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Cancer rumor effects on sense making

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Cancer Rumor Effects on Sense Making

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Dedication

First and foremost, I would like to thank my Lord and Savior Jesus Christ, for being my rock and my spiritual guide. I dedicate this work to my beloved grandmother, Lelia Land, who watches over me with great pride from the heavens above. Her fight with cancer has motivated me to aspire to great heights, and I will continue to keep her spirit alive through my research in cancer communication. I also dedicate this research to my beautiful mother, Sandra M. Land, whose strength, wisdom and guidance has allowed me to come to a place where all things are possible. Her love of teaching and education has allowed me to see that learning is a privilege. I would like to express my thanks to my advisors, Dr. Keith Jenkins and Dr. Nicholas DiFonzo. I would also like to thank Dr. Bruce Austin, Dr. Rudy Pugliese and the Department of Communication at the Rochester Institute of Technology. Thank you for instilling in me the knowledge to complete this project.

Table of Contents

Abstract……....iv.

Introduction……...1

Justification of Study……....1

Review of Literature…….....2

Methods……...13

Results…… 19

Discussion…….. 29

Conclusion……..34

References……..37

Table 1……39

Table 2……40

Appendix A……....41

Appendix B……43

Appendix C……51

Appendix D……...55

Abstract

A cancer rumor is collective sense making in response to uncertainty or threat regarding a cancer diagnosis. This study explored the types of cancer rumors in circulation, how these rumors spread, why people believed them, and how people made sense of these rumors in order to cope. Web survey responses from 188 participants found that both negative and positive rumors were spread. These rumors were believed due to perceived source credibility and plausibility. While participants held more faith in medical sources, 71 percent changed their behavior after hearing a rumor from a non-medical person. Results suggested that rumor participation aided coping with the disease and its many possible outcomes.

Sense making is a process known to decrease fear at the onset of an abnormal disturbance in life. If a disruption in a normal life pattern doesn't make sense, humans are inclined to figure out why this disruption has occurred. It is in taking away the chaos associated with the unknown that humans are able to continue to conduct their regular affairs (Dervin, 1999). The process known to decrease this fear is the sense making process as described by Weich, Sutcliffe, and Obstfeld (2005) in their research on medical sense making. The fear that is portrayed at the onset of an initial clinical diagnosis of cancer incites the medical sense making process.

Cancer rumors help patients to undergo this sense making process as they believe and spread them within their close-knit community. It seems as long as fear and uncertainty is present, the cancer rumors will continue to spread. "In other words, the notion is that rumors flourish in an atmosphere of uncertainty because they attempt to relieve the tension" (Rosnow, 1991, p. 486). More so, these rumors also serve as "unverified and instrumentally relevant information statements that arise out in contexts of ambiguity, danger, or potential threat, and that function to help people make sense and manage risk" (DiFonzo & Bordia, 2007, p. 13).
It is in examining the current circulation of cancer rumors, evaluating the process undertaken during a cancer diagnosis, and relating this information to relevant research on the sense making approach that we can begin to understand the types of cancer rumors that are in circulation, how these cancer rumors spread, how people make sense of these rumors, and how the sense making process helps cancer patients to cope with their diagnosis.

Justification for Study

Communication about cancer is common, and informal communication can lead to the transmission of rumors. However, little research has been conducted on how people use these rumors to make sense of the disease. This sense making process can determine how people cope

with the disease, how people choose their treatment options, and may also have an affect on their behavioral intentions. These are important factors to understand in the field of health communication when applying them to treatment and intervention methods for the patient and their loved ones.

This study was funded by the National Science Foundation grant BCS-0527371, received by Dr. Nicholas DiFonzo, co-author of *Rumor Psychology: Social & Organizational Approaches* (American Psychological Association, 2007). This grant allowed the researcher to investigate the impact of cancer rumors on the sense making process.

Review of Literature

DiFonzo and Bordia (2007) define a rumor as "collective sense making in response to uncertainty or threat" (p. 35). Rumors are seen as helpful tidbits in noticing events that seem out of the ordinary, generating an initial explanation of those events, and deciding whether or not to search for alternative events. Since medical sense-making works in the same way as this collective sense making regarding rumors (Weich, Sutcliffe, & Obstfeld, 2005), a medical rumor such as a cancer rumor can be defined as the collective sense-making in response to an uncertainty or threat regarding a cancer diagnosis.

Walker (1996) describes two types of rumors: wish and dread. Wish rumors were positive in nature, while dread rumors had negative implications. For example, a cancer wish rumor might be that vitamins cure cancer, while a dread rumor would be that surgery causes cancer to spread. In this instance, the idea that vitamins cause cancer gives those who hear the rumor a sense of hope making it a wish rumor. On the other hand, the dread rumor that surgery causes cancer to spread creates a sense of fear.

Walker (1996) also discusses the two control categories for rumors: primary and secondary. A primary control rumor helps people to cope with a situation by giving them actual control. This type of rumor control is therefore used as a warning so that one can change their behavior to avoid any harmful consequences of the event. Secondary control rumors are used when one cannot do anything to avoid an event. It serves more as an awareness mechanism so that one can better prepare for the event. In this way, people feel more in control because they know of its coming, and can thus be more prepared psychologically.

In his study of rumor diffusion among college students, Walker (1996) used his classification method of dread and wish rumors, along with primary and secondary control functions. He then trained judges to classify the rumors according to the categories. Walker found that out of the 200 rumors being spread, there were more (113) dread than wish (54) rumors. He also found that all of the rumors fell into the secondary control category, meaning that one could not act on the rumor to avoid trouble. Walker concluded by noting that dread rumors remain more virulent than wish rumors because "greater loss control is perceived from them than wish rumors" (p. 4).

Popular Cancer Rumors

Popular cancer rumors found via the Internet focus on cause and prevention; these are presented in Table 1. Rumors predicting how cancer developed fell under the prevention category. Some prevention rumors include: you can prevent skin cancer by applying sunscreen once daily, mega doses of vitamins help to prevent cancer, knowing you have changes in your BRCA genes can help you to prevent development of breast cancer, and you can beat cancer with a positive attitude. It is also under predicting cancer development that another category of rumors emerged which focuses on cancer causes. Rumors relating to the cause of cancer include:

treating cancer with surgery causes the disease to spread, injuries cause cancer, household bug sprays cause cancer, deodorant causes cancer, under wire bras cause breast cancer, hair dye or cell phone usage cause brain cancer, stress causes cancer, birth control pills cause breast cancer, and harmful chemicals in grilled or microwaved food cause cancer.

To evaluate the spread of popular cancer rumors, I looked closely at three popular cancer rumors in circulation today: shaving and deodorant usage causes cancer, treatment of cancer with surgery causes the disease to spread, and cellular phone usage causes brain cancer. These rumors are the most frequent and the most highly debated among cancer websites such as www.health.discovery.com, www.nationalbreastcancer.org, www.mayoclinic.com, and www.about.com, when an Internet search for popular cancer rumors was conducted.

The development of breast cancer through deodorant usage has been circulating for some time, and claims that the chemicals in deodorant enable the body from purging toxins. These alleged toxins deposit themselves into the lymph nodes, especially when the skin is more susceptible due to shaving. This rumor was featured in *Prevention*'s October 2003 article that noted the 10 most popular breast cancer myths (Weist, & Loecher, 2003). According to Whelan (2004), the rumor that frequent underarm shaving combined with deodorant use among women increases breast cancer is inconclusive. There are also no current epidemiologic studies to prove that this rumor is true, but it seems unlikely given that more substances leave the body through urination rather than perspiration (Jones, 2000).

According to www.cancer.org, the rumor regarding surgery and the spread of cancer started years ago when patients already had advanced cancer before they were admitted to surgery. After doctors operated, they found that the cancer could not be treated successfully and subsequently the patient died shortly after the surgery. Observers thought that the surgery itself

had killed the patient, rather than the advanced stage of the disease prior to the surgery. Thus, this rumor is false as cancer specialists are specifically trained to remove entire tumors within the affected region during a biopsy so that the cancer can not spread due to any air exposure of the body during the operating procedure.

In terms of cellular phone usage and brain cancer, both the Federal Drug Administration and the World Health Organization claim that there is no evidence to prove that mobile phone usage poses a health risk (Jones, 2000)— the rumor being that radio frequency emissions from mobile phones could possibly affect human health. However, according to the American Cancer Society website, "considerable research has also found no clear association between any other electronic consumer product and cancer. Cell phones, microwave ovens and related appliances emit low-frequency radiation… [and] low frequency, non-ionizing radiation does not cause [cancer]." Yet the question becomes, if there is no direct evidence to support these cancer rumors, why are people still inclined to spread and believe them?

Rumor Diffusion and Acceptance

The Spread of Cancer Rumors

Any rumor, including a cancer rumor, evolves in three stages-birth, adventure, and death (Kimmel, 2004). The birth stage is a "fertile breeding ground" for the conditions of a rumor to arise. It is usually characterized with a high degree of fear (p. 103). This can be a high degree of fear and uncertainty regarding a cancer threat or after a diagnosis. The birthing of a rumor allows for the patient and/or their loved ones to obtain some "facts" or information in order to reduce this psychological discomfort. The adventure stage occurs when the credibility of a rumor is evaluated. If the rumor appears to be trustworthy, then the rumor spreads. Finally, the death stage

surrounds the demise of a rumor as it becomes irrelevant, the circumstances change, or those spreading the rumor grow tired of it.

The spread of any rumor is known as the diffusion process. Kimmel (2004) describes two ways in which a rumor is diffused. One method is through word-of-mouth. This method involves strong social ties such as two close friends, or relatives. Another method is through the media, as the media serves as a rumor conduit. Kimmel suggests that people first learn of rumors through newspapers and magazines, whereas television and the Internet cause rumors to travel faster to a larger number of people. As the rumor spreads, the media serves to affect attitudes and behaviors of those spreading the rumor. Television stories that share "news" which may seem credible, and the new emergence of the Internet for rumor transmission pose a greater likelihood that the rumor will pass to someone else. Rosnow (1980) further claims that the tendency to credit any story portrayed by the news media as the truth gives rise to rumors as being more complete. This credibility given to the media can even help the rumor to sustain after it has been discredited by highly credible sources.

In addition to the methods used to spread rumors, the personalities of those involved in carrying the rumor are important as well. For example, individuals who hear a rumor, but don't pass it along are known as "dead-enders" (Kimmel, 2004, p. 111). On the opposite end of the spectrum are "isolates," those who fail to pass a rumor simply because they don't hear it. These isolators remain outside the rumor network. Lastly, in the equation of those involved in rumor diffusion are opinion leaders. These are the motivators along with the media. Their credibility allow for the degree and motivation in which a person will pass on a rumor. Opinion leaders act as an "expert" in the diffusion of a rumor, or the person who is "in the know."

The diffusion process for a cancer rumor is likely to be similar to the diffusion process as described by Kimmel (2004). A cancer patient, for example, may see that many of those diagnosed with cancer who chose surgery as a treatment option died shortly after the procedure. Those patients who were later diagnosed with cancer, heightened with fear and uncertainty regarding their own diagnosis, may seek out advice in order to better understand this cancer disruption in their normal life pattern. Whether they find rumors circulating via the Internet, newspapers, television, or hear it from an opinion leader in their community, if the source seemed credible (or the rumor itself seemed plausible), the patient passes on this information to other patients, their family, or their friends. Thus the rumor will continue to spread as it "thrives on the absence of firm evidence" (Rosnow, 1980, p. 578). Later, the patient begins to evaluate the accuracy of the rumor. They are likely find a rebuttal to the surgery rumor or listen to a rebuttal from someone more credible than the initial opinion leader. This new source of information may inform them of the fact that patients died from an advanced stage of their disease prior to surgery as opposed to the operation itself. Now able to better manage their fears, the patient may also be able to compare the plausibility of the rumor with that of the rebuttal.

Cancer Rumor Believability

According to DiFonzo and Bordia (2007), people believe rumors when they already coincide with a person's already held beliefs, the rumor comes from a source perceived to be credible, the rumor is repeatedly heard, and there is no rebuttal. In fact, the deodorant rumor was rebutted by medical and health information organizations only after it had alarmed a growing number of people (Jones, 2000). Health officials were aware that if a proper rebuttal wasn't given for the rumor in circulation, the rumor would continue to spread. However, many

organizations, including many major businesses, fail to refute a statement as quickly as they should (Crawford, 1999). This leaves room for rumors to spread within the community.

According to Buckner (1965), when rumors already coincide with a person's already held beliefs, they create a "snowball" effect in which new ideas about the rumor are added to the person's already held set of ideas. However, Buckner's argument is that this snowball effect can only be accomplished if a person fails to choose a critical approach in analyzing a rumor. This critical approach allows a person to separate truth and falsity, and to test the truth of a particular rumor in this way. If this is the case, then the snowball effect stops when the truth or falsity of a rumor is reached. The general idea here is that a rumor is an unconfirmed message passed along at the time of transmission. Once this message is confirmed it will stop.

Evidence supporting the fact that rumors are passed when they already fit an individual's already held pattern of beliefs is seen in rumor transmission when an individual will eliminate parts of a rumor to fit their current beliefs, or selectively forget information regarding the rumor that does not seem to fit with what was previously thought. Buckner (1965) argued, "If a person is unable to exercise critical ability…he may tend to speculate on the rumor to fit it into his framework of ideas, prejudices, and attitudes" (para. 20). A person may do this by distorting the rumor and then passing it on, coming up with a version of the rumor to fit his or her psychological needs, or come up with a different rumor altogether. Kimmel (2004) further describes this when he stated that rumors can be produced from an individual's personal experiences, feelings, behaviors, and set patterns of thought.

Repetition of a rumor provides "substantial knowledge" regarding that rumor whether or not it is right or wrong (Buckner, 1965). The researcher points out that if you hear a rumor from one person, you only have your own background knowledge to help you analyze that rumor.

However, if you hear the same rumor from multiple parties or multiple times by the same party, you now have a larger "knowledge" bank to draw from in analyzing such a rumor. This repetition is especially likely on the World Wide Web, where there are more than 100 million websites, and individuals who post over 250,000 messages on the web per day (Crawford, 1999). It is then that the rumor is able to spread quickly, and be seen multiple times by different parties.

DiFonzo and Bordia (2007) also note that people believe these rumors when the sources seem credible. Steverna Fields, head of National Cancer Institute's Public Inquires Office, summarizes this notion by stating that, "part of the problem is that some rumors hold just enough logic to sound convincing to anyone who is not an expert" (Jones, 2000, para. 16). In fact, rumors which aren't spread by trustworthy sources still have the ability to be effective, as these rumors still provide an outlet for venting any frustrations among those who spread them. It is also important for opinion leaders, or those who are the driving force of rumor diffusion. These opinion leaders are still able to gain attention through the spreading of the rumor, utilize their role as an advice giver, and still appear as if they are "in the know" (Kimmell, 2004, p. 75).

Observe the rumors presented in Table 1. Some of these rumors seem plausible to non-experts, for example: mammograms prevent breast cancer and pap smears prevent cervical cancer. It is only in being an expert in the field of oncology that will allow you to realize that these rumors are only partly true. These experts are well-equipped to know that mammograms are not performed to prevent breast cancer, but in fact to screen for the development of the disease so that it can be caught in its early stages. The same is true regarding pap smears and cervical cancer. Yet, these rumors continue to spread in order for patients to gain an understanding of their risks of developing the disease. Slovic, Peters, Finucane, and MacGregor (2005) suggest that this risk perception is defined in two ways: risk as feelings when replying to

danger, and risk as logic. This risk perception is the very aspect that influences decision making, treatment, and prevention methods. It is also this very same risk perception that influences the sense making process as well.

Sense Making and Cancer Diagnosis

Sense making is the approach used in order to think through and organize life situations. Weich, Sutcliffe, & Obstfeld (2005) define sense making as "turning circumstances into a situation that is comprehended explicitly in words that serve as a springboard into action" (p. 409). It is a process used to label an experience, when that experience is different from an expected experience. Patients are able to label their cancer so as to better understand it. Sense making helps patients to better handle their cancer diagnosis when the current state of the cancer patient's world is different than their expected state. As Sellnow, Seegar and Ulmer (2002) note, it is a process of moving from chaos to order.

The sense making process regarding cancer rumors can be understood using the Seven Aspects of Sense Making by Weich, Sutcliffe, & Obstfeld (2005). This process involves sense making as being social in nature, so that communication between human beings is necessary in attempting to make sense of the situation. For example, cancer patients may contact friends or relatives to make sense of their diagnosis. They may also participate in chat rooms and health forums to debate the cause of their cancer. Welch et al. note that this sense making process is also driven by plausibility rather than accuracy.

According to Weich et al. (2005), "sense making is not about truth and getting it right" (p. 415). It is more about making sense of a disruption in life. In this case, it is about making sense of a cancer diagnosis, and getting the information to continue on through a communication exchange process in order to later find accuracy. At the initial onset of a diagnosis, cancer

rumors are used in the sense making process because people are in a “need to know” state. It is usually a state of urgency, so that the need for information outweighs the accuracy of that information. This creates the proper breeding ground for cancer rumors to spread among the population.

Coping through Sense Making

Sense making helps patients cope with their diagnosis by decreasing the fear attached with the unknown. It is in decreasing this fear that patients can begin to understand, and thus manage their cancer. The sense making process incited by rumors forces the patient to start thinking about how exactly to manage their diagnosis. Once patients are able to effectively manage their cancer diagnosis, they will thus be able to better cope with its outcome. Even simply expressing those fears surrounding a diagnosis can help the patient cope and help to improve their adjustment to the illness (Low, Stanton, Danoff-Burg, 2006).

In Low, et al. (2006) research studying 60 early stage breast cancer patients, the researchers found that writing one’s deepest feelings, including the fear surrounding their diagnosis, significantly resulted in fewer medical visits, decreased physical symptoms, and better management of their disease. They note that patient exposure to negative emotions was needed in order for the women to effectively adapt to their condition. This is the expected outcome when engaging in the sense making process, in that by attempting to understand and thus make sense of your condition, you are better able to adapt to it. The patient is able to use these coping strategies to create meaning in life, either through religious activities or positive reaffirmations (Jim, Richardson, Golden-Kreutz, & Anderson, 2006). This positive expectancy creates an optimistic outlook in regards to perceived risk and general patient worry about cancer (McGregor, Bowen, Ankerst, Anderson, Yasui, & McTiernan, 2004).

For example, a brain cancer patient may believe the cancer rumor that cellular phones cause brain tumors. By narrowing down their diagnosis to a particular cause, cellular phones, the patient is better able to "understand" why they developed the disease. In attempting to make sense of their diagnosis, they are able to decrease their uncertainty somewhat by locating a direct cause. According to Kleinke (1998), patients are able to find a sense of meaning through searching for an explanation of why their cancer occurred, and in finding this explanation they are able to attribute personal meaning to their cancer experience. In turn, they feel more in control to effectively manage or deal with their cancer. They are thus able to develop effective coping strategies for better management of their feelings ("I don't know how I developed brain cancer," as opposed to "I developed brain cancer because of cell phone radiation,") and their disease itself ("Should I ever recover from brain cancer I won't know how to prevent it from happening again," to "I can stop this cancer from reoccurring by limiting or ceasing my cellular phone usage").

Consequently, the patient is now able to turn the difficult circumstance of having cancer into their own adaptive coping style by eliminating some of their uncertainties (Bellizzi & Blank, 2006). In doing so, it is not the accuracy of the cancer rumor that reduces this fear, but the plausibility of the rumor. For example, it is the plausibility that unnecessary radiation can cause cancer that is first heard, and later the accuracy regarding the amount of radiation to the body is considered. Plausibility is acceptable in this instance in that since the cause of cancer is not fully understood by medical science, patients have the need to find a reason for their cancer on their own (Kleinke, 1998).

It is in examining the current circulation of cancer rumors, evaluating the process undertaken during a cancer diagnosis, and relating this information to relevant research on the

sense making approach that we can begin to answer the following research questions: What types of cancer rumors exist? Through what communication channels do cancer rumors spread? Why do people spread these cancer rumors? Why do people believe these cancer rumors, and how does cancer rumors help people cope with cancer?

Methods

Participants & Sample Characteristics

Participants were both men and women who were members of an online cancer forum or discussion group from eight websites as of January 15, 2008. These cancer websites were chosen based on specific inclusion criteria, which included member-only access, forum administrators and cancer-related support groups. Participants were also gathered using three social networking sites: facebook.com, xanga.com (a popular blogging site), and craigslist.com. Email requests were also sent for participation. Invitations for study participation were sent between January 15, and January 20, 2008. A response rate for this study could not be calculated because there was no way to determine how many group members from each website actually read the study invitation. Study results are therefore not generalizeable. Rather, this study is intended to be a preliminary exploration of rumor dynamics and sense making. The researcher was able to calculate the breakdown of sample by source: 20.9% of respondents heard the invitation to participate at cancer sites, 52.4% from social networking sites, 2.1% from email invitations, and 23.0% responded “other/don’t know.”

Respondents were eligible to complete the full questionnaire consisting of 35 questions if they could recall anything they heard about cancer from a non-medical source. This was someone who did not work in or were training to work in a medical profession at the time the survey was given. If a member did not meet this requirement, they were asked to provide

demographic information only. Entries with only demographic information were later discarded from the study sample.

Data was collected and recorded for the 203 respondents who completed the questionnaire between January 15, 2008 and February 15, 2008. A total of 188 of these responses were useable. In this group, there were 45 men and 139 women. Four participants did not provide their sex. The mean age of respondents was 35. Sixty-two percent were Caucasian, 22 percent were African American, 3 percent were Hispanic, 2 percent were Native American, 2 percent were Asian, and 3 percent reported 'other.' Twenty-eight percent of participants had cancer, and 95 percent knew someone who had cancer. Twenty-four percent of participants reported having earned a graduate degree, 15 percent reported taking some graduate classes, 24 percent had a bachelor's degree, 4 percent had an associate's degree, 26 percent attended some college, while 3 percent attended a trade school. Eight percent of participants reported having a high school diploma, and 4 percent attended some high school. Table 2 presents this summary data for study participants.

Sample Recruitment

Cancer websites for sample recruitment (Appendix A) were chosen by conducting a Google search containing various search terms such as: cancer, cancer forums, and cancer discussion groups. A search was also done for a forum for each cancer type. These search terms yielded a list of cancer groups, bulletin boards surrounding the discussion of specific types of cancer, informative websites on cancer, and web links to cancer discussion groups. Cancer websites for the study were chosen based on the number of site hits, active members, member registration, and relevant discussion materials.

Websites were then divided into categories based on the major type of cancer being discussed. Cancer categories were taken from a list of the most common cancers produced by the National Cancer Institute. These study categories were breast, colon, leukemia, lung, lymphoma, prostate, and skin. A general cancer category was added for forums that discussed cancer of different types. These categories were produced to ensure that participants who were affected by different forms of cancer would be included in the study.

Forum member registration was also required for cancer websites to be included in the study. This was done because the registration requirement indicates that forum participants take the site content more seriously as opposed to sites where non-registered users can post anonymous opinions. Among these forums, a membership list was also included. These membership lists provide the contact information for all active members utilizing that particular forum or bulletin board.

In addition, other forms of sample recruitment were done using the various social networking sites: facebook.com, craigslist.com, and xanga.com, along with sending the survey link within email messages to increase survey participation. In utilizing facebook.com, a number of participants of various cancer support groups sponsored by the site were reached. Xanga.com, a popular blogging network, was used to target additional members of the online community. Last, email messages were sent out to colleagues and friends who may have been affected by cancer. The email messages included the survey link with an invitation to forward the survey along to others who may also want to participate in the study.

Measures

A web questionnaire containing 35 questions (Appendix B) was developed to address the research questions posed. The questionnaire also included demographic information, which

asked for the respondent's age, primary ethnicity, sex, income, and education level. Finally, participants were also asked to provide the website from which they retrieved the survey.

Types of Cancer Rumors. To address what types of cancer rumors were in circulation, the definition of "non-medical people" was presented to participants. For purposes of this study, non-medical people were people who didn't work in the medical field, such as doctors, nurses, pharmacists, or students training to be a doctor, nurse or pharmacist. The term non-medical people was used so that respondents' confidence or belief in the rumors heard would not be affected by the transmitter's credibility in the medical field. Respondents were then asked, "Have you ever heard anything said about cancer that was of interest to you when you were with non-medical people?" If yes, the respondent was asked to answer the second item, "In these conversations with non-medical people, what was one thing you heard about cancer that was of interest to you? (this information can be true, false or questionable)." The original item which stated, "Have you heard anything about cancer that was of interest to you?" was modified after the first 18 respondents. This slight change increased the number of responses that included cancer rumors. The remainder of the questionnaire was based on the participants' responses to these two items. Therefore, the following item asked, "Why were you having this conversation?" In this way, the context behind the rumor presented could be identified.

The rumors collected from the study were then split into the four categories as described by Walker (1996): dread-primary, dread-secondary, wish-primary, and wish-secondary (These are presented in Appendix C). Three judges who were blind to the study hypotheses were asked by the researcher to verify each rumor according to the classification scheme: dread, wish, primary, and secondary. These judges were given definitions (see Appendix D) for each category and asked to categorize each rumor. Broad or ambiguous sample statements that could

not be classified as a rumor such as, “effects of treatment,” or “how it spreads” were not used for rumor analysis. For dread/wish classification, judge A agreed with judge B 90% of the time, judge A agreed with judge C 90% of the time, and judge B agreed with judge C 100% of the time. Therefore, the average inter-rater agreement for wish/dread classification was 93%. Similarly, for primary/secondary classification, judge A agreed with judge B 85% of the time, judge A agreed with judge C 80% of the time, and judge B agreed with judge C 90% of the time. Therefore, the average inter-rater agreement for primary/secondary classification was 85%. Any disagreements were resolved by voting on the best explanation for rumor categorization.

Importance, Anxiety, Confidence and Uncertainty. Importance of the information was assessed in item five, (“How important was this information at the time you first heard it?”), fear or anxiety in item six, (“How worried were you at the time you first heard this information?”), and confidence in item seven, (How confident were you that this information was true?”); each was measured using a Likert-type scale from 1 (“not at all”) to 5 (“extremely”). Finally, uncertainty was assessed with item nine which stated, “How would you have rated your knowledge about cancer?” Cancer knowledge was then rated using a Likert scale from one to five with 1 being “very poor” and 5 being “excellent.” This scale was later reversed to create the uncertainty variable. Therefore, a participant who rated their knowledge of cancer as “excellent,” would then have the lowest possible uncertainty score. Finally, in an attempt to address whether participants held more confidence in medical or non-medical people, item 16 asked “Which information did you put more faith in?” This item also used a Likert-type scale ranging from 1 to 5, where 1 was “all non-medical information” and 5 was “all medical information.”

Rumor Diffusion and Transmission. In order to assess the different communication channels through which cancer rumors were being spread, respondents were asked, “Where did

you hear this information?" This item allowed participants to check all that applied from the following list: friend, family, acquaintance, a person who had cancer, an online chat room, an online bulletin board, a website, a face-to-face discussion group, or 'other.' Respondents were then asked to provide the means by which they heard the rumor if they checked 'other.'

To understand why people spread these cancer rumors, motivational questions were asked regarding rumor transmission. Item eleven asked respondents, "Did you ever talk about this information with other non-medical people?" and item twelve asked, "If you talked about this information with a non-medical person, why did you do so?" Similarly, item 13 asked, "Did you talk about this information with a medical person (e.g. doctor or nurse)?" This was followed by item 14 which asked, "If you talked about this information with a medical person, why did you do so?"

Item ten, "Since you first heard it, how many people did you share this information with?" and item 15, "How many non-medical people did you talk to before you talked about this information with a medical person?" assessed rumor transmission. Responses from questions pertaining to rumor transmission were then used to dummy-code the rumor transmission variable which indicated whether or not a participant had talked about the information they heard with a non-medical person. For purposes of this study, a '0' was entered for those who had answered no to sharing with a non-medical person, and a '1' was used for those who had answered yes to talking with a non-medical person about the information they heard.

Rumor Coping. Coping information was gathered from participant responses to items 17-22 of the questionnaire. Item 17 asked, "Did you think about changing any of the following?" Respondents were asked to check all that applied from the list. This list included eating healthier, exercising, stopping smoking, taking vitamins, and visiting my doctor. An 'other' option was

also included for respondents to record any behavioral changes that were not listed. Next, item 18 asked, “Did you actually do any of the things you checked off in the last question?” To address reasons for behavioral change, item 19 asked, “If yes, why did you change your behavior?”

Finally, questions regarding the participant’s own cancer history and/or knowledge of someone they knew that had cancer were asked. Item 20 asked respondents, “Have you ever had cancer?” and item 21 asked, “If yes, what type(s) of cancer did you have?” Similarly, item 22 asked respondents, “Have you ever known anyone who had cancer?” and item 23 asked, “If yes, what type(s) of cancer did they have?” Item 24 then asked participants, “Did this person die from their cancer?” These items were asked in order to understand the extent to which a person was impacted or affected by the disease. This was also used to examine how cancer history affected participants’ responses to the rumor they heard, and how they coped with the disease itself.

Results

What Types of Cancer Rumors Exist?

The different types of cancer rumors being spread among the study group were classified according to Walker’s (1996) rumor classification scheme dealing with dread and wish rumors of primary and secondary control types. Both dread and wish rumors were found among the sample. Each rumor was then grouped into four categories: dread-primary, dread-secondary, wish-primary, and wish secondary. Walker stated that primary rumors are rumors in which a participant can take an active role in preventing, and secondary rumors are those in which a participant can do nothing about, but in hearing this type of rumor the participant is able to emotionally prepare for its occurrence. Therefore, a primary rumor is spread to allow the listener to take action before it is too late, while a secondary rumor is spread so that those hearing the rumor can prepare for the inevitable.

Of the 126 rumors found and analyzed from respondent answers, there were more dread rumors (n=92) than wish rumors (n=34), χ^2 (1) =26.70, p<.0005. Rumors were determined based on judge agreement of whether a statement fit into the wish, dread, primary or secondary categories. Examples of dread rumors found throughout the study sample included: "I have heard that microwave plastic when heating your food could be an agent for giving you cancer," "Dietary fat causes cancer," "Never have chemo as it was so bad and you are going to die anyways," and "Everyone dies of cancer, it only takes time." Examples of wish rumors from the study group included: "Vitamin D can help prevent certain forms of cancer," If you don't drink diet cola's you are less likely to get cancer," "There is a cure for cancer," and "Tumors the size of grapes are better than tumors the size of golf balls."

More secondary (n=86) than primary (n=40) control rumors were found throughout sample responses, χ^2 (1) = 16.79, p<.0005. The number of dread rumors outweighed wish rumors in both primary and secondary control categories, but the proportion of dread rumors was much greater in the secondary control category (χ^2 (1) = 7.16, p=.007). There were 23 dread rumors, and only 17 wish rumors in the primary control category. In the secondary control category, there were 69 dread rumors, but only 17 wish rumors. Example dread-secondary type rumors from sample responses included phrases such as: "Cancer always comes back," "Everyone with cancer is subject to chemotherapy and radiation," "The fight never seems to go away and that somehow the immune system is compromised," and "You can do all the right things and still get cancer."

Many rumors contradicted each other within the secondary category. For example, many people listed cancer as a death sentence, while other respondents would combat this statement by saying that cancer was no longer a death sentence due to the many advances in treatment. While

one respondent wrote, “It [cancer] is random because it does not always happen because of habits,” many other respondents reported certain actions or habits as causes for cancer. These habits ranged from using certain deodorant, talking on the cell phone, eating certain foods, or drinking diet sodas. Therefore, while some respondents thought that cancer was a disease of fate, others targeted specific causes for developing cancer.

Consequently, many people focused on the same type of rumor, but the wording of the rumor determined whether it was classified as a wish or dread rumor. For example, one respondent wrote this statement that was later classified as a dread-secondary rumor: “If your parents had cancer, you will probably get it too.” Similarly, another participant wrote, “I don’t have any family history [of breast cancer], so I’m not that worried about it.” This statement was later classified as a wish-secondary rumor. While both statements dealt with the idea that genetics caused cancer, the wording of the statement caused it to either take a negative or positive spin. The same is true regarding chemotherapy as a treatment option. One respondent wrote, “Everyone is subject to chemotherapy and radiation,” while another respondent wrote that “Chemotherapy is not always needed after having a mastectomy.” The first statement is phrased to be a dread-secondary type rumor because it implies that there is nothing you can do about the negative consequences that await you as a cancer patient. However, the second statement is classified as a wish-primary rumor because it implies that there is a choice in choosing between having chemotherapy as a result of a mastectomy. The listener feels a sense of hope in that maybe they too will survive without being forced to undergo chemotherapy.

Popular Internet rumors were also evident in the study sample. One respondent mentioned the rumor regarding anti-perspirants, two respondents mentioned cell phone usage as a cause for developing cancer, two respondents noted microwave usage as a cause of cancer, and

one participant mentioned vitamins as a cure for cancer. One participant mentioned grilled (burnt) foods as a cause for developing cancer, while another two participants said that having surgery caused cancer to spread throughout the body. Another participant noted the rumor that having a positive attitude could help you beat cancer, while another participant reported that cancer was contagious. These rumors were found on various websites as the most popular cancer myths. The remaining rumors among the study sample were not identified on medical websites. This suggests that there are more rumors circulating among the non-medical community of which the medical community is not aware. The sample also contained conspiracy type rumors such as, "The government has a cure for cancer, but they just won't tell us," "Blacks are getting cancer at an disproportionate rate," "A Vietnam vet saying prostate cancer is caused by Agent Orange," "The medical community is holding cures from the sick," and "There will never be a cure for cancer as long as the medical community is making profits from cancer treatments."

Through what Communication Channels do Cancer Rumors Spread?

Out of 182 responses to item three in the study questionnaire, information heard through a non-medical source was spread through word-of-mouth (92.6%) or the media (2.7%). The remaining 1.6 percent reported that they didn't remember how they heard the information. A few members (2.1%) reported that they discussed information about cancer while participating in a cancer support group, while 1.1 percent discussed information they heard during cancer support marathons. However, the majority (71.6%) of respondents talked about information they heard among other non-medical people after they or someone they were close with was diagnosed with the disease. This included family members (56.4%), friends (66.5%), and coworkers (2.1%). One respondent stated, "I was talking to a friend because my husband was diagnosed with cancer," while another respondent stated, "the place where I work at has had five or six employees that

were either diagnosed or died from cancer." These instances set the stage for cancer discussion, and thus the spread of cancer rumors.

The media also played a role in the diffusion of rumors. One respondent said they discussed a rumor after they read about it in a newspaper article. Another respondent stated, "We were watching ESPN." One participant even mentioned that the topic of cancer rumors came about after watching the film "I Am Legend." The movie is centered around the discovery of a cure for cancer. However, in the movie, the cancer cure experiment goes wrong when it either kills or turns its victims into zombies. This leaves actor, Will Smith, to be the only human alive. The participant noted that the movie sparked a conversation discussing whether or not this theory could be true. This resulted in a rumor that there may be a cure, but if released could be more deadly to society than the current societal burden of the disease.

Why Do People Spread Cancer Rumors?

The reasons why participants shared the rumor they heard with medical people, such as their doctor or nurse, were different from why they shared the same information with non-medical people. Out of the 45 percent who reported sharing the rumor they heard with medical personnel, the greatest percentage of these reasons (47.1%) was to inquire about the rumor's validity and clarify any misunderstandings about what was heard. For example, a 43-year-old Caucasian female stated that she wanted to "verify and clarify any questions or concerns" she had upon hearing that cancer was a death sentence. Other participant responses included: "I wanted to find out more information," "I wanted to know my chances," and "I wanted to be completely up-to-date so I know what to expect." Participants also shared these rumors with medical people to obtain their opinion (17.6%) on what could be done given the new knowledge they had gained. They then inquired about any actions that could be taken based on the rumor

they heard. For example, one male participant heard a rumor about the role genetics played in getting cancer. He then talked to his medical provider about his genetic history. Another participant asked her doctor if she could take a blood test to see if she had cancer. A number of respondents who heard rumors about alternative therapy treatments asked their doctors if those treatments were actually available. On the other hand, one 54-year-old male stated that he shared the rumor regarding new diets that helped prevent cancer to his doctor in order to "get a good laugh" out of it. This came from his belief that such diets have never been tested to confirm that they prevented the disease.

Out of the 71 percent who reported sharing the rumor they heard with non-medical people, the majority (46.7%) simply wanted to share their experiences regarding their or a loved one's diagnosis, or participate in general conversation. Respondents noted that many of their opportunities to share came from participating in conversations where they were able to express their feelings or share their cancer journey with others. One participant even noted that they shared their feelings immediately after a funeral of a loved one who had died of cancer. Another respondent mentioned that "many of us need to speak to people who are going through the disease." Other participants reported that they shared their experience after other non-medical people asked about their or a loved one's wellbeing during their battle with cancer. These conversations took place in the home or at work. One participant even noted that these conversations were merely "water-cooler" talk. Many participants also felt that after hearing the rumor, it was their duty to educate (19.7%) other non-medical people on the importance of the new information they gained. These responses included phrases such as: "I wanted to make people aware," and "I wanted to spread knowledge because I feel it is very important to teach people things that are going on."

Participant answers also emphasized their need to gain relief (8.2%) after hearing the information by sharing it with other non-medical people. Many reported examples included: "I wanted to get relief," "I wanted to get it off my chest," "I needed to share it," "…to get out the frustration that we could not change what was," "I was hurt and afraid," "I feel better when I talk to people about it," and "I had to talk to someone because it was a rough time." As for wish rumors, participants spread these rumors as way of encouraging themselves (9.0%) or someone who had cancer. Responses included: "I wanted to encourage them in their cancer experience," I need to feel like I wasn't broken…I needed support," "To reassure and keep their spirits up," "I was trying to help others facing the disease," and "to give hope."

Participants also spread these rumors because they wanted to confirm the information's validity (7.4%) among other non-medical people. For example, respondents said they wanted to "confirm the validity," "I wanted them to know it wasn't true," "I was trying to figure out if the information was true or false," and "I tried to clarify the truth." Confirming validity was also a reason as to why participants shared rumors with the medical community as well, but in sharing with other non-medical people they were able to debate this validity if it did not fit with their already held beliefs regarding the information they heard.

Finally, results show that rumor transmission is dependent upon importance of information, participant belief or confidence in the rumor, and whether or not the participant was anxious upon first hearing the information. Therefore, these factors also determined why a participant would spread a cancer rumor. After dividing the sample (n=169) into two groups according to responses to item eleven on the study questionnaire: those who transmitted the rumor to at least one person (n=133), and those who did not (n=36), t-tests were performed on anxiety, importance, belief, and uncertainty scores between the two groups. Data showed that

transmitters were more anxious ($t(166)=3.64$, $p<.05$), considered the rumor more important ($t(44.68)=4.26$, $p<.05$), believed the rumor more strongly ($t(45.63)=3.80$, $p<.05$), but were not more uncertain ($t(165)=-1.03$, $p>.05$), than non-transmitters. (Separate-variances *t* statistics are reported here for importance and confidence because homogeneity of variance assumptions were not met).

Why Do People Believe these Rumors?

Study results show that perceived source credibility was a major reason for rumor believability. Respondents wrote that they trusted their family and/or friends as a reason for having confidence that the rumor they heard was true. The mean reported confidence score was 3.67 with a standard deviation of 1.37, indicating that the average participant was "mostly confident" that the rumor they heard was true. The frequency distribution of rumor confidence ratings was negatively skewed. The majority of respondents (62.2%) either felt "mostly" or "extremely" confident in the validity of the information they shared. Further, those who reported that they heard these rumors mostly from friends (66.5%) reported a mean confidence rating of 3.71 (SD=1.33, n=124). Those who reported the source of the rumor as family (56.4%) reported a mean confidence rating of 3.75 (SD=1.29, n=105). Therefore, participants' family and friends became highly credible sources for respondents' belief in the information they heard. For example, when asked why he felt so confident in the rumor he was spreading, a 23-year-old African American male stated, "I trust my family, don't you?" Other responses included comments such as, "it came from trusted, long-time friends," "people don't just make things up," and "it came from people I trusted."

Another reason as to why these rumors were believed was upheld by Weich's (2005) explanation of plausibility over accuracy. These rumors did not have to be justified as accurate

for participants to believe what they heard, rather they only had to seem likely based upon the participants' experience, or the credibility of those spreading the rumor (DiFonzo & Bordia, 2007). As an example, one participant mentioned that "the rumor seemed feasible." Another stated that the rumor "made sense." In addition, Buckner's description of rumor transmission—rumors' fitting with a person's already held beliefs, was another reason for rumor believability. One participant stated, "It fits with what I heard." Another respondent replied, "It was consistent with my understanding of the disease." Plausibility and rumors fitting with a person's already held beliefs, was evident in one particular respondent who felt that the medical community was holding back cures from the sick. The respondent reported the reason for confidence as "I just was." The respondent also reported that they transmitted this information to others, but did not talk to a medical person about what they heard. Likewise, a 54-year-old female respondent, whose husband has prostate cancer, was extremely confident in the truth behind her claim that "a cure for cancer was never going to found due to the profit of cancer treatments." Her reason for being so confident was that, "Cancer has been around for quite sometime. Why no cure? With all the technology and studies we should be closer to a cure." This participant also transmitted the information she heard to non-medical people because of its plausibility, but did not discuss this statement with a medical person.

Rumor repetition was also found as a reason for believing a rumor heard from a non-medical source. For example, one participant reported that they believed the rumor they heard because "I keep hearing it from others so I figured they must be right." One 61-year-old Caucasian female even stated, "I'd personally like to believe it," as a reason for confidence in spreading the rumor that cancer was not a death sentence. Very few respondents reported statistical backing for their degree of confidence.

How Does Cancer Rumors Help People Cope with Cancer?

Respondents who transmitted the rumor also reported that the information they heard helped them to understand the disease ($t(169)=4.32$, $p<.005$) better than non-transmitters. By talking through what they heard with others, transmitters were able to better make sense of their experience. However, transmitters were not able to better decide what to do about the disease than non-transmitters ($t(141)=1.71$, $p>.05$). Transmitters also did not feel any better about the disease than non-transmitters ($t(149)=1.84$, $p>.05$).

By attempting to make physical or mental changes, participants may have been able to reduce any anxiety they may have surrounding the rumor and the disease itself. Participants were asked if they would change any of their unhealthy behaviors after they heard the information. These behaviors included eating healthier, exercising, stopping smoking, taking vitamins, or visiting their doctor. Respondents were also able to list other behaviors they thought about changing as a result of the rumors they heard. Results showed that 64 percent thought about eating healthier, 58 percent thought about starting an exercise program, while only 18 percent said that they thought about stopping a smoking habit. Thirty-seven percent contemplated taking vitamins, and another 37 percent wanted to visit their doctor. Respondents also thought about changing other behaviors such as drinking more water, practicing meditation techniques in order to reduce stress, doing self-breast examinations, and stopping their consumption of sugar and refined carbohydrates. One participant even contemplated moving because of the number of residents in his area that developed cancer.

Although there is a small portion of respondents who did not trust the medical community, the mean score of 4.1 indicated that the average participant reported having more faith in “mostly medical information.” Nonetheless, 71 percent decided to follow through with

some of their intended behavioral changes after hearing a rumor from a non-medical source. The main reasons for changing their behavior were to "reduce the risks to my health," "to stay healthy and cancer-free," "to feel better," "to boost my immune [system]," "to be more proactive than reactive," and because "data shows that diet and exercise greatly affects [cancer] risk factors." One participant even noted that fear was his main reason for changing his behavior. Consequently, another participant took on a reflective period, thinking about all the things she could have done differently to avoid having cancer. She stated, "When you get cancer you question many things." Yet another participant, a 37-year-old female, decided to give up drinking diet sodas after hearing that diet cola may cause cancer.

These responses to the information heard correspond with the four phases of the sense making process regarding cancer diagnoses and fear given by Simon, Crowther, & Higgerson (2007). The level of fear in the first stage is reduced, as noted by the significant relationship between rumor transmission and anxiety. Second, participants consider the impact that the cancer will have in their lives, and then begin to take an active role in changing any behaviors that will help them deal with that change. Lastly, by talking to others for emotional support, participants were able to better prepare themselves for an uncertain prognosis.

Discussion

Types of Cancer Rumors

Walker (1996) stated that dread rumors were spread more than wish rumors. However, the reasons for this are still unclear. Walker argued that in his study, dread rumors were more virulent because "a greater loss is perceived with them than with wish rumors" (p. 4). In the present study, more dread rumors were also reported than wish rumors. If this is because a greater loss of control is perceived with dread rumors, this would also be the case when hearing

cancer rumors because cancer is perceived as a disease over which the individual has no control. This may also account for the fact that more dread rumors were given versus wish rumors.

It seemed as if respondents were able to deal with their loss of control by pinpointing a direct cause for developing the disease. These respondents wrote that by practicing certain habits over time, these habits would lead to cancer. These included habits such as microwaving foods, talking on a cell phone, or eating red meat. It was also because these rumors were primary, that it gave people a way of understanding and thus controlling whether or not they developed the disease. For example, if the respondent stopped eating red meat, then they would not get cancer. Whether or not this is true, the rumor may have helped to lower anxiety related to the uncertainty of getting the disease. Out of the many unknown causes for cancer, the respondent knows that they are taking control against the disease by acting on this one known "cause" of the disease—avoiding red meat. It is by taking action that they can reduce their anxiety by "decreasing their risks" of getting cancer.

In addition, many respondents may have felt that by utilizing wishful thinking in regards to treatment options, they would be able to overcome their fear in regards to their mortality and morbidity. This may also be due to the fact that cancer is an unpredictable disease. This is described in the Simon et al. (2007) cancer coping process where taking action allowed patients to face mortality and morbidity issues. Respondents also transmitted rumors regarding better treatments, diets that cure cancer, treatments that destroy cancer cells, and an increase in survival rates. Responses such as these correspond to participants' reasons for talking to non-medical people—to encourage and give hope. According to the study sample, participants even shared what they heard to medical people so that they could verify these survival rates, or gain access to possible treatments.

Rumor Transmission

Reasons for rumor transmission to non-medical and medical people differed. Non-medical and medical people are perceived as having different in-group status. One respondent even referred to non-medical people as "us" and medical people as "them." This participant stated that, "the medical community doesn't understand us." This implies that those dealing with cancer would rather discuss rumors with people outside the non-medical community. This is because other non-medical people would be able to better relate to their feelings. This may also account for the reason as to why respondents spread rumors to non-medical people as a way of expressing or sharing their feelings, as opposed to spreading the same rumor to a medical person as a way of getting expert confirmation. In this way, they were able to emotionally express their experience to other non-medical people, and then turn to medical personnel for a logical explanation.

While many people chose to share the rumor they heard with a non-medical person (71%), the sample was divided on whether or not they shared the same information with a medical person. When asked if they shared information with medical people, 47 percent answered 'no,' and 45 percent answered 'yes.' These percentages suggest that sample respondents were clearly more comfortable sharing what they heard with other non-medical people, but were not so sure about sharing the same information with a medical person. Respondents did not go to their doctor to talk about how they felt; they went to other non-medical people. Likewise, very few respondents went to other non-medical people to confirm validity (7.4%), as opposed to forty-seven percent who went to a medical source to gain expert validation. So, while respondents' were comfortable sharing rumors with other non-medical

people, ultimately sharing information with a medical person was still needed in order to gain expert opinion.

Finally, those who believed the rumor to be true were more likely to spread the rumor to others. Likewise, those who were more anxious at the time they first heard the rumor, and felt the rumor to be of importance, were more likely to transmit the rumor as well. Walker (1996) stated in his study conclusions that anxious people transmit rumors more than those who are not anxious. For this study, the same conclusion regarding anxiety and rumor transmission can be drawn. However, transmitters were not more uncertain than non-transmitters. So, reported knowledge about the disease did not hinder participants from spreading the information they heard.

Rumor Coping

Confidence in the rumor and importance of the rumor were both correlated with participants' agreement that the information helped them better decide what to do about their disease (r= .31, p<.005 and r=.30, p<.005 respectively). Similarly, confidence and importance were also both correlated with participants' responses that the information helped them to feel better about the disease (r=.40, p<.005, and r=.30, p<.005 respectively). This suggests that rumors in which participants' were highly confident, or felt were of importance, helped them to take further action regarding the disease and to feel better about their disease. This is also discussed in past research by Simon et al. (2007) regarding the sense making process. For example, the idea of surgery spreading cancer may have been classified as false. However, for someone who is sure that this statement is true, they may use this confidence to decline surgery as a treatment option. Likewise, if you have full confidence that cancer survival rates have improved, this understanding may also allow you to feel confident about any treatment you will

undergo. Therefore, your belief or confidence in the rumor may also lead to confident decision making in terms of prevention and treatment options, as well as lifestyle changes.

Ironically, even those respondents who admitted that the rumor they heard was absurd changed their behavior as a result of hearing this information. For example, a participant would be sure to acknowledge that they knew the statement was false. However, the same participant would later admit to exercising more or changing their eating habits after hearing the rumor. This implies that simply contemplating a cancer rumor may generate some behavioral changes. It could be that simply discussing the general idea of developing cancer could have created enough anxiety in the participant to alter their way of life.

Many respondents seemed to justify these behavioral changes not by admitting that they had been affected by a rumor they held no confidence in, but because they needed to develop a healthier lifestyle apart from what they heard. For example, one respondent wrote, “I needed to lose weight anyway.” However, some respondents did admit that the rumor directly affected their behavior. One respondent wrote, “I don’t want to die of cancer,” while another said they changed their behavior to “increase my chances of survival.” While behavior changes were reported after hearing primary rumors, they were also reported after hearing secondary type rumors as well. Even the respondent who claimed there would never be a cure for cancer started eating healthier and exercising. A possible reason for this may be that because the respondent saw no cure for cancer in sight, she needed to take action to decrease her risk of developing the disease in the first place. Other reasons for actual behavior change may be that by taking an active role in lowering their risks of getting cancer, even if it was simply by drinking more water, many respondents felt more in control of the disease than if they did nothing at all.

Conclusion

In this study, cancer rumors and their effect on the sense making process was explored. After analyzing data collected from questionnaire responses from 188 participants, it was found that transmitters of rumors were more anxious, considered the rumor to be of more importance, and held more confidence in the rumor heard than their non-transmitting counterparts. Participants spread both dread (negative) rumors, as well as wish (positive) rumors. They also spread primary control rumors, which helped participants exert control over events, and secondary control type rumors, which helped participants when they did not have control over events. These rumors were believed because they were seen as plausible and because the source spreading the rumor was perceived as credible. These sources were mainly family and friends.

Rumors were spread to other non-medical people as a way of sharing experiences, educating and encouraging others, or as a venting outlet. They were spread to members of the medical community in order to validate whether or not the rumor was true, to explore treatment options as it related to the rumor, or to obtain expert opinion. Consequently, transmitters also reported better understanding of the disease than non-transmitters. Finally, reported behavioral changes as a result of hearing the rumor were evident throughout the study sample. While the majority of participants reported that they held more faith in medical information, 71 percent changed their behavior as a result of hearing the rumor from a non-medical source.

Limitations

The initial question used to incite reported rumors among the sample, (What is something you heard about cancer when talking with non-medical people?) was not specific enough to generate rumors related to cancer. Many people wrote vague responses such as, “effects of treatment.” As a result, the second question had to be changed to “What is something you heard about cancer that was of interest to you when talking with non-medical people? (this information

can be true, false or questionable)" after 18 responses to the web survey. Therefore, most of the answers prior to rewording this question were discarded. Furthermore, the survey itself may need to be simplified in a further study to avoid any confusion or misunderstandings on the part of the sample and the researcher. For example, a question such as "Did this information help you feel better about the disease" seemed clear to the researcher. However, to a cancer patient, no information besides the fact that they were cured would make them feel better about having cancer. As a result, many participants did not correctly answer this question.

In general, the process of administering a web questionnaire proved difficult. Many people felt reluctant to provide personal information over the Internet. This resulted in missing data. There was also a need to increase sample size by including social networking sites such as facebook.com, xanga.com, and craigslist.com, due to the low response rate of an online survey. In addition, there were more females who responded to the survey requests as opposed to males. As a result, the number of female participant responses far outweighed their male counterparts, which may skew the study's implications. Thus, it is not positive whether there might have been a difference in study results if there were an equal number of males and females included in the sample.

Another limitation that exists with the administration of surveys is self-reported data. The data collected in this study was based upon participant reports of what occurred, and what was felt as a result of that event. This may or may not reflect the actual events or feelings at the time of occurance. This is particularly true in the case of cancer diagnoses, when emotions are elevated. This may cloud respondents' perceptions of what actually took place. They may have underestimated or overestimated the circumstances surrounding the cancer diagnosis, what was

said, and how they responded. Thus, an error rate in data to account for this occurance is possible.

Heuristic Dimensions

Further studies may include a more in-depth look at cancer rumor and rumor transmission among different age and ethnic groups. Although the current study did not find any significant correlations between study variables, age, and ethnicity, a larger sample may show otherwise. A study exploring source credibility, anxiety, and behavioral changes may also be of interest. This study hints at these correlations. However, there may be many other behavioral changes not mentioned in this study that can result from acting on cancer rumors.

Future research related to the topic may also include rumors circulating about other diseases such as HIV. One may also look at rumors related to illnesses such as diabetes and hypertension. Further research can also be conducted on rumors as they relate to mental illnesses such as clinical depression, or age-related diseases such as dementia.

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Table 1
Popular Cancer Rumors

Prevention	Cause
You can prevent skin cancer by applying one application of sun screen	Micro waved foods cause cancer
Some cancers are contagious	Treating cancer with surgery causes it to spread
A mammogram prevents breast cancer	Harmful chemicals in grilled meat cause cancer
Knowing you have changes in your BRCA genes can help you prevent breast cancer	Injuries cause cancer
There is a cure for cancer but the medical industry won't tell	Cell phones cause cancer
You can prevent/beat cancer with a positive attitude	Deodorant causes cancer
Cervical cancer is not preventable	Hair dye causes brain cancer
A regular pap smear prevents cervical cancer	Living in a polluted city causes cancer.
There are no drugs to help prevent cancer	Breastfeeding causes breast cancer
Mega doses of vitamins can help fight cancer	Birth control pills cause breast cancer
	A mammogram causes breast cancer

Note. Cancer rumors were divided into prevention and cause rumors.
Sources: health discovery, imaginis, about.com, nationalbreastcancer.org, mayoclinic, breastbiopsy.com.

Table 2
Sample Characteristics

	Total Sample N=188			
Variable	M	SD	*n*	%
Age	35	14	182	
Sex				
Male			45	24
Female			139	74
Ethnicity				
Caucasian			117	62
African- American			42	22
Hispanic			6	3
Native American			3	2
Asian			4	2
Other			6	3
Education level				
Less than high school diploma			8	4
High school graduate			15	8
Trade school			5	3
Some college			48	26
Associate's degree			12	6
Bachelor's degree			45	24
Some graduate school			28	15
Graduate degree			23	12

Appendix A

Cancer Websites for Sample Recruitment by Cancer Type

Site Name	URL	Active Members
	General	
Caring 4 Cancer	http://www.caring4cancer.com/go/community/forums	---
Discuss Cancer	http://www.discusscancer.org	711
Talking Cancer	http://www.talkingcancer.org	191
Cancer Forum	http://www.thecancerforums.com	628
Cancer Survivor	http://www.acscsn.org/Forum/Discussion/?msgrid=2	--
	Breast	
Daily Strength	http://dailystrength.org/support-groups/Cancers/Breast_Cancer/	409
Healing Well	www.healingwell.com	--
Health Boards	http://www.healthboards.com	--
	Colon	
Daily Strength	http://dailystrength.org/support-groups/Cancers/Colon_Cancer/	167
Health Boards	http://www.healthboards.com	--
	Leukemia	
Daily Strength-Acute Lymphocytic	http://dailystrength.org/support-groups/Leukemias/Acute_Lymphocytic_Leukemia_ALL/	112
Daily Strength-Acute Myelogenous	http://dailystrength.org/support-groups/Leukemias/Acute_Myelogenous_Leukemia_AML/	60
Daily Strength-Chronic Lymphocytic	http://dailystrength.org/support-groups/Leukemias/Chronic_Lymphocytic_Leukemia_CLL/	50
Daily Strength-Chronic Myelogenous	http://dailystrength.org/support-groups/Leukemias/Chronic_Myelogenous_Leukemia_CML/	52
Health Boards	http://www.healthboards.com	--

Site Name	URL	Active Members
	Lung	
Daily Strength	http://dailystrength.org/support-groups/Cancers/Lung_Cancer/	242
Health Boards	http://www.healthboards.com	--
	Lymphoma	
Daily Strength-Hodgkins	http://dailystrength.org/support-groups/Lymphomas/Hodgkins_Lymphoma/	66
Daily Strength-Non-Hodgkins	http://dailystrength.org/support-groups/Lymphomas/Non-hodgkins_Lymphoma/	85
Health Boards	http://www.healthboards.com	--
	Prostate	
Daily Strength	http://dailystrength.org/support-groups/Cancers/Prostate_Cancer/	101
Health Boards	http://www.healthboards.com	--
	Skin	
Daily Strength	http://dailystrength.org/support-groups/Cancers/Skin_Cancer/	104
Health Boards	http://www.healthboards.com	--

Appendix B

Consent Form & Study Questionnaire for Web Survey

Study on Informal Communication about Cancer

Instructions:

Dear Study Member,

How do people talk about cancer with other people? This is an important topic because these conversations affect how people think about cancer. This is a topic that we know very little about.

As a member of a cancer discussion group, you are someone who is especially able to help us learn about this topic by participating in this brief, online, anonymous survey. Your help would be greatly appreciated.

This questionnaire should take no more than 10 minutes of your time.

RISKS
You might feel slightly emotional as you talk about your own cancer or someone you know who had cancer.

BENEFITS
By joining this study you can learn more about research studies of this type. You will also be helping us to understand what is discussed when people talk about cancer.

ANONYMITY
The information obtained through this study will not be used to identify you. Your name and other personal information will not be on the questionnaire. Demographic information (age, sex, education level) will be collected but only for statistical purposes; this information will not be used to identify you.

CONTACT
If you have any questions about this study, you may contact the researcher, Nicole Robinson, Communication & Media Technologies program at Rochester Institute of Technology, at nmr1264@rit.edu.

PARTICIPATION
Joining this study is completely up to you. You may refuse to answer any questions, and you may stop at any time.

CONSENT
By continuing, you agree that you understand the study and the information given to you.

Thank you for joining this study.

("Non-medical people" are people who don't work in the medical field. They are people who are NOT doctors, nurses, pharmacists, or students in training to be a doctor, nurse or pharmacist.)

1. **Have you ever heard anything said about cancer that was of interest to you when you were with NON-MEDICAL people? (if NO please SKIP to question 28)**

   - ☐ Yes
   - ☐ No

2. **In these conversations with NON-MEDICAL people, what is one thing you heard about cancer that was of interest to you? (this information can be true, false, or questionable)**

3. **Why were you having this conversation?**

4. **Where did you hear this information? (check all that apply)**

   - ☐ friend
   - ☐ family
   - ☐ acquaintance
   - ☐ a person who had cancer
   - ☐ an online chat room
   - ☐ an online bulletin board
   - ☐ a website
   - ☐ face-to-face discussion group

☐ Other...

	Extremely	Mostly	Somewhat	A Little	Not at All
5. How important was this information to you at the time you first heard it?	☐	☐	☐	☐	☐
6. How worried were you at the time you first heard this information?	☐	☐	☐	☐	☐
7. How confident were you that this information was true?	☐	☐	☐	☐	☐

8. **Why were you this confident about the information?**

	Excellent	Good	Average	Poor	Very Poor
9. At the time, how would you have rated your knowledge about cancer?	☐	☐	☐	☐	☐

10. **Since you first heard it, how many people did you share this information with?**

11. **Did you ever talk about this information with other NON-MEDICAL people?**

- [ ] Yes
- [ ] No
- [ ] I don't know

12. If you talked about this information with a NON-MEDICAL person, why did you do so?

13. Did you talk about this information with a MEDICAL person (e.g. doctor, nurse)?

- [ ] Yes
- [ ] No
- [ ] I don't know

14. If you talked about this information with a MEDICAL person, why did you do so? (if not leave blank)

15. How many NON-MEDICAL people did you talk to before you talked about this information with a medical person? (write number here, otherwise leave blank)

	Does not Apply	All Medical Info	Mostly Medical Info	About Equal	Mostly Non Medical Info	All Non Medical Info
16. Which information did you put more faith in?	☐	☐	☐	☐	☐	☐

17. **Did you think about changing any of the following? (check all that apply)**

- ☐ Eating healthier
- ☐ Exercising
- ☐ Stopping smoking
- ☐ Taking vitamins
- ☐ Visiting my doctor
- ☐ Other...

18. **Did you actually do any of the things you checked off in the last question?**

- ○ Yes
- ○ No
- ○ I don't know

19. **If yes, why did you change your behavior?**

20. **Have you ever had cancer?**

- ○ Yes
- ○ No

21. **If yes, what type(s) of cancer did you have?**

22. **Have you ever known anyone who had cancer?**

- ○ Yes
- ○ No
- ○ I don't know

Please think of one person's cancer experience that affected you the most.

23. If yes, what type(s) of cancer did that person have?

24. Did this person die from his or her cancer?

- ☐ Yes
- ☐ No
- ☐ I don't know
- ☐ Does not apply

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree	Does not Apply
25. The information I heard from a non-medical source helped me better understand my/their disease	☐	☐	☐	☐	☐	☐
26. This information made me feel better about my/their cancer	☐	☐	☐	☐	☐	☐
27. This information helped me decide what to do about my/their cancer	☐	☐	☐	☐	☐	☐

28. Please provide the name of the website where you found our survey:

29. **What is your ethnicity?**

- ☐ Caucasian (not of Hispanic origin)
- ☐ African American (not of Hispanic origin)
- ☐ Hispanic
- ☐ Native American
- ☐ Asian
- ☐ Don't know
- ☐ Do not wish to provide
- ☐ Other...

30. **What is your sex?**

- ☐ Male
- ☐ Female

31. **What is your age?**

32. **What is the highest level of education you have completed?**

- ☐ Some elementary school
- ☐ Elementary school
- ☐ Some high school
- ☐ High school graduate
- ☐ Trade school
- ☐ Some college
- ☐ Associate's degree
- ☐ Bachelor's degree
- ☐ Some graduate school
- ☐ Graduate degree

33. **What is your total annual household income before taxes?**

- ☐ Less than $25,000
- ☐ $25,000 - $49,999
- ☐ $50 - $74,999
- ☐ $75 - $100,000
- ☐ More than $100,000

34. **Including yourself, how many people did this income support? (write number here)**

35. **Was anything in this survey unclear? If so, please describe here.**

IF YOU ARE HAVING ANY EMOTIONAL DISCOMFORT BECAUSE OF JOINING THIS STUDY, CONTACT YOUR DOCTOR OR YOUR LOCAL COUNSELOR. TO FIND A COUNSELOR IN YOUR LOCAL AREA, PLEASE CALL 1-800-964-2000 OR VISIT THE APA WEBSITE AT WWW.LOCATOR.APA.ORG.

Thanks for participating.

Appendix C

Dread and Wish Rumor Responses by Type

DREAD RUMORS	
PRIMARY	SECONDARY
A high calcium level in the blood is a sign of cancer	How it keeps affecting people at a younger age
That people who bottled up emotions or held back opinions were more prone to cancer	How it can grow for no reason
I have heard that microwave plastic when heating your food can be an agent for giving you cancer	How there are many people who get lung cancer that don't even smoke
I was surprised to hear that the types of foods [we eat] can give you cancer. This was interesting to me because growing up it was always said you had to eat what was on your plate	There's no cure for it
Dietary fats cause cancer	That early menopause due to hormonal treatment and chemo can change your skin texture and weight distribution
Eating red met increases your risk of colon cancer	There's no cure….the cancer cells are always there it's just something usually triggers them
That you do not get community support and advice until you are in pre-terminal stages	Everyone considers it a death sentence and immediately starts looking past the person to the diagnosis as a way to cope
The chemo is almost as bad as the disease	Cancer always comes back-I know it isn't true but this person believed that even if her mother went into remission it would just come back down the road
Never have chemo as it was so bad and you are going to die anyway	That everyone with cancer is subject to chemotherapy and radiation
You can get cancer from using anti-perspirants	The way they finally die, how much it hurts and what it's like
You can get cancer from using a microwave	One of the most common things I heard was that I would 'be fine' once I had my cancerous organ removed. This was, indeed, extremely false

DREAD RUMORS

PRIMARY	SECONDARY
That cancer is a result of the contaminants in the foods we eat, especially in Caribbean countries	That people who have breast cancer in the family will be at risk of getting it
You can get cancer from eating burnt foods Talking on the cell phone causes cancer	That everyone dies of cancer, it only takes time Cancer survival rates for young adults ages 15-40 have not improved over the last 30 years
How quickly the cancer tends to spread once exposed to air after explorable surgery	So many black families have it and are dying disproportionately
Cancer is spread by having surgery	The fight never seems to go away and that somehow the immune system is compromised so there is always fear of infection/reoccurrence
	People lose their hair and die a tragic death because of cancer
	The government has a cure for cancer but won't tell us
	If your parents had cancer, you will probably get it too
	That you can do all the right things and still get cancer. It's a disease that doesn't discriminate Agent Orange used during the Vietnam war causes prostate cancer
	People think that once you have cancer that is it- you can't recover from it
	Colon cancer can be in your body for years without you knowing because the symptoms don't show up
	The medical community is holding back cures from the sick
	You could die at anytime
	Death sentence
	Reality is that there will never be a cure for cancer as long as there is so much profit being made from cancer treatments

DREAD RUMORS

PRIMARY	SECONDARY
	Every 3 minutes a woman is diagnosed with breast cancer
	1 in 3 people will have cancer before they die

WISH RUMORS

PRIMARY	SECONDARY
That vitamin D can help prevent certain forms of cancer	In reference to breast cancer: "I don't have any family history so I'm not worried about it."
I have heard people say things like, "If you do not drink diet cola's you are less likely to get cancer."	Depending on what type of cancer someone has and what stage it's in, it can be highly curable
You can get tests to see if you are at risk for cancer	When I was a small child…that it was a death sentence, but as an adult there are various new studies and possible causes for cancer and treatments
Ability of certain foods to shrink tumors, cancerous growths	That we can live with it and it doesn't end all things.
That chemo is not always needed after having a mastectomy	Prostate cancer is a good cancer you don't have to worry about
Sugar feeds cancer, as cancer cells have extra sugar receptors so a diet without sugar might cure cancer	Pediatric and geriatric cancer survival rates have significantly improved
There are treatments that destroy blood supply to a cancerous growth and there are treatments which signal the cancerous cell to trick its RNA replication	Cancer does not have to be terminal
I heard that your attitude is a huge part of the cure	Tumors the size of golf balls are better than those the size of grapes
That there is an alternative natural cure that is being used in Mexico	65.3% survive ALL (Acute Leukemia)
That hydrogen peroxide will cure cancer (this isn't a medical fact at all)	
Anticipation of death or ailment brings families closer together	

WISH RUMORS

PRIMARY	SECONDARY
Most cancers are beatable if found early	
New treatments such as the gamma knife and marijuana are used to stop tumor growth	
There is a cure for cancer	
There are new treatments to cure it	
One company has developed a drug undergoing trials which many think will successfully treat a number of cancers	

Appendix D

Coding Definitions for Cancer Rumor Analysis

Cancer Rumor- information that can be useful and of concern to the general community.

Dread- statements with negative implications that cause a sense of fear. E.g.: "You can get cancer by using a microwave."

Wish- statements that are positive in nature and carry with it a sense of hope. E.g.: "You can cure cancer by taking Vitamin C."

Primary Control- helps people to cope by giving them actual control over an event. E.g.: "Eating red meat causes cancer."

Secondary Control- helps people to cope by psychologically preparing them for an uncontrollable event. E.g.: "Cancer is caused by genetics."