes the study of publics imperative for scholars interested in modern public relations practice because the ease of shared cognition creation through inter-public communication could hasten the creation of



activists moved to take action on an issue. L. Grunig (1992) describes activists as “two or more individuals who organize in order to influence another public or publics through action that may include education, compromise, persuasion tactics, or force” (p. 504). The success of attempts to change organizational behavior stems from activists’ ability to access resources such as funding, public support, media resources, and political leverage (Heath, 1988). Although activists who attempt to influence how organizations behave have traditionally found themselves on the lesser end of a major power differential when it comes to accessing resources, the open nature of online communication could change this power dynamic (Coombs, 1998; Coombs & Holladay, 2007). Savvy web users today are able to distribute messages through online mass communication channels, which enables activists to spread ideas across virtual networks (Coombs, 2007). Primary influencers in interest-based networks are of major concern to public relations practitioners because they are highly engaged in issues and have access to powerful communication networks for information dissemination.

The results of the cluster analysis of the term “community” hinted at the role of influencers in leading community members in organized actions. One of the prominent cluster of terms around mentions of community referred to activism. The websites for young adult cancer resource organizations Planet Cancer, Stupid Cancer, and Livestrong all provide materials to aid young adults in advocating on behalf of young adult cancer issues. For example, the second week in April is national Young Adult Cancer Week. For nearly a month leading up to the event, the Planet Cancer and Stupid Cancer websites posted front page content encouraging readers to contact their political representatives and ask for increased financial support for young adult cancer care.

The cluster analysis also revealed examples of calls for direct action on specific issues. For example, in 2008 Planet Cancer published a blog post about a young soldier diagnosed with leukemia during basic training. The soldier was denied medical insurance because his cancer was labeled a preexisting condition. The author of the post called for readers to contact the public affairs office at the training base in question and published its direct phone number and email address. Although the cluster analysis did not reveal the outcome of these calls to action, the very fact that primary influencers in organized publics use their positions to encourage community action underscores their importance to public relations practitioners.

Highly organized members of active publics have already built structured communities with established communication channels and have established a distinct culture. Influencers in web-based organized publics, because they are central to the communication process within the online community, are in a position to immediately launch community action in response to specific issues. These features distinguish organized publics from the latent, aware, and active publics identified in the situational theory of publics and make them of particular concern to public relations practitioners. The situational theory of publics is a useful framework for understanding public development online, but the definition of active publics must be adjusted to include a subcategory of organized publics.

### **Empowered Publics**

The results of this study attribute a degree of power to publics that far exceeds that which Grunig (1997) prescribed in his development of the situational theory of

publics. The situational theory of publics has been criticized for making assumptions about the state of consciousness of publics defined by their relationship to issues without addressing the complex nature of the communication practices that lead to the development of a group consciousness (Vasquez & Taylor, 2001). Over the last decade, theory building work in public relations has shifted away from expansions of excellence theory (Sallot, et. al, 2008) and toward critical-cultural research (Vasquez & Taylor, 2001). Researchers taking a cultural-economic perspective on public relations practices address the meaning-making processes that occur within publics, rather than studying publics primarily in relation to an organization. Within cultural-economic theory, fluid power relations are of utmost importance for understanding publics and their shifting memberships and identities (Gaither & Curtin, 2005) because all identities, including that of organizations, issues, topics, and publics, are constructed within and through discourse (Hall, 1996).

This research shows that a cultural-economic approach to public relations can be used to expand and improve upon the situational theory of publics. Although Grunig was not a cultural theorist, the structure of the situational theory of publics does an admirable job of providing a framework for publics research that has been added to and adjusted over time (Grunig, Grunig, & Toth, 2007). This dissertation contributes to the continued development of the situational theory of publics by using a cultural approach to public relations research to show the power of publics.

Public relations theory recognizes the importance of publics, but as a field of study public relations scholars have not devoted adequate resources to the study of the complex nature of publics. Online interest-based networks are particularly ripe for further

study given their potential to challenge power dynamics and organize around issues of interest to the community.

## **Limitations and Future Research**

### **Online Network Analysis**

The online network analysis data presented in this study show the results of link mapping and a fairly simple application of social network analysis methods. The measures of density and centrality, the two measurements used to map influence in this study, are some of the more basic measures of social network interactions. This project barely scratches the surface of what online network analysis tools can show about the social interactions between members of a community.

In future network analysis studies of online, interest-based publics, I plan to map clustering coefficients to map cliques of information sharing within networks. Clustering coefficient is the measure of the degree to which nodes tend to cluster together within a network graph. It would be interesting to see if, for example, websites addressing particular types of diagnosis tended to cluster together. If shared interest in young adult cancer issues is the dominant shared issue that bonds this community, mapping clustering coefficients could provide insight into what secondary issues may create groups within the young adult cancer community.

It would also be interesting to examine networks for structural cohesion to see how important particular individuals are to the structure of a group. Structural cohesion is a measure of unity in social groups and is defined as the minimum number of actors that would need to be removed to disconnect members of the community. For example, I

would like to determine what the effect of removing the two bloggers identified as primary influencers in the young adult cancer community from the network map would have on the structure of the network. Would the young adult cancer community still have clear paths of communication if the five influencers discussed in this study were removed from the network map? This would provide information on the role of influencers, all of which are young adult cancer resource providers, in creating a cohesive communication network.

### **IssueCrawler**

The raw data for the network analysis were collected using the free online web crawler program IssueCrawler. By using IssueCrawler I automated the process of mapping links between websites. While this allowed me to map a large number of web links in a short period of time, it also removed some of my control as a researcher. IssueCrawler does not recognize every kind of link. For example, if a web producer embeds a link in an image, IssueCrawler will not recognize or map it. IssueCrawler also cannot be programmed to identify links by date. Therefore, a link published within a week of the web crawl will be recorded the same way as a link that is more than a year old. This became a clear issue when the network crawls in this study repeatedly showed the now defunct website [everythingchangesbook.com](http://everythingchangesbook.com) as highly influential within the young adult cancer network. I chose to use IssueCrawler, despite the limitations of the tool, because it enabled a broad search and mapping of links that would have been far too time intensive to record by hand.

This study uses links between websites to indicate information flow among different web users. The presence of links, however, does not necessarily mean that web users access those links. Furthermore, IssueCrawler records and maps links regardless of their location on a website. So, a link placed in a prominent position on a website's homepage is given the same prominence within a network as a link buried on an internal webpage. I chose to use link data collected by IssueCrawler to measure influence because the presence of a link indicates a clear desire on the part of a website producer to share linked content with readers. While IssueCrawler is an excellent tool to provide a broad map of links between websites, it does not account for other possible indicators of influence within links such as position of the link on a site or date that the link was published. The benefits of using a web crawl program to map a large network of links were determined to outweigh the costs in specificity of link data.

### **Cluster Analysis**

The research in this dissertation is not replicable. As a case study, this study of the young adult cancer community shows network connections and patterns of influence at a certain point in time, and my worldview as the researcher informs the findings. Although the results of this research are not broadly generalizable, the number of websites included in the online network analysis and the consistent findings in the study of primary influencer's rhetoric suggest that the results of this study are likely representative of many online communities. The findings from the online network analysis and cluster analysis allow for inferences to be made about patterns of influence in online, interest-

based networks. Further research is needed to confidently extend the claims to all online communities that form around different interests or issues of shared concern.

The members of the young adult cancer community researched in this study are bound by a common interest, but the research does not address major aspects of personal identity such as class, gender, race, or ethnicity. Individuals develop a sense of self by imagining how they appear to others (Cooley, 2004; Goffman, 1983). In attempting to discern the worldview of primary influencers in the young adult cancer community, this study could be enhanced by addressing major cultural constructs that help to shape personal understandings of self. The research in this dissertation indicated that young adults with cancer bonded over their shared identity as cancer patients and survivors. No attempt was made to discern other characteristics, such as gender, race, class, ethnicity, and sexual orientation, that may further bond (or perhaps isolate) members of the young adult cancer community.

### **Directions for Future Study**

Future research into the communication patterns and shared cultural development of online, interest-based communities must incorporate study of the social structures within which these communities develop. Although the percentage of adults in the United States with consistent access to high-speed Internet has risen steadily over the last decade (Pew Internet Research Center, 2011b), members of lower economic means and racial minorities still lag in terms of technological access and expertise (Pew Internet Research Center, 2011a). Future research into the role of influencers in online, interest-based

communities will examine the cultural identity of these key members on online communities.

This research shows that a handful of primary influencers are at the center of information flow in the online, interest-based community that has developed around the issue of cancer in young adults. Further research is needed to determine if the same patterns of influence emerge in different online, interest-based communities. While the case study itself is not replicable, I put forth concepts in this dissertation that can be used to facilitate future studies of information flow in online communities.

The patterns of online communication observed in this dissertation suggest that a transmissive flow model of information dissemination is inadequate to describe the communication activities of members in online, interest-based communities. The finding that information flows from primary influencers, rather than through them, calls into question dominance of mass media as sources of influence interest-based communities. Further study is needed into the information processing role of online influencers. This research indicates that gatewatching, a theory that has been applied primarily to studies of multi-media journalism (Bruns, 2005), could be a useful way to conceptualize the role on primary influencers in online publics. I recommend additional research into the information gathering and distribution processes of primary influencers, perhaps using content analysis, to determine the content sources favored by community influencers. Further study into the ways content is distributed by primary influencers, and how they contextualize content for readers, is needed to refine this study's findings on the gatewatching role of online influencers.



The examination of influencers in an active, online public suggests that the situational theory of publics (Grunig, 1975, 1978a, 1978b, 1983, 1987, 1989, 1992, 1997; Grunig & Hunt, 1984) should be updated to include recognition of organized publics as a sub-group of active publics. Initial research shows that organized publics are likely to organize quickly and effectively as issues arise, attributable to existing communication networks and advocacy support. Additional research is needed to see if the inference that organized publics will respond more quickly and effectively to issues than do general members of active publics hold true in practice. This can be accomplished through additional case studies or perhaps survey data from practitioners who have experienced issue-based activism stemming from organized publics.

This study showed that members of online, interest-based publics respond to community participants who exhibit authentic behavior as defined by the group's shared culture. While this is a significant finding for public relations professionals struggling to build mutually beneficial relationships through social media, further research is needed to determine how exactly public relations professionals can exude authenticity in online communities. To date, public relations firms have taken to hiring Internet users who are already influential in online communities of interest to communicate on behalf of an organization. Further research is needed to determine the effectiveness of this approach to building online relationships and also to see if authenticity can be developed in other ways more in keeping with traditional public relations practices.

This examination of communication processes within an online community dedicated to health issues has opened a number of avenues for future research into online health communications. This case study shows a strong community of patients who

organize around a shared health concern. The findings indicate the emergence of vibrant patient networks sharing information and advice about health issues outside of existing medical structures. Given the tendency of health communicators to ignore the efficacy of patients in their treatment process (Ferguson, 2007), this study shows the need to study the value of peer-support and advice for those with long-term and chronic diseases. Further research is needed into the study of how patients use the web to become empowered in their treatment and recovery process.

### **Conclusion**

In the summer of 2010 I attended a conference on health marketing and communications hosted by the National Centers for Disease Control (CDC). The hot topic at the event, as it is in many areas of persuasive communication both in research and in practice, was the way new media tools are changing the practice of health communication. I estimate that about three quarters of the presenters discussed some aspect of new media in their sessions or poster presentations. Despite the wide range of views on the application of new media in persuasive health communications campaigns, however, nearly every presentation asked the same question: “How can we better use new media to get our message to our health services consumers?”

The health communicators at the CDC conference were focused exclusively on the question of transmitting messages, but the results of this research show that an understanding of the culture of patients and potential patients is paramount to success in social media communications. The young adult cancer community case study indicates that a shared medical diagnosis can be a powerful issue around which disparate

individuals connect online. This research suggests that the rise of e-patients, healthcare consumers who use the Internet to gather and share information about a medical condition of particular interest, are challenging the information status quo in health communication (Ferguson, 2007). Instead of relying on medical professionals and media content as exclusive sources for health information, e-patients such as the young adult cancer patients discussed in this study rely on a broad range of online sources for information about a medical situation or condition. Primary influencers in health-based online communities act as collectors, collators, and distributors of information and resources in health communities. Their role positions them as key influencers for online healthcare consumers.

The health system in general has not responded positively to patients' use of the web to access health information (Ferguson, 2007). Many medical practitioners express concern that web-based communications facilitate the unsupervised exchange of misinformed health information (Ferguson, 2007). The results of this study show that web-based communities are far more than places for healthcare consumers to share information about a disease or condition; they facilitate the development of shared cultures around particular health issues. Online health based communities provide a space for patients to belong during isolating medical processes. The young adult cancer community case study showed that members of online health communities perceive medical professionals as outsiders. Public health officials and professional health communicators are still generally perceived as credible sources of information (Avery, 2010), but this research shows that patients strive to become empowered in their treatment and recovery process through online networking and information sharing. To

facilitate effective online communication through social media, health communication professionals must recognize that the connections afforded by online patient communities do more than provide a space to commiserate; they enable patients to develop self-efficacy and gain control over their disease experience.

The true value of social media to public relations and health communication practitioners is not as a channel to distribute messages to key publics but as a way to learn about the concerns and needs of those publics. This study shows that influence in online, interest-based publics is earned by engaging with a community, not talking to them.

Leonard Saffir, author of several books targeted to public relations practitioners (Saffir, 2000; Saffir, 2007; Saffir & Tarrant, 1993) is widely quoted as saying, “The formulation of a public relations strategy properly begins with *listening*, not *talking*.” This project shows that public relations professionals must do more than just listen—and not just at the start of a campaign, but through every part of the relationship building process. Public relations professionals must observe and engage with online communities before any attempts are made to influence that community. Interest-based publics develop a shared culture. They expect members to exude authenticity as defined by their shared cultural norms. In the cancer community used as a case study for this dissertation, authenticity is achieved through undergoing the inevitable transitions that come with a cancer experience. In other communities, adhering to a shared language, tone, or values; proving expertise in a certain subject area; or providing evidence of offline participation in a certain activity could be ways to exhibit authenticity.

As mass media sources become increasingly fragmented, public relations professionals struggle to communicate with key publics (Kent & Taylor, 2002). Depending on the target audience, a viral video can be just as effective at increasing awareness among a public as an article in the *New York Times* or a lead story on the national nightly news. This fragmentation has led to many public relations practitioners discovering (or rediscovering) the importance of interpersonal communication in public relations (Kent & Taylor, 2001). As interpersonal communication practices are increasingly occurring in hypermediated environments, the public relations profession must adapt with revised strategies and tactics.

Instead of focusing efforts on communicating with key publics through mainstream media sources, public relations professionals should shift their efforts toward research and incorporation of the values and concerns of key publics. At the moment, public relations professionals largely use media relations tactics such as news releases, media advisories, and media events to communicate with active members of online publics. But online communities form around shared issues and concerns, not a desire to broadcast news and information to a broad audience. Members of online communities use media tools to facilitate interpersonal communications publically, but they are not members of the media and should not be treated as such. Online, interest-based publics consist of individuals with a shared passion for a common issue or interest. They may not be formal experts in their topic area, but they have very likely built informal credibility within the community. Members of online active publics expect to be included in communications campaigns, not the target of one-way messaging.

Primary influencers in online communities are tantamount in importance to public relations practitioners looking to build relationships in online publics. Online, interest-based communities depend on a handful of highly influential members for information and leadership. Primary influencers are also harbingers of cultural developments and changes within online publics and therefore valuable resources for public relations practitioners to understand and engage.

In the anecdote I shared in the introduction of this dissertation, I discussed my personal frustration that patients are generally overlooked during health communication conferences. This issue is not unique to publics with a shared interest in health. Publics in general are understudied in public relations, except as they relate to organizational goals (Vasquez & Taylor, 2001). This study of an active e-patient community shows the value of understanding the meaning-making process of an active, online public. This dissertation shows that publics are not just worthy of study; comprehensive examination of interest-based online communities is necessary for successful new media public relations efforts. The public relations industry has a long history of privileging the needs of organizations over the needs of publics. Through online collaboration in interest-based communities, members of active publics are becoming empowered participants in communication campaigns. Online publics are organized, engaged, and passionate; they are poised to bring about change.

The industry has struggled because we devalue the communication activities that occur within and between active publics regardless of organizational concerns. Issues are not the only features that give rise to publics, shared interests do too. Publics form, connect, and develop a shared culture online around interests of common concern. These

groups are of the utmost importance to public relations professionals because they are not only likely to become activists, they have established the tools, relationships, and influence to do so quickly and effectively.

This research provides a solution to the challenges professional communicators face when attempting to build relationships using social media. Both an understanding of communication as message transmission and as ritual process are necessary to successfully work with online, interest-based publics. Primary influencers are key to the information dissemination process within online, interest-based publics, but to build relationships with these influencers, public relations professionals must show they understand and value the culture of a network. It is not enough for public relations professionals to be transparent when communicating with web-based communities, they must also exude authenticity in their online communication efforts.

## APPENDIX

### YOUNG ADULT CANCER BLOGS USED AS SEED NODES

Cancer and Careers	BugginWord
First Descents	Lift Living
Leukemia Lymphoma Society	Me Versus Cancer
Imerman Angels	The Struggle With Cancer
Oncofertility Consortium	The Good Hodgkin's
Tamika and Friends	Life's a Beach
Making Cancer My B*tch	Bits of Myself
Brad's Leukemia Blog	The Cancer Kid
WTF Cancer Diaries	Chris's Thoughts
The B-Cell Blog	The Yellow Diaries
The Journal of a Prizefighter	Writer • Editor • Teacher
The Adventures of BaldyLocks	A Fertility Endeavor
'kin Hodgkin's	Cancerous Capers
My Blood Hates Me	Cancer Diary
Mine is The Year of Living Dadlessly	Chicken Soup for the Cancerous Soul
Cancer: A Spiritual Journey	Silhouette Of You
Kill It In The Butt	Anastasia's Cancer Experience
Leukemia & Lymphoma Resources,	Gonna Kick Lymphoma's @ss
Articles, Reports, Trial Updates	My Journey Battling Cancer
Inside Steve's Head	Katie's Hodgkin's Journey
Life Comes at You Fast!	Jug Thug
Surviving Cancer Surviving Anything	Average Guy Hits The Road
How You Live	In My Life
(Fuzzy) Cancer Socks	Team April
Nicole Cowen	Margaret Mead Was Right
Eyes Peeled, Always	Mother Thoughts
Change is Possible	Welcome To The Dallehouse
Nobody Gets Out Of Here Alive	Living It Up!
Life, Drama and Chocolate	My Breast Cancer Blog
Family Life, Business, Surviving	Radiation Daze
Cancer, Traveling	Kicking Cancer In The Pants, Sir!
Back Off Cancer!!	Chemo Babe
35 and MDS	Every Day I Am Killing Cancer
The GPS Geek	My Journey To Get New Boobs
Chronicles of a Cancer Survivor	Dina's Boob Blog
The Beginning of a Journey	Keep Going Maria!
B-R-O-K-E-N-M-A-N	CureToday.com
Kiss My Bald Head	Mel's Cancer Warrior
Chemopalooza	Living With Cancer
The Cancer Dancer	Phoenix Rising
Autumn in January	Hidden Dragons



My Relationship With Cancer  
Red's daily dish  
To Keep You, A Breast  
You Did What?  
The Cancer Culture Chronicles  
The Sweet Mango Ride  
Bena Roberts  
Caroline's Breast Cancer Blog  
Life After Cancer  
Angie's Blog  
One Journey Back  
Two Hands...  
Breast Lump in the Road  
Cuck Fancer  
Sharing My Cancer Crapness  
I Kicked Cancer's Ass  
The Colon Chronicles  
The Cancer Documents/em>  
What's Up Your Butt?  
My Cancer  
Michelle WILL Win Against Colon  
Cancer  
Kickin Cancer's Butt  
Live Fit and Sore  
Cancer is So Funny  
Ray's Blog  
Soayacs: Stories of a Young Adult  
Cancer Survivor  
plasticcastles  
What's Going On  
Shannon's Page  
Kicking Cancer's Arse  
Life with(out) Ted  
They Call Me Galvez  
Especially Heather  
Ciao Cancer!  
Fried Pink Tomato  
The Eye Of The Storm  
Wonky Eye  
A Little Limp Goes a Long Way  
My Brain Tumor  
Jen's Road To Remission  
Cancer, Life, and Me  
The Liz Army  
Sawatdee

Life is like a sandwich...enjoy the big  
bites.  
i am naomi's brain  
Turquoise Gates  
CaringBridge  
See Emily Play  
Shawn's F.A.C.T.S  
Black Gyrl Cancer Slayer  
Why Aren't They Playing Reggaeton? I  
have Cancer!  
A Single Cell  
Whispers of Ovarian Cancer  
Redheaded Bald Chic  
Lynn's Fight Against Prostate Cancer  
Sam and Leslie  
Journey to Medical School and Beyond  
Should I Shave it?  
Jaelyn, Unclassified  
The Road To Repair  
"Happy and Healthy" A Cancer Free  
Living Blog  
Obsessed With Life  
Cancer Ate My Foot  
I've Still Got Both My Nuts  
Miss Melanoma  
Happily Ever After  
Hope and Jason  
My Blog  
The One Nut Wonder  
The Audacity of Pope  
Scarys Lunatic Rants  
Death By Lettuce  
The Adventures And Misadventures  
Of One Miss Kelly Bergin  
Bacon's Boots Blog  
My Thyroid Story  
Too Much On Our Plait  
This Crazy Miracle Called Life  
Cancer Can Bite Me  
Multiple Myeloma For Dummies  
After Cancer, Now What?  
Hope. Love. Run.  
My Journey  
OncoLibido  
BRICKS for Young Adults  
Tales from the Upper East Side

We Are Wonder Women!  
Ain't Nuthin' but a B Thang  
Umm, that wasn't the diagnosis you  
originally gave me....  
Everything Changes  
Women With Cancer  
Chemo≠Therapy  
Somewhere in Between  
Not Quite Tom Riddle's Diary  
100 Cancer Resolutions

The Small Story  
In Pursuit Of A New Strategy  
For The War On Cancer  
The Cancer Assassin  
The Boitson's  
The Carcinista  
Dan's Unusual Adventure  
Life, With Cancer  
Waeger Will Win  
Crazy Widow

## REFERENCES CITED

- American Cancer Society (2007). *Cancer statistics 2007: A presentation from the American Cancer Society*. Retrieved May 25, 2008 from the American Cancer Society Web site: [www.cancer.org/downloads/STT/Cancer\\_Statistics\\_Combined\\_2007.ppt](http://www.cancer.org/downloads/STT/Cancer_Statistics_Combined_2007.ppt)
- Anderson, C. (2006). *The long tail: Why the future of business is selling less of more*. New York: Hyperion.
- Avery, E. (2010). The role of source and the factors audiences rely on in evaluating credibility of health information. *Public Relations Review*, 36(1), 81-83. 36 doi:10.1016/j.pubrev.2009.10.015.
- Avery, E., Lariscy, R., & Sweetser, K. D. (2010). Social media and shared-or divergent-uses? A cororientation analysis of public relations practitioners and journalists. *International Journal of Strategic Communication*, 4(3), 189-205.
- Barzilai-Nahon, K. (2009). Gatekeeping: A critical review. *Annual Review of Information Science and Technology*, 43, 433-478.
- Basille, D. (2009). *Social media influencers are not traditional influencers*. Retrieved July 30, 2010, from <http://www.briansolis.com/2009/11/social-media-influencers-are-not-traditional-influencers>
- Bennett, T. (1982). Theories of the media, theories of society. In M. Gurevitch, T. Bennett, J. Curran & J. Woollacott (eds.) *Culture, society and the media* (pp. 10-55). London: Methuen.
- Bennett, W., & Manheim, J. (2006). The one-step flow of communication. *The Annals of the American Academy of Political and Social Science*, 608(1), 213-232.
- Berkowitz, S. D. (1982). *An introduction to structural analysis: The network approach to social research*. Toronto: Butterworths.
- Botan, C. H., & Hazleton, V. (2006). Public relations in a new age. In C. H. Botan & V. Hazleton (Eds), *Public relations theory II*, (pp 1-18). Mahwah, NJ: Lawrence Erlbaum Associates.
- Broom, A. (2005). Virtually healthy: The impact of Internet use on disease experience and the doctor-patient relationship. *Qualitative Health Research*, 15, 325-345.
- Bruns, A. (2005). *Gatewatching: Collaborative online news production*. New York: Peter Lang Publishing.

- Bruns, A. (2007) Methodologies for mapping the political blogosphere: An exploration using the IssueCrawler research tool. *First Monday* 12(5). Retrieved January 12, 2012 from [http://firstmonday.org/issues/issue12\\_5/bruns/index.html](http://firstmonday.org/issues/issue12_5/bruns/index.html)
- Burke, K. (1966). *Language as symbolic action: essays on life, literature, and method*. Berkeley: University of California Press.
- Burke, K. (1967). *The philosophy of literary form; studies in symbolic action*. Baton Rouge: Louisiana State University Press.
- Burke, K. (1969). *A rhetoric of motives*. Berkeley: University of California Press.
- Burt, R. S. (1999) The social capital of opinion leaders. *Annals of the American Academy of Political and Social Science*, 566, 37-54.
- Cain, M. M., Sarasohn-Kahn, J., & Wayne, J. C. (2000, August). Health e-people: The online consumer experience. Institute for the Future, written for the California HealthCare Foundation. Retrieved April 21, 2011 from <http://www.chcf.org/publications/2000/08/health-epeople-the-online-consumer-experience>
- Carey, J. W. (2009). *Communication as culture: Essays on media and society*. New York, NY: Routledge.
- Castells, M. (1996). *The rise of the network society*. Malden, Mass: Blackwell Publishers.
- Centers for Disease Control (2009). 10 Leading causes of death by age group, United States – 2009. Retrieved April 11, 2012 from <http://www.cdc.gov/injury/wisqars/LeadingCauses.html>.
- “Change in Internet access by age group 2000 – 2010,” (2010). *Pew Internet and American Life Project*. Retrieved September 3, 2011 from <http://www.pewinternet.org/Infographics/2010/Internet-access-by-age-group-over-time-Update.aspx>
- Chau, M., & Xu, J. (2007). Mining communities and their relationships in blogs: A study of online hate groups. *International Journal of Human-Computer Studies*, 65(1), 57-70.
- Cooley, C. H. (2004) The self as sentiment and reflection. In S. Cahill (Ed), *Inside social life: Readings in sociological psychology and microsociology*, (pp 26-30). Los Angeles, Calif: Roxbury Pub. Co.
- Coombs, W. T. (1998). The Internet as potential equalizer: New leverage for confronting social irresponsibility. *Public Relations Review*, 24, 289-303.

- Coombs, W. T. (2007). Protecting organization reputations during a crisis: The development and application of situational crisis communication theory. *Corporate Reputation Review*, 10(3) 163-176.
- Coombs, W. T., & Holladay, S. J. (2007). *It's not just PR: Public relations in society*. Malden, MA: Blackwell Pub.
- Cozma, R. (2009). Online health communication: Source or eliminator of health myths?. *Southwestern Mass Communication Journal*, 25(1), 69-80. Retrieved from Communication & Mass Media Complete database.
- Creighton, C. (2010). Using social media to increase awareness of inhalant abuse. *Journal of Communication in Healthcare*, 3(3/4), 197-213. doi:10.1179/175380710X12688262020632
- Delia, J. G. (1987). Communication research: A history. In C. R. Berger and S. H. Chaffee (Eds.), *Handbook of communication science* (pp. 20- 98). Newbury Park, CA: Sage.
- Dewey, J. (1927). *The public and its problems*. New York: Holt.
- Diaz, J. A., Griffith, R. A., Ng, J. J., Reinert, S. E., Friedmann, P. D., & Moulton, A. W. (2002). Patients' use of the internet for medical information. *Journal of General Internal Medicine*, 17(3), 180–185.
- DiNucci, D. (1999). DESIGN & NEW MEDIA - fragmented future - Web development faces a process of mitosis, mutation, and natural selection. *Print*, 53(4), 32.
- Dutta-Bergman, M. J. (2005). Civil society and public relations: Not so civil after all. *Journal of Public Relations Research*, 17(3), 267-289.
- Everett, J. L. (1990). Organizational culture and ethnoecology in public relations theory and practice. *Public Relations Research Annual*, 2, 235-252.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *Bmj: British Medical Journal (international Edition)*, 328, 7449.
- Ferguson, T. (2007). e-Patients: How they can help us heal healthcare. Retrieved December 10, 2010, from [http://www.e-Patients.net/e-Patients\\_White\\_Paper.pdf](http://www.e-Patients.net/e-Patients_White_Paper.pdf)
- Foss, S. K. (1984). Women priests in the Episcopal Church: A cluster analysis of establishment rhetoric. *Religious Communication Today*, 7, 101–115.

- Foss, S. K. (2004). *Rhetorical criticism: Exploration and practice 3<sup>rd</sup> edition*. Waveland Press: Long Grove, IL.
- Fox, S. (2011a). *Health topics*. Washington, DC: Pew Research Center. Retrieved December 1, 2011 from <http://www.pewinternet.org/Reports/2011/HealthTopics/Summary-of-Findings.aspx>
- Fox, S. (2011b). The social life of health information. *Pew Internet & American Life Project*. Retrieved December 1, 2011 from <http://www.pewinternet.org/Reports/2011/Social-Life-of-Health-Info/Summary-of-Findings/Section-2.aspx>
- Fox, S. (2011c). Health. *Pew Internet & American Life Project*. Retrieved February 21, 2011, from <http://www.pewinternet.org/topics/Health.aspx>
- Fox, S., & Rainie, L. (2000). The online health care revolution: The Internet's powerful influence on "health seekers" *Pew Internet & American Life Project*. Retrieved February 21, 2011 from <http://www.pewinternet.org/Reports/2000/The-Online-Health-Care-Revolution/Summary.aspx>
- Fox, S., & Rainie, L. (2002). Vital decisions: How Internet users decide what information to trust when they or their loved ones are sick. *Pew Internet & American Life Project*. Retrieved from <http://www.pewinternet.org/Reports/2002/Vital-Decisions-A-Pew-Internet-Health-Report.aspx>
- Gaither, T. K., & Curtin, P. A. (2005). Privileging identity, difference, and power: The circuit of culture as a basis for public relations theory. *Journal of Public Relations Research*, 17(2), 91-115.
- Gans, H. J. (1980). *Deciding what's news: A study of CBS evening news, NBC nightly news, Newsweek, and Time*. New York: Vintage Books.
- Ganz, P. A. (2011). The 'three Ps' of cancer survivorship care. *BMC Medicine*, 9, 14.
- Gauntlett, D. (2007), *Creative explorations: New approaches to identities and audiences*. London: Routledge.
- Gauntlett, D. (2009). Media studies 2.0: a response. *Interactions: Studies in Communication and Culture*, 1(1), 147-157.
- Gillam, K. (January 1, 2009). The UK anti-war movement online. *Information, Communication & Society*, 12(1), 25-43.
- Gillin, P. (2008). New media: New influencers and implications for public relations. *Society for New Communications Research*. Retrieved July 23, 2011 from <http://www.mendeley.com/research/new-influencers-implications-public-relations/>

- Gilpin, D. (2010). Organizational image construction in a fragmented online media environment. *Journal of Public Relations Research*, 22, 265-287.
- Gilpin, D. (2010) Working the twittersphere: Microblogging as professional identity construction. In Z. Papacharissi (Ed.), *The networked self: Identity, community and culture on social network sites* (pp. 232-250). New York: Routledge.
- Gitlin, T. (1978). Media sociology: The dominant paradigm. *Theory and Society*, 6, 205-253.
- Glanz, K., Lewis, F. M., & Rimer, B. K. (1990). *Health behavior and health education: Theory, research, and practice*. San Francisco: Jossey-Bass Publishers.
- Goffman, E. (February 01, 1983). The interaction order. *American Sociological Review*, 48, 1.
- Granovetter, M. S. (1973). The strength of weak ties, *American Journal of Sociology*, 78(6), 1360-1380.
- Grunig, J. E. (1975). A multi-systems theory of organizational communication. *Communication research*, 2(2), 99-136.
- Grunig, J. E. (1978b). Defining publics in public relations: The case of the suburban hospital. *Journalism Quarterly*, 55, 109-118.
- Grunig, J. E. (1978b). Organizations and publics: Testing a communication theory. *Journalism Monographs*, 46.
- Grunig, J. E. (1983). Communicating behaviors and attitudes of environmental publics: Two studies. *Journalism Monographs*, 81.
- Grunig, J. E. (1987, May). When active publics become activists: Extending a situational theory of publics. Paper presented at the meeting of the International Communication Association, Montreal, Canada.
- Grunig, J. E. (1989) Sierra Club study shows who become activists. *Public Relations Review* 15(3), 3-24.
- Grunig, J. E. (Ed.). (1992). *Excellence in public relations and communication management*. Hillsdale, NJ: Lawrence Erlbaum Associates.
- Grunig, J. E. (1997). A situational theory of publics: Conceptual history, recent challenges and new research. In D. Moss, T. MacManus, & D. Vercic (Eds.), *Public relations research: An international perspective* (pp. 3-48). London: International Thomson Business Press.

- Grunig, J. E., Grunig, L. A., & Toth, E. L. (2007). *The future of excellence in public relations and communication management: Challenges for the next generation*. Mahwah, N.J.: Lawrence Erlbaum.
- Grunig, J. E., & Hunt, T. (1984) *Managing public relations*. New York: Holt, Rinehart & Winston.
- Grunig, J. E., & Ipes, D. (1983). The anatomy of a campaign against drunk driving. *Public Relations Review*, 9(2), 36-52.
- Grunig, L. A., (1992). Activism: How it limits the effectiveness of organizations and how excellent public relations departments respond. In J. E. Grunig (Ed.) *Excellence in public relations and communication management: Contributions to effective organizations*. (pp. 503-530). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Haase, J. E., & Phillips, C. R. (2004). The adolescent/young adult experience. *Journal of Pediatric Oncology Nursing*, 21(3), 145-149.
- Hall, S. (1996). Introduction: Who needs 'identity'? In S. Hall & P. du Gay (Eds.), *Questions of cultural identity* (pp. 1-17). Thousand Oaks, CA: Sage.
- Hallahan, K. (2008). Organizational-public relationships in cyberspace. In T. Hansen-Horn and B. D. Neff (Eds.), *Public relations: From theory to practice* (pp. 46-73). Boston: Allyn & Bacon.
- Harik, I. F. (1971). Opinion leaders in the mass media in rural Egypt: A reconsideration of the two-step flow of communication hypothesis. *American Political Science Review* 65, 731-40.
- Heath, R. L. (1988). *Strategic issues management: How organizations influence and respond to public interests and policies*. San Francisco: Jossey-Bass Publishers.
- Heath, R. L., Liao, S.-H., & Douglas, W. (1995). Effects of perceived economic harms and benefits on issue involvement, use of information sources, and actions: A study in risk communication. *Journal of Public Relations Research*, (7)2, 89-109.
- Herring, S. C., Kouper, I., Paolillo, J. C., Scheidt, L. A., Tyworth, M., Welsch, P., Wright, E., & Yu, N. (January 1, 2005). Conversations in the blogosphere: An analysis "from the bottom up." *Proceedings of the Annual Hawaii International Conference on System Sciences*, 107.
- Hurwitz, R. (1999). Who needs politics? Who needs people? The ironies of democracy in cyberspace. *Contemporary Sociology*, 28(6), 655-661.



- Jenkins, H. (2006). *Fans, bloggers, and gamers: Exploring participatory culture*. New York: New York University Press.
- Jin, Y., & Liu, B. F. (2010). The blog-mediated crisis communication model: Recommendations for responding to influential external blogs. *Journal of Public Relations Research, 22*(4), 429-455.
- Kaiser Permanente. (2011). Mission. In *Cancer Communication Research Center*. Retrieved August 12, 2011, from <http://www.crn-ccrc.org/about-us/mission.aspx>
- Karlberg, M. (1996). Remembering the Public in Public Relations Research: From Theoretical to Operational Symmetry. *Journal of Public Relations Research, 8*(4), 263-278.
- Katz, E. (April 01, 1957). The two-step flow of communication: An up-to-date report on an hypothesis. *Public Opinion Quarterly, 21*(1), 61-78.
- Katz, E., & Lazarsfeld, P. (1955). *Personal influence*. The Free Press: Glencoe, Illinois.
- Keller, E. B., & Berry, J. L. (2003). *The influentials: One American in ten tells the other nine how to vote, where to eat, and what to buy*. New York: Simon & Schuster.
- Kent, M. L., & Taylor, M. (1998). Building dialogic relationships through the World Wide Web. *Public Relations Review, 24*(3), 321.
- Kent, M. L., & Taylor, M. (2002). Toward a dialogic theory of public relations. *Public Relations Review, 28*(1), 21-37.
- Kim, J., Wyatt, R., & Katz, E. (1999). News, talk, opinion, participation: The part played by conversation in deliberative democracy. *Political Communication, 16*(4), 361-385.
- Kontos, E. Z., Emmons, K. M., Puleo, E., & Viswanath, K. K. (2010). Communication inequalities and public health implications of adult social networking site use in the United States. *Journal of Health Communication, 15*, 216-235. doi:10.1080/10810730.2010.522689
- Kuhn, T. S. (1970). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Lariscy, R., Reber, B. H., & Paek, H. (2010). Examination of media channels and types as health information sources for adolescents: Comparisons for black/white, male/female, urban/rural. *Journal of Broadcasting & Electronic Media, 54*(1), 102-120. doi:10.1080/08838150903550444

- Lasswell, H. D. (1938). *Propaganda techniques in the world war*. New York: P. Smith.
- Lazarsfeld, P. F. (1940). Remarks on administrative and critical communication research. *Studies in Philosophy and Social Science*, 9, 2-16
- Lazarsfeld, P. F., Berelson, B., & Gaudet. H. (1944). *The people's choice*. New York: Columbia University Press.
- Learmonth, M. (2008). How Twittering critics brought down Motrin Mom campaign. *Ad Age Digital*. Retrieved September 18, 2011, from <http://adage.com/article/digital/twittering-critics-brought-motrin-mom-campaign/132622/>
- Li, C., & Bernoff, J. (2008). *Groundswell: Winning in a world transformed by social technologies*. Boston, Mass: Harvard Business Press.
- Lopez, L. (2009). The radical act of 'mommy blogging': redefining motherhood through the blogosphere. *New Media & Society*, 11(5), 729-747.
- Madden, M. & Zickuhr, K. (2011). *65% of online adults use social networking sites*. Retrieved from Pew Internet & American Life Project website: <http://pewinternet.org/Reports/2011/Social-Networking-Sites.aspx>
- Major, A. M. (1998) The utility of situational theory of publics for assessing public response to a disaster prediction. *Public Relations Review*, 24(4). 489-508.
- McLeod, K. (1999). Authenticity within hip-hop and other cultures threatened with assimilation. *Journal of Communication*, 49(4), 134-150.
- McNab, C. (2009). What social media offers to health professionals and citizens. *Bulletin of the World Health Organization*. 87(8). pp. 566-568.
- McNally, R. (2005). Sociomics! Using the IssueCrawler to map, monitor and engage with the global proteomics research network. *Proteomics*, 5(12) 3010-3016.
- Mendelsohn, J. (2010, March 10). Honey, don't bother mommy. I'm too busy building my brand. *The New York Times*, p. ST1.
- Moffitt, M. (1992). Bringing critical theory and ethical considerations to definitions of a "public". *Public Relations Review*, 18(1), 17.
- Molleda, J. C. (2009). Construct and dimensions of authenticity in strategic communication research. *Anagramas*, 8(15), 85-97.
- Neff, J. (2008). P&G relies on power of mommy bloggers. *Advertising Age*, 79(27), 4-24.

- Nisbet, M. C., & Kotcher, J. E. (2009). A two-step flow of influence?: Opinion-leader campaigns on climate change. *Science Communication, 30*(3), 328-354.
- Noar, S. M. (2006). A 10-year retrospective of research in health mass media campaigns: where do we go from here?. *Journal of Health Communication, 11*(1), 21-42.
- Ostrow, A. (2009). FTC to fine bloggers up to \$11,000 for not disclosing payments. *Mashable*. Retrieved March 13, 2010, from <http://mashable.com/2009/10/05/ftc-blogger-endorsements/>
- Pew Research Center. (2011a). *Demographics of internet users*. Retrieved December 11, 2011, from Pew Internet & American Life Project website: <http://pewinternet.org/Static-Pages/Trend-Data/Whos-Online.aspx>
- Pew Internet Research Center. (2011b). Change in Internet access by age group, 2004-2009. Retrieved March 10, 2010, from <http://www.pewinternet.org/Infographics/2010/Internet-access-by-age-group-over-time.aspx>
- Pearce, K., & Pearce, W. (February 01, 2001). The public dialogue consortium's school-wide dialogue process: a communicative approach to develop citizenship skills and enhance school climate. *Communication Theory, 11*, 1, 105-123.
- Price, V. (1992) *Public opinion*. Newbury Park, CA: Sage.
- Rains, S. A. (2008). Seeking health information in the information age: The role of Internet self-efficacy. *Western Journal of Communication, 72*(1), 1-18.
- Rheingold, H. (1993). *The virtual community*. Reading, MA: Addison-Wesley.
- Robinson, J. P. (1976). Interpersonal influence in election campaigns: Two-step-flow hypotheses. *Public Opinion Quarterly, 40*, 204-319.
- Rosenstock, I. M. (1966). Why people use health services. *The Milbank Memorial Fund Quarterly, 44*(3), 94-127.
- Sallot, L. M., Lyon, L. J., Acosta-Alzuru, C., & Jones, K. O. (2008). Aardvark to zebra redux: An analysis of theory development in public relations academic journals into the 21<sup>st</sup> century. In T. Hansen-Horn and B. D. Neff (Eds.), *Public relations: From theory to practice* (pp. 343-387). Boston: Allyn & Bacon.
- Shoemaker, P. (1991). *Gatekeeping*. Newbury Park, CA: Sage.
- Slater, M. D., Chipman, H., Auld, G., Keefe, T., & Kendall, P. (1992). Information processing and situational theory: A cognitive response analysis. *Journal of Public Relations Research, 4*(4), 189-203.

- Society for Participatory Medicine. (2009, July). A declaration of participation. Retrieved May 7, 2011, from <http://participatorymedicine.org/>
- Solis, B., & Breakenridge, D. (2009). *Putting the public back in public relations: How social media is reinventing the aging business of PR*. Upper Saddle River, N.J: FT Press.
- Sontag, S. (1978). *Illness as metaphor*. New York: Farrar, Straus and Giroux.
- Stake, R E. (2005). Qualitative case studies. In N. K. Denizen & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed.) (pp. 443-466). Thousand Oaks, CA: Sage.
- Stansberry, K. (2008). "We've done drugs Keith Richards never heard of:" *A mixed methods study of identity development among young adult cancer survivors* (Masters Thesis). University of Oregon, Eugene, OR.
- Stansberry, K. (2011). Mapping mommy bloggers: Using online social network analysis to study publics. *PRism* 8(2): [http://www.prismjournal.org/fileadmin/8\\_2/Stansberry.pdf](http://www.prismjournal.org/fileadmin/8_2/Stansberry.pdf)
- Surowiecki, J. (2004). *The wisdom of crowds: why the many are smarter than the few and how collective wisdom shapes business, economies, societies, and nations*. New York: Doubleday.
- Tancer, B. (2008). *Click: What millions of people are doing online and why it matters*. New York: Hyperion.
- Taylor, M., & Kent, M. L. (2010). Anticipatory socialization in the use of social media in public relations: A content analysis of PRSA's Public Relations Tactics. *Public Relations Review*, 36(3), 207-214.
- Thomas, D. M., Seymour, J. F., O'Brien, T., Sawyer, S. M., & Ashley, D. M. (2006). Adolescent and young adult cancer: A revolution in evolution? *Internal Medicine Journal*, 36, 302-307.
- Thompson, S. (2009). Do you know why it's not just hair to me? The importance of eliciting breast-cancer survivors' explanatory models throughout the cancer continuum. *Journal Of Communication In Healthcare*, 2(2), 148-158.
- Traffikd (2010). Categorized list of social media and social networking websites. Downloaded April 20, 2012, from <http://traffikd.com/social-media-websites/>
- Vasquez, G. M., & Taylor, M. (2001). Public relations: An emerging social science enters the new millennium. *Communication Yearbook*, 24, 319-344.

- Vorvoreanu, M. (2009). Perceptions of corporations on Facebook: An analysis of Facebook social norms. *Journal of New Communications Research*, 38, 123-127.
- Wang, Z., Walther, J. B., Pingree, S., & Hawkins, R. P. (2008). Health information, credibility, homophily, and influence via the Internet: Web sites versus discussion groups. *Health Communication*, 23(4), 358-368. doi:10.1080/10410230802229738
- Weiman, G. (1982). On the importance of marginality: One more step into the two-step flow of communication. *American Sociological Review* 47, 764-773.
- White, D. M. (1950). The "gate keeper": A case study in the selection of news. *Journalism Quarterly*, 27(4), 383-390.
- Williams, P., Nicholas, D., & Huntington, P. (2003). Health information on the Internet: A qualitative study of NHS Direct Online users. *Aslib Proceedings*, 55(5/6), 304-312.
- Witte, K., & Green, E. C. (2006). Can fear arousal in public health campaigns contribute to the decline of HIV prevalence?. *Journal of Health Communication*, 11(3) 245-259.
- Wright, D. K., & Hinson, M.D. (2006a, March). "Weblogs and employee communication: Ethical questions for corporate public relations. Paper presented to the 9th Annual International Public Relations Research Conference, South Miami, Florida.
- Wright, D. K., & Hinson, M.D. (2006b, November). How blogs are changing employee communication: Strategic questions for corporate public relations. Paper presented to the Public Relations Society of America International Conference, Salt Lake City, Utah.
- Wright, D. K., & Hinson, M.D. (2007a, March). Technology's impact on communication theory: Rethinking traditional communication models. Paper presented to the 10th Annual International Public Relations Research Conference, South Miami, Florida.
- Wright, D. K., & Hinson, M.D. (2007b, October). Assessing the impact blogs and social media are having on the communication process. Paper presented to the Educators Academy, Public Relations Society of America International Conference, Philadelphia, PA.
- Wright, D. K., & Hinson, M.D. (2008a, March). Examining the increasing impact of social media on public relations practice. Paper presented to the 11th Annual International Public Relations Research Conference, Coral Gables, Florida.

- Wright, D. K., & Hinson, M.D. (2008b, April). Assessing the impact of new technologies on the practice of public relations. Invited presentation to the Board of Trustees, Institute for Public Relations, New York.
- Wright, D. K., & Hinson, M.D. (2008c, May). How the new technologies are changing public relations: Results of an international survey. Presentation to the Public Relations Executive Forum, c-sponsored by the Arthur W. Page Society and the Institute for Public Relations, Chicago, Illinois.
- Wright, D. K., & Hinson, M.D. (2008d). How blogs and social media are changing public relations and the way it is practiced. *Public Relations Journal*, 2(2), Accessed at: <http://www.prsa.org/prjournal/spring08.html>.
- Wright, D. K., & Hinson, M.D. (2008e, October). Studying the impact of the new technologies on the practice of public relations. Paper presented to the Public Relations Society of America International Conference, Detroit, Michigan.
- Wright, D. K., & Hinson, M.D. (2009a, March). An analysis of the increasing impact of social and other new media on public relations practice. Paper presented to the International Public Relations Research Conference, Coral Gables, Florida.
- Wright, D. K., & Hinson, M.D. (2009b, July), "An analysis of social media use in public relations," a paper presented to the BledCom Symposium, Bled, Slovenia.
- Wright, D. K., & Hinson, M.D. (2009c, October), "Assessing the use of social and professional networking sites by public relations practitioners," paper presented to the International Association of Online Communicators annual conference, Washington, D.C.
- Wright, D. K., & Hinson, M.D. (2009d, November), "Social media and public relations practice: An analysis of the impact," presentation to the Public Relations Society of America International Conference, San Diego, California.
- Wright, D. K., & Hinson, M.D. (2009e), "An updated look at the impact of social media on public relations practice," *Public Relations Journal*, 3(2), Accessed at: [http://www.prsa.org/Intelligence/PRJournal/Spring\\_09/](http://www.prsa.org/Intelligence/PRJournal/Spring_09/)
- Wright, D. K., & Hinson, M.D. (2009f), Examining how public relations practitioners actually are using social media," *Public Relations Journal*, 3(3), Accessed at: [http://www.prsa.org/Intelligence/PRJournal/Summer\\_09/](http://www.prsa.org/Intelligence/PRJournal/Summer_09/)
- Wright, D. K., & Hinson, M.D. (2010), "An Analysis of new communications media use in public relations: Results of a five-year trend study," *Public Relations Journal*, 26(4), Retrieved October 10, 2011 from: [http://www.prsa.org/Intelligence/PRJournal/Spring\\_10/](http://www.prsa.org/Intelligence/PRJournal/Spring_10/)

- Yin, R. K. (1998). The abridged version of case study research: Design and method. In I. Bickman & D. I. Rog (Eds.), *Handbook of applied social research methods* (pp. 229-259). Thousand Oaks, CA: Sage.
- Zebrack, B. (2009). Information and service needs for young adult cancer survivors. *Supportive Care in Cancer, 17*(4), 349-357.
- Zhou, X. (January 01, 2009). The political blogosphere in China: A content analysis of the blogs regarding the dismissal of Shanghai leader Chen Liangyu. *New Media & Society, 11*(6), 1003-1022.