BREAST CANCER CAMPAIGNS AND RESEARCH FUNDING:
THE PERFECT STORM
A THESIS SUBMITTED TO THE GRADUATE SCHOOL
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE
MASTER OF ARTS
BY
DEANA E. POTTERF, APR
DR. DUSTIN W. SUPA – ADVISOR
BALL STATE UNIVERSITY
MUNCIE, INDIANA
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Cancer has brought extreme grief to our family, and we will forever be changed by it. It is our duty to look for signs of hope in the face of sorrow.

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Chapter 1

Introduction

What is cancer?

According to the American Cancer Society 1 in 2 men will develop cancer in their lifetimes, while 1 in 3 women will develop the disease (Society, Cancer Statistics 2008: A Presentation from the American Cancer Society). “Cancer has afflicted humans throughout recorded history,” says the American Cancer Society. Further, “Some of the earliest evidence of cancer is found among fossilized bone tumors, human mummies in ancient Egypt, and ancient manuscripts” (Society, The History of Cancer).

The oldest description of cancer, though the term wasn’t actually used, dates back to approximately 1600 B.C. The writing “describes eight cases of tumors or ulcers of the breast that were treated by cauterization, with a tool called ‘the fire drill.’ The writing says about the disease, ‘There is no treatment’” (Society, The History of Cancer).

The word cancer can be credited to the Greek physician Hippocrates (460-370 B.C.). Considered the Father of Medicine, Hippocrates “used the terms carcinos and carcinoma to describe non-ulcer forming and ulcer-forming tumors.” Carcinos means “crab” in the Greek language and was probably used to describe cancer because of its similar shape and “finger-like spreading projections” (Society, The History of Cancer).
Today, the National Cancer Institute, a component of the National Institute of Health, says that “Cancer is a term used for diseases in which abnormal cells divide without control and are able to invade other tissues” (Institute, Common Cancer Types).

Cells are the basic unit of life. The American Cancer Society says, “Normal body cells grow, divide, and die in an orderly fashion. During the early years of a person’s life, normal cells divide more rapidly until the person becomes an adult. After that, cells in most parts of the body divide only to replace worn-out or dying cells and to repair injuries. Because cancer cells continue to grow and divide, they are different from normal cells. Instead of dying, they outlive normal cells and continue to form new abnormal cells” (Society, The History of Cancer).

“The genetic material (DNA) of a cell can become damaged or changed, producing mutations that affect normal cell growth and division,” says the National Cancer Institute (Institute, Common Cancer Types). According to the American Cancer Society, usually when the body encounters damaged DNA it can repair it. However, sometimes the DNA isn’t repaired; the body may have inherited damaged DNA or been exposed to something in the environment that damaged its DNA (Society, The History of Cancer).

During mutation, “cells do not die when they should and new cells form when the body does not need them. The extra cells may form a mass of tissue called a tumor,” says the National Cancer Institute (Institute N. C., What Is Cancer?).

Not all tumors are cancerous. Some may be benign, while others are malignant. Benign tumors may be removed and most often do not come back. They do not spread to other parts of the body. Malignant tumors are cancerous and may spread to other parts of the
body in a process called metastasis. Some cancers, like bone marrow cancer and blood cancer called leukemia, do not even form tumors.

The National Cancer Institute says, “Cancer is not just one disease, but many diseases.” More than 100 types of cancer exist, and most are named for the organ or type of cell where they start. For example, cancer that starts in the pancreas is called pancreatic cancer, while it may also spread to the liver and the lungs. “Cancer cells can spread to other parts of the body through the blood and lymph systems” (Institute N. C., What Is Cancer?).

According to the National Cancer Institute, cancers can be classified into broader categories, including (Institute, Common Cancer Types):

- **Carcinoma** – in the skin or tissues that line or cover internal organs.
- **Sarcoma** – in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.
- **Leukemia** – in blood-forming tissue such as the bone marrow and causes large number of abnormal blood cells to be produced and enter the blood.
- **Lymphoma and myeloma** – in the cells of the immune system.
- **Central nervous system cancers** – in the tissues of the brain and spinal cord.

**What causes cancer?**

The American Cancer Society says that during the 1970s, “scientists discovered two important families of genes – oncogenes and tumor suppressor genes.” Oncogenes are mutated genes that cause cells to become cancerous, while tumor suppressor genes are normal genes that slow cell growth and tell genes when to die (Society, The History of Cancer).
In the 1990s, the BRCA1 and BRCA2 “breast cancer genes” were discovered. These genes do not mean that the carrier will definitely develop breast cancer, but do predict a higher probability of developing the disease. Scientists have also discovered certain familial genes that cause just less than 15 percent of all cancers, especially of the colon, rectum, kidney, ovary, thyroid, pancreas, and skin (Society, The History of Cancer).

Certain carcinogens, such as sarcoma, tobacco, coal tar, asbestos, and radiation were discovered as far back as 1911 and throughout the past century. Several viruses are now linked to cancer, including hepatitis B or C, the Epstein-Barr virus – a variety of the herpes virus, the human immunodeficiency virus, and human papilloma viruses otherwise known as HPV. The American Cancer Society also cites the World Health Organization’s International Agency for Research on Cancer (IARC), that as of 2008 the IARC “has identified more than 100 chemical, physical, and biological carcinogens” (Society, The History of Cancer).

According to the CDC, “the most important modifiable risk factors for cancer are tobacco use, a diet high in saturated fats and with an insufficient intake of fresh fruits and vegetables, and infection with viruses or bacteria that cause cancer.” They also cite other risk factors including physical inactivity, ultraviolet radiation, alcohol use, occupational exposure, obesity, environmental pollution, and food contaminants (Prevention).

**Screening and prevention options**

Some cancers may be discovered before they cause symptoms. When doctors check people who don’t have symptoms for cancer or conditions related to cancer, this is called screening. Because cancer treatment is generally more effective when cancer is caught early, screening is extremely important.
According to the National Cancer Institute, “screening tests are used widely to check for cancers of the breast, cervix, colon, and rectum.” They indicate that other screenings may be routinely done, but “at this time, [they] do not know whether routine screening with these other tests save lives. The NCI is supporting research to learn more about screening for cancers of the breast, cervix, colon, lung, ovary, prostate, and skin.” Screening does have its disadvantages. Some screenings may not be as accurate as others and may require follow-up tests or surgery (Institute, What You Need to Know About Cancer - An Overview - Screening).

The American Cancer Society has a few targeted program initiatives for detection. Their Colon Cancer Initiative works with doctors, health plans and community partners to increase screening for colon cancer. The American Cancer Society also works with the CDC’s Division of Cancer Prevention and Control to operate the National Breast and Cervical Cancer Early Detection Program. The program provides breast cancer screenings to low-income, under-represented women who do not have health insurance (Society, ACS Prevention and Detection Programs).

The CDC’s Division of Cancer Prevention and Control also operates the National Comprehensive Cancer Control Program, the National Program of Cancer Registries, and the Cancer Prevention and Control Research Network, along with several prevention, education, and control initiatives including colorectal cancer, hematologic cancer, lung cancer, ovarian cancer, gynecologic cancers, prostate cancer, skin cancer, and cancer survivorship (Control).

Two preventative cancer vaccines have been approved by the Food and Drug Administration (FDA). In 1981, the FDA approved the HBV vaccine. According to the
National Cancer Institute, “Chronic HBV infection can lead to liver cancer.” In 2006, the FDA also approved a vaccine known as Gardasil that protects against two types of HPV infections, which are known to cause approximately 70 percent of all cases of cervical cancer world-wide. The FDA expanded its approval of Gardasil in 2008 “to include its use in the prevention of HPV-associated vulvar and vaginal cancers” (Institute, Cancer Vaccines).

The American Cancer Society also has several programs for cancer prevention. Their Generation Fit program targets teenagers and promotes a more physically active lifestyle full of nutritious foods. The American Cancer Society’s Active for Life program is a “10-week employee wellness program that encourages people to be more active on a regular basis. It reduces employee stress, boosts morale, and improves job performance.” They also have a Meeting Well program that helps people in the workplace “plan healthy meals and activities for meetings and events,” a School Health program that advocates for school environments that promote healthy lifestyle choices and policies, as well as a program called Let’s Talk About It “designed to increase awareness and knowledge of prostate cancer among African-American Men” (Society, ACS Prevention and Detection Programs).

A healthy diet and physical activity also prevent cancer, according to the American Cancer Society. They recommend that people: “maintain a healthy diet throughout life, adopt a physically active lifestyle, eat a healthy diet with an emphasis on plant sources” and limit alcohol. They also advocate on the community level for “healthful foods in schools, worksites, and communities; safe, enjoyable spaces for physical activities in schools; and safe, physically active transportation (such as biking and walking) and recreation in communities” (Society, At a Glance - Nutrition and Physical Activity).
Treatment options

The type of cancer and the stage of the disease, whether caught early or in its advanced stages, are key factors when creating a treatment plan. The plan varies depending on the age of the patient and their general health, and whether the disease may be eradicated or is merely controlled to reduce symptoms and help lengthen the patient’s life. Treatment plans typically include surgery, radiation therapy or chemotherapy, or a combination of all three. Treatments may be local or systemic, depending on the type of cancer.

If the surgery option is taken, the surgeon typically removes the tumor and the tissue surrounding it. They may also remove nearby lymph nodes to eliminate the cancer and check to see if it has spread.

Radiation therapy “uses high-energy rays to kill cancer cells.” It may be external, via a large machine; internal with a seed, needle, or thin plastic tube; or systemic using a pill or liquid that’s either taken orally or as an injection.

Chemotherapy uses drugs to kill cancer cells. It’s either given by mouth or through a vein and enters the bloodstream to affect cancer cells throughout the body.

Other types of cancer treatment include hormone therapy that “blocks cancer cells from getting or using the hormones they need,” biological therapy that helps the immune system fight cancer, and stem cell transplantation (Institute, What You Need to Know About Cancer - An Overview - Treatment).

Mortality and other statistics

According to the American Cancer Society, cancer is the second highest cause of death in the United States, with heart disease ranking number one. Heart disease causes nearly 27
percent of all deaths in the U.S., followed closely by cancer at nearly 23 percent (Society, Cancer Statistics 2008: A Presentation from the American Cancer Society).

The National Cancer Institute names 13 most commonly diagnosed types of cancer. Table 1.1 lists them in order of highest estimated number of deaths for 2008 (Institute, Common Cancer Types).

Table 1.1 – Leading Cancer Deaths and Cases by Type

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Estimated New Cases</th>
<th>Estimated Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung (Including Bronchus)</td>
<td>215,020</td>
<td>161,840</td>
</tr>
<tr>
<td>Colon and Rectal (Combined)</td>
<td>148,810</td>
<td>49,960</td>
</tr>
<tr>
<td>Breast (Female -- Male)</td>
<td>182,460 -- 1,990</td>
<td>40,480 -- 450</td>
</tr>
<tr>
<td>Pancreatic</td>
<td>37,680</td>
<td>34,290</td>
</tr>
<tr>
<td>Prostate</td>
<td>186,320</td>
<td>28,660</td>
</tr>
<tr>
<td>Leukemia (All)</td>
<td>44,270</td>
<td>21,710</td>
</tr>
<tr>
<td>Non-Hodgkin Lymphoma</td>
<td>66,120</td>
<td>19,160</td>
</tr>
<tr>
<td>Bladder</td>
<td>68,810</td>
<td>14,100</td>
</tr>
<tr>
<td>Kidney (Renal Cell) Cancer</td>
<td>46,232</td>
<td>11,059</td>
</tr>
<tr>
<td>Melanoma</td>
<td>62,480</td>
<td>8,420</td>
</tr>
<tr>
<td>Endometrial</td>
<td>40,100</td>
<td>7,470</td>
</tr>
<tr>
<td>Thyroid</td>
<td>37,340</td>
<td>1,590</td>
</tr>
<tr>
<td>Skin (Nonmelanoma)</td>
<td>&gt;1,000,000</td>
<td>&lt;1,000</td>
</tr>
</tbody>
</table>

Notice that the most commonly diagnosed cancer, nonmelanoma skin cancer, also has the least amount of associated deaths. Lung cancer is the leader of deaths, followed by colon and rectal cancer when considering both sexes, breast cancer in women, pancreatic cancer, and prostate cancer, obviously found only in men. The most estimated new cases after
nonmelanoma skin cancer and lung cancer include prostate cancer in men, breast cancer in women, and colon and rectal cancer.

Considering the data by sex, lung cancer is the most common fatal cancer in men (31 percent), followed by prostate (10 percent), colon and rectum (8 percent), pancreas (6 percent), and liver (4 percent) rounding out the top five. In women, lung (26 percent), breast (15 percent), colon and rectum (9 percent), pancreas (6 percent), and ovary (6 percent) are the top five leading sites of cancer death (Society, Cancer Statistics 2008: A Presentation from the American Cancer Society).

The American Cancer Society compared the change in United States death rates by cause, including heart diseases, cerebrovascular diseases, influenza and pneumonia, and cancer from 1950 to 2005. They found that while cancer deaths had decreased slightly, the other diseases had a profound decrease over the 55 year period. The nation’s leading killer, heart disease, decreased from 587 deaths per 100,000 people in 1950 to 211 deaths per 100,000 in 2005 – a decrease of 376 deaths per 100,000 people. Cancer only decreased from 194 deaths per 100,000 people in 1950 to 184 deaths per 100,000 people in 2005 – a decrease in deaths of only 10 per 100,000 people (Society, Cancer Statistics 2008: A Presentation from the American Cancer Society).

“From 2002 to 2003 and from 2003 to 2004, the decline in the cancer death rate, about 2 percent, was large enough to overcome the impact of the growth and aging of the population and result in the first declines in the actual number of cancer deaths since mortality recording began in 1930,” claims the American Cancer Society. “From 2004 to 2005, the decline in the cancer death rate slowed back to the rate of decline from 1991 to 2002, about 1 percent. The smaller decline in the death rate (1 percent compared to 2
percent) could not offset the growth and aging of the population and resulted in an increase in the number of cancer deaths reported in 2005” (Society, Cancer Statistics 2008: A Presentation from the American Cancer Society). In other words, cancer death rates have begun to slowly turn around, but not very quickly nor to a great degree.

When cancer death rates are considered by sex, “the death rate from all cancers combined has decreased by 2.6 percent per year among men and by 1.8 percent per year among women since 2002. Cancer death rates have been decreasing since 1991 in men and since 1992 in women. Compared to the peak rates in 1990 for men and 1991 for women, the cancer death rate for all sites combined in 2004 was 18.4% lower in men and 10.5% lower in women” (Society, Cancer Statistics 2008: A Presentation from the American Cancer Society).

According to the National Cancer Institute, “for the first time since the report was first issued in 1998, both incidence and death rates for all cancers combined are decreasing for both men and women, driven largely by declines in some of the most common types of cancer.” The report goes on to say, “Based on the long-term incidence trend, rates for all cancers combined decreased 0.8 percent per year from 1999 through 2005 for both sexes combined; rates decreased 1.8 percent per year from 2001 through 2005 for men and 0.6 percent per year from 1998 through 2005 for women.”

The report claims that “the decline in both incidence and death rates for all cancers combined is due in large part to declines in the three most common cancers among men (lung, colon/rectum, and prostate) and the two most common cancers among women (breast and colon/rectum), combined with a leveling off of lung cancer death rates among women.”
While the report cites declines in the common cancers, it also reports increases in cancer incidence rates among men for liver, kidney, and esophagus, as well as for melanoma, non-Hodgkin lymphoma, and myeloma, along with level cancer incidence rates for bladder, pancreas, brain/nervous system, and leukemia. In women, the report also points out increases in cancer incidence rates for lung, thyroid, pancreas, brain/nervous system, bladder, and kidney, as well as for leukemia, non-Hodgkin lymphoma, and melanoma (Institute, Annual Report to the Nation Finds Declines in Cancer Incidence and Death Rates: Special Feature Reveals Wide Variations in Lung Cancer Trends across States).

According to the Center for Disease Control’s Division of Cancer Prevention and Control, “The cancer community has made extraordinary progress during the past two decades in developing and using cancer prevention strategies, early detection interventions, and cancer treatments. Nonetheless, every year cancer claims the lives of more than half a million Americans.” They cite the National Institute of Health as saying that in 2007 “cancer cost this country an estimated $219 billion, including nearly $130 billion for lost productivity and $89 billion in direct medical costs” (Control).

The following literature review explores cancer mortality rates to develop a deeper understanding about who develops the disease, how many lives are lost, and the progress that’s been made in the war that’s been waged against it. Finally, the paper examines the money and campaigns behind the top cancer related organizations, both research and general associations. It compares research dollars to fundraising dollars for a better understanding of who’s spending the money, who’s receiving it, which cause gets the most funding, and how they are raising the funds.
The thesis seeks answers to two questions: Why does breast cancer funding top lung cancer funding by more than two to one? And what can we learn from those highly successful breast cancer campaigns?

These questions are critical to public relations practitioners to understand how health advocacy campaigns affect public perceptions and their influence on research funding and fundraising efforts. The study will add to the body of knowledge for practitioners, so the success of breast cancer campaigns may be replicated or used as a foundation to build upon.
Chapter 2

Literature review

Cancer research and funding

The American Cancer Society claims that “cancer research is currently advancing on so many fronts that it is difficult to choose the ones to highlight here.” They have named four advancements including more targeted therapies, nanotechnology, robotic surgery, and RNA expression profiling proteomics (Society, The History of Cancer).

The National Center for Charitable Statistics claims that 984 public charities reported assets or income related to voluntary health associations with a cancer discipline. Gross receipts totaled nearly $5 billion and assets over $5 billion. They cite the American Cancer Society as the largest such organization, which received nearly $1.8 billion in gross receipts in 2007 with more than $1.3 billion in assets (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)). Table 2.1 lists the top ten public cancer charities by gross receipts.
### Table 2.1 - Top 10 Cancer Health Associations by Gross Receipts

<table>
<thead>
<tr>
<th>Organization</th>
<th>Gross Receipts</th>
<th>Total Assets</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Cancer Society Inc (Atlanta, GA)</td>
<td>1,761,326,867</td>
<td>1,331,977,160</td>
</tr>
<tr>
<td>American Cancer Society Inc (Atlanta, GA)</td>
<td>706,122,377</td>
<td>1,322,457,879</td>
</tr>
<tr>
<td>Dana Farber Cancer Institute Inc Steven Connolly (Boston, MA)</td>
<td>699,606,896</td>
<td>1,020,082,260</td>
</tr>
<tr>
<td>Leukemia &amp; Lymphoma Society Inc (White Plains, NY)</td>
<td>378,726,595</td>
<td>171,069,338</td>
</tr>
<tr>
<td>Susan G Komen Breast Cancer Foundation Inc (Dallas, TX)</td>
<td>129,151,812</td>
<td>152,797,513</td>
</tr>
<tr>
<td>Susan G Komen Breast Cancer Foundation Inc (Dallas, TX)</td>
<td>124,772,163</td>
<td>95,496,994</td>
</tr>
<tr>
<td>Central Arkansas Radiation Therapy Institute Inc (Little Rock, AR)</td>
<td>90,387,648</td>
<td>68,016,972</td>
</tr>
<tr>
<td>H Lee Moffitt Cancer Center and Research Institute Foundation Inc (Tampa, FL)</td>
<td>54,817,318</td>
<td>64,036,689</td>
</tr>
<tr>
<td>West Penn Allegheny Oncology Network (Pittsburgh, PA)</td>
<td>50,916,719</td>
<td>9,818,574</td>
</tr>
<tr>
<td>Mountain View Cancer Associates LLP (Pittsburgh, PA)</td>
<td>41,842,228</td>
<td>7,878,523</td>
</tr>
</tbody>
</table>

The National Center for Charitable Statistics claims that 215 public charities reported assets or income related to cancer research with gross receipts totaling nearly $2 billion and assets nearly $2 billion. They found that Health Research Incorporated was the largest cancer research organization with $563 million in gross receipts and $273 million in total assets (Table 2.2) (Statistics, Public Charities --- NTEE = H3 (Medical Research: Cancer Research, including NTEE subcategories)).
Table 2.2 – Top 10 Cancer Research Charities by Gross Receipts

<table>
<thead>
<tr>
<th>Organization</th>
<th>Gross Receipts</th>
<th>Total Assets</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Research Incorporated (Rensselaer, NY)</td>
<td>563,056,161</td>
<td>273,369,324</td>
</tr>
<tr>
<td>Fred Hutchinson Cancer Research Center (Seattle, WA)</td>
<td>358,857,442</td>
<td>512,942,119</td>
</tr>
<tr>
<td>Wistar Institute of Anatomy &amp; Biology (Philadelphia, PA)</td>
<td>157,653,000</td>
<td>109,684,000</td>
</tr>
<tr>
<td>Ludwig Institute for Cancer Research (New York, NY)</td>
<td>104,827,188</td>
<td>32,471,621</td>
</tr>
<tr>
<td>Barbara Ann Karmanos Cancer Institute (Detroit, MI)</td>
<td>78,456,915</td>
<td>77,239,205</td>
</tr>
<tr>
<td>American Association for Cancer Research (Philadelphia, PA)</td>
<td>52,053,847</td>
<td>46,820,249</td>
</tr>
<tr>
<td>Moncrief Cancer Foundation (Dallas, TX)</td>
<td>42,070,855</td>
<td>57,987,768</td>
</tr>
<tr>
<td>Van Andel Research Institute (Grand Rapids, MI)</td>
<td>39,943,129</td>
<td>71,174,394</td>
</tr>
<tr>
<td>Nsabp Foundation Inc (Pittsburgh, PA)</td>
<td>38,771,960</td>
<td>53,027,004</td>
</tr>
<tr>
<td>Fred Hutchinson Cancer Research Center Foundation (Seattle, WA)</td>
<td>33,320,476</td>
<td>4,404,881</td>
</tr>
</tbody>
</table>

According to the National Cancer Institute, several active clinical trials of cancer treatment vaccines are ongoing for many types of cancer, including bladder cancer, brain tumors, breast cancer, cervical cancer, kidney cancer, melanoma, multiple myeloma, leukemia, lung cancer, pancreatic cancer, prostate cancer, and solid tumors. They also cite several active clinical trials of cancer preventative vaccines for cervical cancer (Institute, Cancer Vaccines).

A review of the National Cancer Center Clinical Trial Results Web page shows increased knowledge and advancements just since the beginning of 2009 on several fronts including follicular lymphoma, myelodysplastic syndromes, prostate screenings, breast cancer, multiple myeloma, colorectal cancer, and leukemia.
It’s difficult to discern if one particular type of cancer is researched more than other cancers. So, the simplest approach may be to follow the federal money. As previously mentioned, the National Cancer Institute is a component of the National Institute of Health, a federal agency. As such, it receives government funding by congressional appropriations. Table 2.3 shows the 20 types of cancer that received the most government research funding in 2008 (Institute, FY 2008 Research Funding by Cancer Type (Site)).
Breast cancer research received the most federal funding at more than $572 million.

Prostate cancer was next with more than $285 million in federal funding, followed by
colon/rectum cancer at more than $273 million. It’s interesting to note that lung cancer, while responsible for three times more deaths than any other cancer, was fourth on the list for federal funding at just under $248 million. Rounding out the top five cancers for federal funding was skin cancer at just over $190 million.

Breast cancer research hasn’t always been the leader in receiving federal funding. In 1990, it received less than $100 million in government funding. However, breast cancer research saw a steady increase in funding each year of that decade (Lerner, 2002).

According to the Dermatology Times, Dr. John Niederhuber, director of the National Cancer Institute since 2006, lost his wife to breast cancer in 2001. Niederhuber told the New York Times, “I’ve sat at a lot of bedsides and held a lot of hands, including the hands of a beautiful woman who was very special to me. It gives me passion to get up in the morning and make a difference” (Dermatology Times 27 Number 11, 2006, p. 6).

Niederhuber asked Congress for an extra $800 million for 2007 and an additional $335 million annually for the following five years. Niederhuber acknowledged that the National Cancer Institute faced budgetary challenges when he arrived and said that some programs would need to be phased out. Clearly, breast cancer research wasn’t under consideration for cuts. He said that he planned to make high-tech drug discovery and cancer centers at universities their priorities (Dermatology Times 27 Number 11, 2006).

BioWorld Today cites Jim Greenwood, CEO of the Biotechnology Industry Organization, as saying that biotech companies are truly the ones who take the research from the National Institutes of Health and other federal agencies and “turn it into real medicines that have real effects on the lives of patients.” He claims that “By reducing the
incidence of cancer and various other diseases we have the capacity to achieve $4 trillion in savings.” Greenwood acknowledged President Obama’s $6 billion increase in the 2010 budget proposal for cancer research as a step in the right direction, but noted that the current economy paired with the proposed patent reform legislation makes it difficult to secure capital investment, thus making the quest for a cure even more challenging (2009, p. 3).

**Health communications**

Dr. Pauline C. Hamel, adjunct faculty in Boston University’s Master of Science in Health Communication, says “With the rising number of health issues facing the public today, a clear, comprehensive health communication approach is becoming even more critical to ensure the safe and efficient delivery of health services, avoid medical errors and implement health care policy reform…PR experts have unique skills to bridge the gap between the health system and the consumers it serves by creating and optimizing relationships and community partnerships.”

A national report called *Healthy People 2010: Understanding and Improving Health* defines health communications as “the art and technique of informing, influencing and motivating individual, institutional and public audiences about important health issues. The scope of health communication includes disease prevention, health promotion, health care policy and the business of health care as well as enhancement of the quality of life and health of individuals within the community” (Hamel, 2008, p. 22).

In an analysis of the efficacy of health campaigns on behavior change in the United States, it was discovered that those campaigns successfully changed behavior for 8 percent of
the population. The rate of change was closely linked to the type of behavior, whether the campaign was trying to stop an addictive behavior or commence a healthy behavior. For example, the average smoking cessation campaign conducted in the media only garnered a 2 percent decrease in smokers (Snyder, 2007).

Another study, which examined cancer risk and efficacy perception, found that “In the case of breast cancer and in particular colon cancer prevention, it may be important that campaign messages target both comparative risk and efficacy beliefs, whereas for prostate cancer prevention, the primary focus should be on targeting efficacy beliefs” (Wong, 2009, p. 103). Since many cancer campaigns already deal with prevention and motivation for screening, the logical next step may be the effectiveness of those screenings as related to early detection and their success rate at making cancer more treatable.

The study also found that people don’t often attribute their risk of developing cancer with their lifestyle behaviors. “They could attribute their high cancer risks to other factors such as family history and/or genetics, and environmental factors. If this is the case, then it may not be surprising to find the lack of a relationship between cancer risk perception and intent to adopt a healthier lifestyle. Given the positive association between cancer efficacy beliefs related to lifestyle behaviors and intentions to adopt a healthier lifestyle, it may be more effective to use positive message framing (e.g., emphasize the benefits of exercise for reducing cancer risks) than negative message framing (e.g., emphasize the health risks associated with physical inactivity) to motivate people to adopt a healthier lifestyle” (Wong, 2009, p. 103).

A study that considered health communication channels for cancer prevention found that publics should be reached through a variety of means including their social networks,
doctors, workplaces and the media (Wilkin & Bell-Rokeach, 2007). For example, for prostate exam promotion, more men had heard about the test from their doctors or a PSA (65 percent) in newspapers, magazines, and the Internet, than those men who relied most heavily on family, friends, and co-workers for health goal attainment. In order to reach more of the men who hadn’t heard about the prostate exam, the campaign needed to reach out to them through their social networks or workplaces.

Regarding fruit and vegetable consumption as a means of cancer prevention, the study also found that “connections to newspapers, books, magazines, Internet, radio, doctors/health professionals, and non-traditional health care providers is related to increased fruit and vegetable consumption” (Wilkin & Bell-Rokeach, 2007, p. 20). People who had strong connections to co-workers for health information had lower fruit and vegetable consumption that those who had the other connections. The study also found that “people connecting to the Internet, health professionals, and/or family and friends for health goal attainment exercise fewer days per week on average than those who do not indicate that these are important health resources” (Wilkin & Bell-Rokeach, 2007, p. 20). So, social networks, the Internet and health professionals are prime vehicles for information about exercise and its benefits for cancer prevention.

A study conducted in 2005 found that “nearly one half of the American public (44.9 percent) had personally sought cancer information at some point in their lives; of these, 76.1 percent searched within the past 12 months” (Arora, Hesse, Rimer, Viswanath, Clayman, & Croyle, 2008, p. 225). As described in the next section, plenty of cancer associations and research organizations exist, and access to cancer information is readily available. However, the study found that:
• 50.1 percent wanted more information but did not know where to find it;
• 48.3 percent indicated that it took a lot of energy to find the information they needed;
• 46.5 percent indicated that they did not have enough time to get all the information they needed;
• 41.9 percent felt frustrated during their search for cancer information;
• 58.3 percent were concerned about the quality of the information they found; and
• 37.7 percent thought the information the found was too hard to understand (Squiers, et al., 2006, p. 118).

Non-profit organizations, social marketing and fundraising

According to the *Library Journal*, “the United States is home to about 1.3 million organizations that fall under the IRS’s 501(c)(3) classification of ‘[tax]-exempt organizations’ known informally as nonprofits. A nonprofit is defined as a formally incorporated nongovernmental organization that operates in the public interest, rather than in order to make a profit. Its income, in other words, is used to enact its mission. Nonprofits may include schools and universities, social service and religious organizations, cultural and scientific groups, hospitals, and public libraries.” The journal also says that tax-exempt status doesn’t mean that non-profits don’t pay any taxes, nor does it mean that all contributions are tax-deductible (Koss, 2007, p. 54).

While for-profit companies generally operate to make money for their owners and investors, non-profit organizations operate to create social change for the greater good. Non-profits typically use a mix of volunteers and skilled workers to manage and operate the company (Hull & Lio, 2006).
Philip Kotler of the Kellogg School of Management says:

Until 1970, marketing language and theory focused on explaining how goods and services are priced, promoted, and distributed in commercial markets by for-profit firms. Transactions and payment were considered central to the definition of markets and marketing. Other domains of exchange activity, such as the efforts of museums, performing-arts groups, churches, social agencies, city governments, social action groups, and celebrities to attract and serve visitors, members, donors, clients, fans, and others, were outside the purview of marketing and its concepts. The problems that such groups faced were examined, if at all, by public relations practitioners and press agents. (Kotler, 2005, p. 114)

Kotler also says, “In the late 1960s, some scholars began to believe that these noncommercial organizations faced ‘marketing-like’ problems that could be fruitfully addressed with marketing language and concepts.”

Kotler continues by saying:

As marketing language and concepts began to enter into each of these domains [including health care], serious opposition emerged from the old guard. Consider the following… museums directors and staff felt uncomfortable about introducing marketing talk in their discourse. It smelled of commercialism and might pollute the sacredness of their objects and missions. It had so little to do with beauty and art. At best, they tolerated an education department and fundraising (called development). Today, however, virtually every museum has a marketing person who is responsible for attracting visitors, selling memberships, building an image in the community, helping the development department, assisting the gift shop, and improving the restaurant, public facilities, and signage. (Kotler, 2005, p. 114)

Kotler and Zaltman define social marketing as, “the design, implementation, and control of programs calculated to influence the acceptability of social ideas and involving considerations of product planning, pricing, communication, distribution, and marketing research” (Kotler & Zaltman, Social marketing: an approach to planned social change, 1971, p. 5).
Even in 1971, Kotler and Zaltman quote an American Cancer Society brochure as saying, “An example of careful promotional planning for a social objective is found in the American Cancer Society efforts to raise money for cancer research. In their brochure directed to local units, they attempt to educate the volunteer and professional chapters on the handling of newspapers, pictures, company publications, radio and television, movies, special events, and controversial arguments. For example, in terms of special events: Dramatic special events attract attention to the American Cancer Society. They bring color, excitement, and glamour to the program. Well planned, they will get excellent coverage in newspapers, on radio and TV, and in newsreels…” (Kotler & Zaltman, Social marketing: an approach to planned social change, 1971, p. 8). In other words, increased visibility leads to increased contributions.

According to Giving USA, a special section of the Non Profit Times, the highest percentage of contributions in the United States each year consistently comes from individual donors. In 2008, individuals accounted for 75 percent of all gifts for a total of more than $229 billion. Foundations were next highest at 13 percent and more than $41 billion, followed by bequests at 7 percent and nearly $23 billion, and finally corporations at 5 percent and more than $14 billion. Contributions across the United States in 2008 dropped by $6.4 billion. It was the largest decline on record, and the first time giving dropped since 1987.

“Religion continued to be the largest recipient of charitable dollars, accounting for 35 percent of overall giving, or almost $107 billion, and up 5.5 percent (1.6 percent inflation adjusted), over 2007,” says Giving USA. By comparison, according a chart in that same special section, health organizations received 7 percent of all contributions for a total of
nearly $22 billion. Types of organizations, other than religious, receiving more funding than health, include education with 13 percent of all contributions, gifts to grant-making foundations with 11 percent, human services with 9 percent, and public-society benefit with 8 percent of all contributions (Hrywna, Giving USA: An NPT Special Report, 2009, p. 16).

**Cancer organizations and their campaigns**

The top five public charities for cancer research include Health Research Incorporated, Fred Hutchinson Cancer Research Center, Wistar Institute of Anatomy & Biology, Ludwig Institute for Cancer Research, and the Barbara Ann Karmanos Cancer Institute.

According to the Form 990 filed by Health Research Incorporated, they spent over $436 million in 2006 for cancer research for the purpose of prevention and treatment. It’s also interesting to note that they are affiliated with the New York State Department of Health and the Roswell Park Cancer Institute Corporation. They didn’t claim any fundraising expenses or lobbying expenses (Statistics, Public Charities --- NTEE = H3 (Medical Research: Cancer Research, including NTEE subcategories)).

According to Fred Hutchinson Cancer Research Center’s Form 990, they spent over $317 million in 2006 to discover cancer causes, treatment, and prevention options. They also didn’t spend any money for fundraising. However, they did claim expenses of $147,000 for direct lobbying and $250,000 for grass roots lobbying (Statistics, Public Charities --- NTEE = H3 (Medical Research: Cancer Research, including NTEE subcategories)).

According to the Form 990 filed by the Wistar Institute of Anatomy and Biology, they spent over $33 million in 2006 for “biomedical research and training activities regarding basic cancer research and studies of the immune system and genetics.” They claimed
fundraising expenses of $734,000, but did not disclose the related activities. They also cited lobbying expenses of $126,000 (Statistics, Public Charities --- NTEE = H3 (Medical Research: Cancer Research, including NTEE subcategories)).

According to the Wistar Institute Web site, they annually host a golf tournament to raise money for brain cancer research at the Albert R. Taxin Brain Tumor Research Center, which is located at the institute. Wistar Institute also hosts an annual gala event that benefits all research at their organization (Institute W.).

The Ludwig Institute for Cancer Research claimed research expenses of nearly $95 million for “basic laboratory research, translational research, and also early-phase clinical trials primarily on solid tumor types, in conjunction with non-profit hospitals and universities” on their Form 990 in 2007. They had fundraising expenses of over $1.8 million, but they claimed these as indirect costs with no associated direct costs for that year. They also claimed no lobbying expenses.

According to their Form 990, the Barbara Ann Karmanos Cancer Institute spent more than $12 million for clinical cancer programs that included hospice and cancer detection, as well as community health education and prevention programs. They also spent nearly $12 million on cancer research specifically related to “immunology, cancer metastasis, and developmental and experimental therapeutics.”

Karmanos is located in Detroit and claims to be the only hospital focused solely on cancer in Michigan. The institute had fundraising expenses of $1.7 million, and spent that on an annual dinner, a Komen Race for the Cure, a Partners Golf & Ball, and other special events. Karmanos even included the Komen breast cancer fundraising event in their income.
They also had more than $231,000 of direct lobbying expenses and $250,000 of grassroots lobbying expenses (Statistics, Public Charities --- NTEE = H3 (Medical Research: Cancer Research, including NTEE subcategories)).

The top five public voluntary health associations related to the cancer discipline include the American Cancer Society, Dana Farber Cancer Institute, Leukemia & Lymphoma Society, Susan G. Komen Breast Cancer Foundation, and Central Arkansas Radiation Therapy Institute (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)).

According to the Form 990 filed by the American Cancer Society for their fiscal year ended August 31, 2007, they contributed $147 million for cancer research and nearly $600 million for cancer detection and treatment along with patient services. They also spent nearly $7 million on direct and grassroots lobbying efforts.

The American Cancer Society incurred $164 million in direct and indirect fundraising expenses. Their largest annual fundraising campaign held across the nation is Relay for Life, which grossed nearly $406 million for research and American Cancer Society programs in 2007. They held 4,753 of those events. In addition, they hosted various galas and golf tournaments, which grossed nearly $43 million. They also annually host regional breast cancer fundraising events called Making Strides. In 2007, they held 123 Making Strides events that raised nearly $43 million (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)).

On the American Cancer Web site they claim, “In fact, the Society has invested more in breast cancer research grants over time than any other voluntary public health
organization – $352 million since 1972!” In addition, they say “Since 1993, nearly 5 million walkers have raised more than $340 million through Making Strides events to help fight breast cancer. Thanks to people like you, the American Cancer Society provides help and hope to thousands of breast cancer patients” (Society, ACS: Your Dollars at Work).

The American Cancer Society’s ties to breast cancer can be traced to 1913 “when physicians and laypeople who were concerned with high rates of cancer mortality formed a voluntary association, the American Society for the Control of Cancer (ASCC). As part of its educational mission, the ASCC urged women to promptly show breast lumps to their physicians.” The ASCC became the American Cancer Society by the 1950s. They promoted breast self-examination as a means of finding “smaller cancers that were less likely to have spread” (Lerner, 2002).

The Dana Farber Cancer Institute spent over $283 million in 2006 for patient care, treatment, diagnosis, prevention, and cure of cancer. They spent an additional $277 million for research of the “genetic makeup of cancer cells to developing novel therapies to diagnose, treat, and prevent the disease.” They also spent nearly $12 million to work with community organizations to promote “greater public health.” And they spent $247,587 on lobbying activities. They claimed over $15 million in fundraising expenses (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)). They conduct joint fundraising events with the Boston Marathon and the Boston Red Sox, but none seem to be tied to a specific type of cancer (Institute D.-F. C.).

According to their Form 990 from 2006, the Leukemia and Lymphoma Society spent more than $67 million for research to cure or control leukemia, lymphoma, Hodgkin’s and
non-Hodgkin’s lymphoma and myeloma. They also spent $62 million for patient and community services, $36 million for public health and education, and nearly $8 million for professional cancer research and treatment symposiums. They also had total lobbying expenses of $174,560.

The Leukemia and Lymphoma Society spent nearly $42 million for fundraising. Their gross fundraising income included $3.6 million in gross receipts and nearly $12 million in contributions for the Nike Women’s Marathon, $3.3 million in gross receipts and nearly $11 million for the Rock ‘n Roll Marathon, $2 million in gross receipts and $6 million in contributions for a bike ride, and nearly $33 million in gross receipts and nearly $141 million in contributions for other special events (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)).

According to their Form 990 from 2006, the Susan G. Komen Breast Cancer Foundation spent nearly $67 million to support breast cancer research and clinical investigation. They also spent more than $133 million for breast cancer screening, treatment, and education. The Komen Foundation incurred $724,073 in lobbying expenses.

The Komen Foundation claimed nearly $16 million in fundraising expenses. They raised nearly $67 million through their annual Race for the Cure held nationwide, more than $4 million with the Pink Tie Ball, nearly $1 million through luncheons, and $1.5 million during other events. They raised more than $1 million in pink ribbon merchandise sales alone (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)).
Bank of America has even partnered with the Komen Foundation. The Komen Foundation Web site says, “For each new Susan G. Komen for the Cure branded credit card account opened and used, Komen will receive a minimum of $3, and a minimum of 20 cents for every $100 in purchases made with the card. Komen also will receive $1 for each annual renewal of the card” (Cure).

They also benefit from checking accounts and check cards. “For each new Susan G. Komen for the Cure checking account and/or check card opened and used, Komen will receive $2 and an additional $1 on each annual anniversary of the account opening. Komen will also receive 10 cents for every $100 in purchases made with the check card” (Cure).

And finally, Bank of America has made this guarantee, “From 2009-2011, Bank of America will make a minimum guaranteed contribution of $1,950,000 and a maximum of $2,700,000 to Komen for the Cure in connection with this program” (Cure).

The Central Arkansas Radiation Therapy Institute rounds out the top five cancer associations by gross receipts. According to their 990 from 2006, they spent nearly $83 million for radiation treatment, cancer patient care, and education. They incurred neither fundraising expenses nor any lobbying expenses (Statistics, Public Charities --- NTEE = G3 (Voluntary Health Associations & Medical Disciplines: Cancer, including NTEE subcategories)). Fundraising activities include a golf tournament and holiday activities (Institute C. A.).

Other than the Albert R. Taxin Brain Tumor Research Center located at the Wistar Institute, which researches other cancers, too, and the Leukemia and Lymphoma Society, breast cancer is the only cancer type specifically named by the remaining organizations from
this study. One general cancer research institute, Barbara Ann Karmanos Cancer Institute, even holds an annual Susan G. Komen Breast Cancer Race for the Cure.

Why is breast cancer, the second-leading cancer related cause of death among women, so popular among these organizations?

**Breast cancer campaigns**

Susan Braun of the Susan G. Komen Breast Cancer Foundation says that “there have been four key steps in the advent of breast cancer advocacy: priming the market, engaging consumers, establishing political advocacy, and taking the advocacy mainstream” (Braun, 2003, p. S101).

She says that breast cancer was a secret disease until the 1980s when former First Ladies Betty Ford and Nancy Reagan began sharing their own personal stories about the disease. Susan Komen died of breast cancer at age 36, so Braun even cites Komen’s sister, Nancy Brinker as a change agent since she began talking about her sister’s death in the early ‘80s. And she says that for the first time breast cancer statistics were presented to the public in easy to understand, relatable terms. Braun refers to “priming the market.” According to Baran and Davis, priming is an agenda-setting term – “the idea that even the most motivated citizens cannot consider all that they know when evaluating complex political issues. Instead, people consider the things that come easily to mind…” (Baran & Davis, 2009, p. 281).

To “engage consumers,” Braun says that public health officials were the key to success by setting guidelines for and encouraging breast self exams and clinical exams. Braun also says that the media increased their coverage of the disease, and the Komen Race for the Cure began in 1983. She says that “Funds from these efforts enabled advocates to hold
educational forums and produce educational materials in different media and tailored to different audiences and to become active in the funding of research” (Braun, 2003, p. S101).

The third step, “political action,” saw the uprising of breast cancer advocates in the 1980s and 1990s to “work toward legislative, regulatory, and funding changes, such as passage of the Mammography Quality Standards Act and increased funding for the National Cancer Institute.” Braun says that these efforts quadrupled federal funding for breast cancer research in the 1990s (Braun, 2003, p. S101).

For “going mainstream,” the fourth step in the increase in breast cancer advocacy, Braun cites “establishing a solid base of support” to ensure their progress in “engaging the business, government, and scientific communities as partners in advocacy” (Braun, 2003, p. S103).

Activism for breast cancer can actually be traced as far back as the 1930s when the Women’s Field Army was founded “to educate the public about the breast cancer menace. Emphasizing the need to ‘fight’ the disease, the several hundred thousand Army members wore military garb and earned stripes by recruiting other women to the cause.” However, the pivotal moment for the increased interest in the disease was in the 1970s when women began to question the standard therapy for the disease, radical mastectomy (Lerner, 2002, p. 225).

Activists claim that they emphasize breast cancer over all other cancers “because breast cancer threatens both life and an organ that is associated with sexuality and motherhood” (Lerner, 2002, p. 227), though breast cancer may be accentuated particularly over lung cancer because of a social stigma. The American Lung Association of California recently conducted
an awareness campaign with Dr. Deborah Morosini, who is the sister of the late Dana Reeve. Reeve, a nonsmoker, died of lung cancer at just 44 years old – two years after losing her husband, actor Christopher Reeve.

The American Lung Association cites Morosini as saying, “There is a stigma around lung cancer because so many people think smokers brought it on themselves. The fact is smoking causes lung cancer and if you don’t smoke you lower your risk. But other things can cause lung cancer” (Ascribe Newswire: Health, 2008, p. 1).

On the other side of the breast cancer campaign debate, Michael Baum, ChM, FRCS, of the Royal Free & University College Medical School in London calls breast cancer awareness campaigns “scare mongering.” He claims the statistic that 1 in 12 women will develop the disease “generate[s] an atmosphere of anxiety among inappropriate age groups.” Baum’s point is that the statistic is only valid for women “who live to the ripe old age of 85 and have escaped all the competing risks for premature death.” He counters that younger women are more at risk from traffic accidents and smoking (Baum, 2000, p. 331).

A study of news coverage of breast cancer from 1960-1995 found that “print coverage of breast cancer has mushroomed: the New York Times and all U.S. magazines published a total of three stories in 1960 and 149 stories in 1995” (Corbett & Mori, 1999, p. 229). Interesting, considering that the overall mortality rate for breast cancer in the United States is virtually the same now as it was sixty years ago.

In a content analysis of cancer news coverage for 2002 and 2003, it was discovered that breast cancer received the highest amount of news coverage, followed by colon, prostate, and lung cancer respectively. “Coverage reflected incidence rates more closely than
they did mortality rates, but in both cases coverage under-represented the contribution of lung cancer to morbidity rates and over-represented the contribution of breast cancer” (Slater, Long, Bettinghaus, & Reineke, 2007, p. 1).

In October 1999, during National Breast Cancer Awareness Month, Phyllis Greenberger wrote in the Journal of Women’s Health & Gender-Based Medicine, “At a time when people are thinking about breast cancer, they should also be aware of the toll that other cancers take on women and the need for research to identify the causes, cures, and preventive techniques” (Greenberger, 1999, p. 1133).

She noted that lung cancer is the number one cancer killer of women and said that its primary cause – cigarette smoking – affects women differently than it does men. “Women who smoke the same amount as men are more likely to get lung cancer due to their greater susceptibility to the carcinogens in cigarettes. In fact, women with a shorter smoking history than men appear to be at increased risk for lung cancer” (Greenberger, 1999, p. 1133).

This would imply that an organization or advocacy group chiefly concerned with equality would be very interested in smoking rates and cessation campaigns for women. So, why isn’t lung cancer, the leading cancer related cause of death for both men and women, so highly recognized, researched, and funded?

Agenda-setting theory

Agenda-setting is “the idea that media don’t tell people what to think, but what to think about” (Baran & Davis, 2009, p. 279). The concept of agenda-setting has been around since the mid-1800s. According to Baran and Davis, “Walter Lippmann, in Public Opinion (1922), argued that the people do not deal directly with their environments as much as they
respond to ‘pictures’ in their heads. ‘For the real environment is altogether too big, too complex, and too fleeting for direct acquaintance. We are not equipped to deal with so much subtlety, so much variety, so many permutations and combinations. And although we have to act in that environment, we have to reconstruct it on a simpler model before we can manage it’” (Lippmann, 1922, p. 16) (Baran & Davis, 2009, p. 279).

Critics argue that modern agenda-setting theory is derived from mass society theory. Lippmann, perhaps the founding father of agenda-setting theory, believed that “average people just can’t be trusted to make important political decisions based on these simplified pictures. Average people have to be protected, and the important decisions have to be made by technocrats who use better models to guide their actions” (Baran & Davis, 2009, p. 279).

Bernard Cohen took Lippmann’s original beliefs and refined them into the basics of today’s agenda-setting theory. Baran and Davis credit Cohen with writing, “The press is significantly more than a purveyor of information and opinion. It may not be successful much of the time in telling people what to think, but it is stunningly successful in telling its readers what to think about. And it follows from personal interests, but also on the map that is drawn for them by the writers, editors, and publishers of the papers they read” (Cohen, 1963, p. 13). Baran and Davis also point out that Cohen’s beliefs were biased by limited-effects. The authors propose that Cohen “took a mass society perspective and revised it to make it compatible with the limited-effects perspective” (Baran & Davis, 2009, p. 279).

Maxwell E. McCombs and Donald Shaw conducted important research to add credibility to agenda-setting theory. They interviewed 100 registered voters who hadn’t decided for whom to vote in the 1968 presidential election. McCombs and Shaw asked the voters to list the key issues facing the candidates, whether or not they were actually talking
about them. The researchers then performed a content analysis of television news, newspapers, news magazines, and editorial pages. They found a high correlation between the items discussed in these sources and the key issues identified by the voters.

Critics question the causality cited in this theory. They believe that the McCombs/Shaw research didn’t really prove whether the key issues flowed from the media to the public or vice versa. Baran and Davis even cite McCombs as questioning the limitations of his own study.

However, other researchers, Shanto Iyengar and Donald Kinder, have demonstrated causality in agenda-setting. Baran and Davis cite their writing: “We found that people who were shown network broadcasts edited to draw attention to a particular problem assigned greater importance to that problem – greater importance than they themselves did before the experiment began, and greater importance than did people assigned to control conditions that emphasized different problems. Our subjects regarded the target problem as more important for the country, cared more about it, believe that government should do more about it, reported stronger feelings about it, and were much more likely to identify it as one of the country’s most important problems” (Iyengar and Kinder, 1987, p. 112).

Iyengar and Kinder also found that “dramatic news account undermined rather than increased television’s agenda-setting power” and that “[l]ead stories had a greater agenda-setting effect.” They also demonstrated that “through priming [drawing attention to some aspects of political life at the expense of others] television news [helps] to set the terms by which political judgments are reached and political choices made” (Baran & Davis, 2009, p. 281).
McCombs has expanded the theory by “linking it to a broad range of other media theories” including framing theory and second-order agenda-setting. Framing theory is “the idea that people use sets of expectations to make sense of their social world and media contribute to those expectations.” While second-order agenda-setting is “the idea that media set the public’s agenda at a second level or order – the attribute level (‘how to think about it’), where the first order was the object level (‘what to think about’) (Baran & Davis, 2009, p. 282).

McCombs claims that “conventional agenda-setting research has focused at the object level and has assessed how media coverage could influence the priority assigned to objects (e.g. issues, candidates, events, and problems). In doing this, media told us ‘what to think about.’ But media can also tell us ‘how to think about’ some objects. Media do this by influencing second-order ‘attribute agendas.’ They tell us which object attributes are important and which ones are not” (Baran & Davis, 2009, p. 282).

Further, according to Leslie A. Rill and Corey B. Davis, “Second-level agenda-setting theory explains that through media coverage of an event, the public will develop an opinion about the event based on the type of coverage the news gives to those specific attributes. By covering attributes in either a positive, negative, or neutral tone, the media help the public not only decide on the importance of the issues being covered but also how to feel about the issues” (Rill & Davis, 2008, p. 611). In other words, second-level agenda-setting theory says that media influence how an issue is defined.

Considering that agenda-setting theory directs the public’s attention to a particular issue, and second-level agenda-setting determines that issue’s definition, Robert Entman says about the interlocking theories, “Given limitations of time, attention, and rationality, getting
people to think (and behave) in a certain way requires selecting some things to tell them about and efficiently cueing them on how these elements mesh with their own schema systems. Because the best succinct definition of power is the ability to get others to do what one wants (Nagel, 1975), ‘telling people what to think about’ is how one exerts political influence in noncoercive political systems (and to a lesser extent in coercive ones). And it is through framing that political actors shape the texts that influence or prime the agendas and considerations that people think about” (Entman, 2007, p. 165). This leads to agenda-building.

**The influence of agenda-setting on a particular issue (agenda-building)**

Baran and Davis describe agenda-building as a macro-level theory, as opposed to agenda-setting which they call a micro-level theory. They cite Protess’ definition as “the often complicated process by which some issues become important in policy making arenas” (Protess, et al., 1991, p. 6). Baran and Davis also quote Kurt Lang and Gladys Lang (1983, pp. 58-59), “agenda-building – a more apt term than agenda-setting – [as] a collective process in which media, government, and the citizenry reciprocally influence one another.” In other words, institutions and even people can influence the media agenda.

The authors, Baran and Davis, go on to say that “[a]genda-building presumes cognitive effects (increases in knowledge), an active audience (as seen in the Lang and Lang definition), and societal-level effects (as seen in both definitions). Its basic premise – that media can profoundly affect how a society (or nation or culture) determines what are its important concerns and therefore can mobilize its various institutions toward meeting them – has allowed the line of inquiry, in the words of David Protess and his colleagues (1991), to ‘flourish’” (Baran & Davis, 2009, pp. 281-282).
For example, in a study about the issue agendas of the mass media, Congress, and the public from 1946 to 2004 conducted by Yue Tan and David H. Weaver, the researchers found that “there is a small but definite positive relationship between news coverage and public opinion. The causal direction is from the media to the public for international and government operation issues, and from the public to the media for defense issues.” (Tan & Weaver, 2007, p. 739). This example shows the two-way causal relationship between people, institutions, and the media.

People with direct personal experience are less likely to be influenced by the media than those with no personal experience. Joe Bob Hester and Rhonda Gibson conclude, “Researchers (Demers, Craff, Choi, & Pessin, 1989; Eyal, 1979; Lee, 2004; Winter & Eyal, 1981; Zucker, 1978) have found that agenda-setting effects are more likely to occur with media coverage of those unobtrusive issues with which people do not have direct personal experience. Because of the lack of direct experience, individuals must rely on mass media for information and interpretation of these issues. Thus media agenda-setting cues should be especially powerful. On the other hand, if individuals have a great deal of personal experience with an issue, it is obtrusive, and individuals will rely less on the mass media for salience cues” (Hester & Gibson, 2007, p. 301).

In a conference paper written by Uche Onyebadi, agenda-setting is carried a third step, now toward media influence on public action. The author says, “McCombs and Shaw did not explicitly indicate this third level in their original work, they have since produced other materials that indicate ‘the media may not only tell us what to think about….how and what to think about it, (but) perhaps even what to do about it”’ (Onyebadi, 2007, p. 13).
Given this overview of agenda-setting theory, how has it influenced breast cancer funding and research? Let’s first explore the topic of cancer and then examine the media’s possible role in elevating the importance of breast cancer.

**The influence of agenda-setting theory on breast cancer campaigns**

Many researchers have examined the impact of the media on public health. “Perhaps the earliest evidence of research that attempted to establish the agenda-setting role of the media regarding health behaviors was conducted by Pierce, Dwyer, Chamberlain, Aldrich, and Shelley (1987), who noted the ‘possible importance of an agenda-setting role for the mass media in promoting change’ (p. 816) among smokers targeted in an anti-smoking campaign. Later studies examined the role of media in setting the public agenda for health care reform (Hacker, 1996), AIDS policy (Backstrom & Robins, 1998), tobacco farming diversification (Altman, Strunk, & Smith, 1999), and smoking policy (Sato, 2003). Summarizing, Rogers (1996) specifically noted the importance of the ‘media agenda-setting process for health issues’” (Jones, Denham, & Springston, 2006, p. 97).

According to Jones, Denham, and Springston, mass media have a large role in communicating cancer messages to the public. “In a study of beliefs and expectations of women under 50 regarding screening mammography, Nekhlyudov, Ross-Degnan, and Fletcher (2003) found that, although participants generally preferred screening information supplied by a primary care provider, their providers actually played a limited role; most information came from mass media sources” (Jones, Denham, & Springston, 2006, p. 95).

According to Dr. Jeremy Shiffman, “The subject of public policy agenda setting has inspired considerable research, but little of that is in the field of public health. There has
been much greater attention in public health scholarship to a concept that is related to but distinct from agenda setting: priority setting. While those investigating priority setting in health have studied how scarce resources are allocated among health causes, their predominant concern has been how scarce resources should be allocated, a normative issue. Often they are motivated by uneasiness that resources and attention are not fairly distributed” (Jeremy Shiffman, 2008, p. 1).

About agenda-setting as related to public health, Shiffman continues, “Central to their inquiry is an interest in power. They investigate matters such as which actors are able to put issues on the agenda, how they come to hold this capacity, and how this influence alters agendas away from what might be considered a ‘rational’ allocation of resources” (Jeremy Shiffman, 2008, p. 2).

Shiffman offers an example very relevant to this paper’s research goal. “Reichenbach (2002), for instance, demonstrates that despite epidemiological evidence that cervical cancer presented a higher burden than breast cancer in Ghana, the latter received greater political priority. This outcome was due in part due to local politics as well as the influence of international women’s groups from North America, along with the higher incidence of breast than cervical cancer among wealthier Ghanaian women” (Jeremy Shiffman, 2008, pp. 2-3).

Further, Shiffman says, “…there are thousands of conditions in society causing harm that may become social priorities, including drug addiction, HIV/AIDS, road traffic injuries and homelessness. In practice, however, only a handful of these conditions become widely embraced social priorities (Hilgartner and Bosk 1988). Thus, we cannot explain how some problems become prominent and others are neglected by appeal to material facts alone: we
must also consider social processes, such as how problems are defined and framed, who holds the power to define them, and how interest groups mobilize to advance their agendas” (Jeremy Shiffman, 2008, p. 3).

Non-profit organizations have the power to shape the media’s agenda. According to a study by Patricia Curtin, “Given nonprofit or government agency status, however, if the materials contain news value and are written in news style, the interview data suggest they can pass almost unimpeded through media gatekeepers” (Curtin, 1999, p. 34).

Qi Qui and Glen Cameron said of Curtin’s study, “Actually, according to the reporters and editors being interviewed in Curtin’s study (1999), nonprofits’ public service motivations could translate into news values, which contributes to their power in shaping the media agenda. As evidence, the Media Agenda Building on Prosocial Causes study found that only nonprofit materials have shown up in the hard news content verbatim, and materials from profit-driven public relations practitioners are used only as section fillers or to gather story ideas where PR has no control over the content. By this token, agenda-building is a particularly useful concept in health communication and other pro-social causes that represent the nonprofit, public service-driven sector” (Qiu & Cameron, 2006, pp. 6-7).

Agenda-building may commonly occur through issue advocacy, though that’s not necessarily always to the public’s benefit. “Despite the seemingly innocuous nature of issue advocacy, some researchers suggest that issue advocacy may be a particularly effective means of both image building and influencing policy because of its unique ability to persuade without seeming to do so. Its simplistic nature, often appealing to commonly shared values, belies the potential of issue advocacy to distract attention from serious questions about organizational policies and public issues (Bostdorff & Vibbert, 1994). Moreover, changes in
commercial speech laws and the refinement of marketing techniques have resulted in a blurred line between editorial content, PSAs, and paid advocacy, creating a cacophony of advocacy messages making thoughtful policy discussion difficult (Bostdorff & Vibbert, 1994; Sinclair & Irani, 2005)” says Barbara Miller (Miller, 2006, p. 1).

An organization, such as the Susan G. Komen Foundation, with millions of dollars in funding and an active grass-roots network, may have much influence as an agenda-setting power for the media and the public. “Resource mobilization theory suggests the resources activist groups possess is tied to tactics they employ to achieve their goals, which may include supportive news coverage. Resource-rich groups have the ability to do, say, and produce more things that are newsworthy. Activists could provide news releases, news conferences, and other types of information subsidies that generate news content” (McCluskey, 2008, p. 770).

Further, McCluskey contends, “For instance, Greenpeace used video subsidies to news organizations to gain media access and the National Organization for Women used studies, legal research, campaigns, and a news service as information subsidies. Nearly half of newspapers receiving press kits on an environmental report published stories. Groups with greater resources receive more news coverage. Membership size and budget were linked to more news coverage, both in analysis of the National Organization for Women and a broad range of interest groups” (McCluskey, 2008, p. 770).

McCluskey’s study found that “…some group resources, goals, and communication strategies were tied to publicity beneficial to activist groups, giving them fuel to influence public opinion and potentially change public policy.” Additionally, “[a]nalysis showed that some group resources were significantly tied to the tone of news coverage, expanding upon
previous findings’ that more resources led to more news coverage” (McCluskey, 2008, p. 778).

In a January 2008 article from The Non-Profit Times, while providing a reason for the rise in Komen’s total 2007 expenses of 23 percent, Kevin Speirits, CFO of Komen says, “The additional expenses in the last year have been driven by a couple of things including the sheer growth of the organization and a rebranding initiative for its 25th anniversary” (The Nonprofit Times, 2008, p. 6).

The article continues by saying, “During the next three to five years, Komen seeks other areas to grow, including expanding globally, Speirits said. ‘We really want to try to become a global leader in health awareness in breast cancer,’ he said, which will require investments domestically and overseas” (Hrywna, 2008, p. 6). Speirits also claims that the organization’s revenue has grown at a compounded rate of 22 percent over the past five years.

Based on the previous literature review, this study seeks to answer the following questions.

RQ1: What is the public perception of cancer mortality rates by cancer type?

RQ2: What is the public perception of cancer diagnosis rates by cancer type?

RQ3: Do breast cancer public relations / fundraising campaigns affect the overall perception of cancer mortality and diagnosis rates by type?

RQ4: Why does breast cancer receive so much more federal funding and fundraising efforts than other types of cancers, particularly lung cancer – the leading cause of cancer related deaths?
Chapter 3

Method

This study used a two-step methodological approach of quantitative and qualitative research: an Internet survey and depth interviews. The research method was triangulated, because “…one procedure that almost always produces better data is triangulation: using multiple methods to view a single object” (Huettman, 1993, p. 42).

Internet survey

An Internet survey was conducted first to begin the inquiry of public perceptions and cancer related issues. This pilot study asked a mixture of closed and open ended questions about perceptions regarding leading cancer diagnoses and deaths by type, as well as basic knowledge about local breast cancer awareness and fundraising campaigns.

A link to the Internet survey was e-mailed to registered Ball State University students, faculty and staff with valid e-mail addresses, who were subscribed to relevant Ball State University Communications Center mailings. The population included predominantly individuals between the ages of 18 and 24 from both genders, though the majority of participants were female. Respondents were anonymous.

The e-mailed link garnered 109 surveys, which was less than one percent of all Ball State University Communications Center subscribers. However, the surveys provided enough data to inform the depth interview questions.
Depth interviews

Participants for depth interviews were selected based on snowball sampling. The researcher found populations of experts in the cancer field on national, regional, and local levels that met certain criteria for knowledge related to federal funding, awareness campaigns, and/or advocacy. Initial interview participants were selected based on their knowledge, but referrals were requested from those participants and others in the medical field.

Approximately 50 potential participants were contacted via e-mail and telephone. From the pool of potential participants, the interviewed experts included 12 from national or nationally renowned organizations, 4 from regional organizations, and 9 from local organizations for a total of 25 depth interview participants.

Interviews used a semi-structured format with follow-up questions. Participants from the same types of organizations were asked the same initial questions in the same order to add validity and reliability to the individual interview sessions. All questions were open-ended to gain a better understanding about the reasons behind public perceptions about cancer, cancer research and its funding.

All interviews were recorded and then transcribed. In order to protect the identities of the participants and to allow them to speak freely, any names used during the interviews were changed to pseudonyms when they were transcribed. Organization names and position titles are also not reported with the results. A list of general position titles and organization types can be found in the appendix, along with the randomly assigned code that identifies each participant.
Chapter 4

Results

The following are results from the Internet survey pilot study and depth interviews. Internet surveys were collected May 6 – June 18, 2010. Depth interviews were conducted June 3-16, 2010.

RQ1: What is the public perception of cancer mortality rates by cancer type?

Internet survey

According to the pilot study, 52 percent of respondents believe that lung cancer is the leading cause of cancer related death in the United States, followed by breast cancer at 20 percent and melanoma at 8 percent (Figure 4.1).

Figure 4.1

Perception of Cancer Mortality by Type
Depth interviews

Throughout the course of depth interviews, participants often generalized cancer mortality rates and their own perceptions.

Breast cancer

Participant C said, “…the fact that everyone knows someone who has died of breast cancer” (June 10, 2010).

Participant V said, “Breast Cancer is the number one, it’s the most feared disease cancer that women have” (June 8, 2010).

Lung cancer

Regarding the mortality of lung cancer, Participant P said, “In lung cancer, regrettably, it’s getting better, but regrettably many of these patients will die before they have too many years to reoccur. So it’s a higher [diagnosis] rate but the patient volume coming in to be treated is far less” (June 10, 2010).

And Participant S said, “I really don’t see the deaths in lung cancer as being high, because usually the people that we see are surgically resectable. So we cure them. We just saw a patient last Thursday that is six years out from a stage two lung cancer that we cured. So, we deal more with curing somebody. So, I normally don’t see the patients that are terminal” (June 14, 2010).

Breast cancer vs. lung cancer

Others compared and contrasted the mortality rates of breast cancer and lung cancer. Participant E said:
If you’ve got stage one breast cancer, you’ve got a 98 percent five year survival rate. If you’ve got stage one or two lung cancer you’re probably in the 50 to 60 percent range… And breast cancer has been a disease that’s…affected a large number of American women. It’s second only to lung cancer in its mortality rates…

Whereas with lung cancer… it clearly has a higher mortality rate, is because it’s an environmental impact either through smoking or radon or working in the mines…it develops over a lifetime… There may be a lot more different forms of lung cancer than there are breast cancer[s] and it is therefore [a] much more difficult disease to study or to find a treatment for (June 14, 2010).

Participant W said, “It’s [breast cancer] not the most common cancer killer, it’s second to lung cancer which is only due to the smoking habits women have” (June 9, 2010).

Participant T said:

On the flip side lung cancer… five year survival rates are 15 percent… if you look on the Web sites they’ll talk about it not being a death sentence, but it is a death sentence. If you have lung cancer, you are going to die from it… We don’t have a magic bullet – medication. However, if you look at breast cancer, those survival rates are anywhere between…95 to 98 percent… And lung cancer people, they just don’t survive. So there’s not the same need there (June 14, 2010).

Other cancer types

Many depth interview participants briefly mentioned other cancer types. Participant H said, “Colon is another big one that’s like one in 1200, so it’s still not anywhere close to breast cancer” (June 3, 2010).

Participant E also said, “Well, you know, the ultimate paradigm there is look at the Pancreatic Cancer Action Network. You’ve got from diagnosis to death an average of six months sometimes” (June 14, 2010).

Participant K said, “but some cancers like pancreas cancer has a terribly high mortality and is probably the fourth or fifth most common cancer in the country and doesn’t receive much public attention, because there’s not much that can be done about it” (June 9, 2010).
Participant M said, “The data drives everything that we do. So we looked at the cancer registry data and the top four cancer killers are lung, breast, prostate and colorectal” (June 10, 2010).

Participant N said, “If you look at colorectal which is top one, two or three, I am not sure I know the right number…It’s a top three disease site and only 5 percent of people have a five year survival” (June 3, 2010).

Participant T also said, “But if you are diagnosed with cervical cancer, your chance of survival is much, much lower because you are getting diagnosed much later” (June 14, 2010).

**RQ2: What is the public perception of cancer diagnosis rates by cancer type?**

**Internet survey**

According to the pilot study, 32 percent of participants believe that breast cancer is the most common diagnosed cancer type, followed by nonmelanoma skin cancer at 30 percent, lung cancer at 17 percent, and melanoma at 12 percent (Figure 4.2). Further, 89 percent of participants indicated that they, a family member, or friend had been impacted by cancer. The highest incidence reported by participants touched by cancer was breast cancer at 64 percent (Figure 4.3).
Figure 4.2

Perception of Cancer Diagnosis by Type

- Breast: 32%
- Skin (nonmelanoma): 30%
- Lung: 17%
- Melanoma: 12%
- Other Types: 9%

Figure 4.3

Participants Touched by Cancer
Reported by Type (%)

- Breast: 60%
- Lung: 40%
- Thyroid: 30%
- Pancreatic: 20%
- Melanoma: 15%
- Colon/rectal: 10%
- Leukemia: 5%
- Skin (nonmelanoma): 4%
- Other: 1%
Depth interviews

Throughout the course of depth interviews, participants often generalized cancer diagnosis rates and their own perceptions.

Breast cancer

Many depth interview participants commented on the prevalence of breast cancer among friends and family members. Participant C said:

It’s very relatable, it’s very personal, everybody has a mom, has a sister, has a daughter and many of them have been touched by breast cancer. I don’t know of a single person in my life that hasn’t been touched in some way by breast cancer. And so...the two biggest risk factors for breast cancer are being a woman and getting older. That can’t be said for every cancer. I think there’s a certain element of defenselessness that people relate to (June 10, 2010).

Participant E said, “I think people still have a great fear of cancer, justifiably so, especially breast which affects one in three people in their lifetime” (June 14, 2010).

Participant J said:

I think that from my perspective that we’ve come a really long way in breast cancer. The five-year survivor rate when it’s caught early is now 98 percent. So you have such a larger group of survivors that are able to advocate on behalf of the disease. I think the statistic is 2.5 million survivors…

…Because it affects everyone. I mean, the statistic is one in eight women is diagnosed with breast cancer in their lifetime. So it’s not hard to get eight people in a room and see how many people could be diagnosed. It’s really hard to find someone who doesn’t have a mother, a cousin, a daughter, an aunt, a sister who has been touched by breast cancer. So unfortunately it just touches so many people (June 8, 2010).

Participant H said:

…one out of 184 women are diagnosed every year with breast cancer, where it’s something like one in 800 for lung which is one of the other major diseases. So, that’s like a five-fold difference in the number of women that are affected. So,
the incidence of breast cancer is so high that an enormous number of people are
affected by it either directly or indirectly… (June 3, 2010).

Participant M said, “I think that there’s just this emotional tie to it because all of us
have been touched by it. It’s not just – the women in our lives that are so important to us –
our mothers, our sisters, our grandmothers” (June 10, 2010).

Participant Q said, “You just go back and look at the incidents of cancer and there’s
no doubt that breast is always the leading cause of cancer” (June 14, 2010).

Breast cancer vs. other cancers

Many depth interview participants compared and contrasted breast cancer diagnosis
statistics to other types of cancers.

Participant D said:

…the big three cancers that affect people are lung cancer affects both, prostate
and breast are two that are gender specific…heart disease kills more women than
breast cancer by a lot. But people, women don’t talk about heart disease much.
They do fuss about breast cancer a lot…

…Yes, we are doing much better at diagnosing and treating breast cancer than
we did 20 years ago. For lung cancer, you know I can’t say that we have the same
breakthroughs. I mean the best thing for lung cancer is prevention which is you
know don’t smoke, don’t start and if you are stop. But that’s easier said than
done (June 11, 2010).

Participant H said, “And maybe part of it is this thing that it’s people’s mothers that
are getting breast cancer. But it’s got to be the incidence is so high as well. The other closest
one is lung, which is connected to smoking” (June 3, 2010).

Participant Q said, “Typically in Indiana…your three highest incidence cancers are
breast, prostate and lung. Typically you’ll see colon and then you’ll after that see a cadre of
other cancer sites that are of higher incidence” (June 14, 2010).
Participant W said, “…breast cancer is the most common cancer women have. It’s not the most common cancer killer; it’s second to lung cancer, which is only due to the smoking habits women have. Unfortunately, lung cancer although there’s been progress, it’s nothing like what has happened with breast cancer” (June 9, 2010).

Participant P discussed the differences in required care between breast and other cancers:

So, the overwhelming patient population that we see in our private practice network is breast cancer. It actually, I believe, doubles the next closest patient group that comes in the door, which is non-small cell lung cancer. And so with that understood we look at as a corporation we need to serve the needs of the practices. And the practices in turn are serving the needs of patients walking through the door. But if we just look at who is the customer, overwhelmingly, it’s breast cancer.

…it’s a cultural phenomena. Breast cancer is easier to screen for and so you don’t have to go through an academic center where they might have different facilities in place… So if their disease, like certain types of AML [acute myeloid leukemia] – require hospitalization, then they need to go to an academic hospital system. Breast cancer is not that case. So that’s why the overwhelming number of cases we see that walk through the door are breast cancer.

So, yes, maybe there is more lung cancer, but those patients are required to be hospitalized. And we can’t. The other thing is that breast cancer being treatable – much longer survival rates. Much longer. These patients, incredibly [in] the majority of these patients it will reoccur…10 to 20 years ago [with] breast cancer the patient was treated very early in the stage of their disease. They might reoccur in six months or eight months. Now that same patient might be disease free for two, three, four years but if they reoccur it’s a much better prognosis for that second reoccurrence than before. So these patients are coming into a private practice system because their disease is much more treatable (June 19, 2010).
RQ3: Do breast cancer public relations / fundraising campaigns affect the overall perception of cancer mortality and diagnosis rates by type?

Internet survey

According to the pilot study, 95 percent of all participants were aware of breast cancer campaigns such as Komen’s Race for the Cure or the American Cancer Society’s Making Strides Against Breast Cancer, while 79 percent were aware of fundraising or awareness campaigns for cancers other than breast cancer.

Also according to the pilot study, 37 percent have participated in breast cancer campaigns such as Komen’s Race for the Cure or the American Cancer Society’s Making Strides Against Breast Cancer, while 39 percent have participated in cancer campaigns to raise awareness or funding for cancers other than breast cancer (Figure 4.4).
**Figure 4.4**

**Cancer Campaign Awareness and Participation (%)**

<table>
<thead>
<tr>
<th>Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have participated in other campaigns not related to breast cancer</td>
<td>39</td>
<td>61</td>
</tr>
<tr>
<td>Have participated in breast cancer campaigns such as Komen or Making Strides</td>
<td>37</td>
<td>63</td>
</tr>
<tr>
<td>Aware of other cancer campaigns not related to breast cancer</td>
<td>79</td>
<td>21</td>
</tr>
<tr>
<td>Aware of breast cancer campaigns such as Komen or Making Strides</td>
<td>95</td>
<td>5</td>
</tr>
</tbody>
</table>

**Depth interviews**

To understand the sheer size of one national breast cancer non-profit advocacy group, consider the comments from Participant C:

… The [large national breast cancer organization] is the national and global organization that raises funds through donations, through sponsorships and through the race series. You also have about 120 affiliates nationwide. And they are each affiliated organizations but they have their own organizational structure, their own board of directors. And they raise their own funds. So each one of them, for the most part, they run their own races, they have their own series of fundraisers, they have their own sponsorships. Seventy-five percent of the funds they raise in general stays at the affiliate level and provides breast cancer services through their local community grants for their service area. And then you also have the advocacy aspect. And that is a separate organization as well. It’s a 501(C)4 organization…(June 10, 2010).
Participant R commented on the scope and influence of that national breast cancer organization and used their key messages:

…based upon having volunteered for [large national breast cancer organization] for six years…everywhere you turn someone has been touched by it. Or what I mean by that is someone has a sister, a mother, an aunt, a person they work shoulder to shoulder with every day who’s been touched by it. And it just feels pervasive and in many ways that personal connection is really what drives people to feel passion. We certainly wish it weren’t so pervasive but the good fortune is that treatment and diagnoses have changed over time and we are finding better ways to diagnosis breast cancer…versus pancreatic cancer for example.

And I am not a physician but in many cases, by the time pancreatic cancer is diagnosed, the person is just living in a matter of months – or a nominal amount of years because of the manner in which a diagnosis is found. Whereas with breast cancer for example you can be much more proactive in finding things that seem sufficient at a very early stage. So I would say that’s part of it as well: that there’s a lot of hope around people’s lives with breast cancer that it can be defeated (June 14, 2010).

Of the power that a national breast cancer organization has, Participant T said,

“[National breast cancer organization] has been a part, either a funder in full or a funder in-part of every major breast cancer advancement in research over the last 20 years” (June 14, 2010).

On the partnership with breast cancer national organizations, Participant X said:

[Our] partnership began in 1992, in recognition that breast cancer affected so many women and through affiliating [our organization] with Komen for the Cure we could make an impact in this community and ultimately around the world though the combined investment on local breast cancer programs that provide screening and education as well as (now global) funding of breast cancer research. The high level of focus on breast cancer is the result of the combined factors of high numbers of incidence and mortality, that awareness leads to increased screening which directly affects mortality and the enormous efforts of Susan G. Komen for the Cure over the past nearly 30 years (June 9, 2010).

Participant L said:
When we started from a statistical standpoint...seeing breast cancer diagnoses skyrocket, I mean it was close to surpassing lung cancer, it was close to surpassing cardiac, everyone just started pushing the panic button. And this was in the 90s...it was really just kind of a dark period. We didn’t have a handle on breast cancer at all...it was almost an epidemic. And everyone again just started trying to figure out what to do. Of course, from a business standpoint, this was seen as a large opportunity. And I think that there’s been some just extremely talented people who have gotten involved with that even locally have been involved with breast cancer and they saw the grass roots efforts and they really kind of got behind the emotional story that goes along with the diagnosis. And they are able to tell the story. You think about the Race for the Cure. Although, is that Race for the Cure ever going to raise enough money to find a cure for breast cancer? No – probably not. But you know what it does do? It makes some people think about self breast exams, prevention, awareness. It just puts a story to it (June 16, 2010).

Participant E said:

I think people still have a great fear of cancer, justifiably so – especially breast which affects one in three people in their lifetime. There will always be that desire to fund it so there is hope for treatment or cure. A cure is much more elusive in most people’s understanding, but for most people treatment for a prolonged cancer free life is what a lot of people would be shooting for (June 14, 2010).

About other types of cancer campaigns, Participant U said:

…the American Cancer Society for years promoted the Great American Smoke out and I haven’t heard too much about that lately. And that was because they were aware of the high cost of smoking particularly causing…many different types of cancer not just lung cancer which is a particularly fatal…obviously it’s not totally fatal. But it does have a high mortality and morbidity rate. And many different cancers not just the lung cancer so they really pushed that for years as an awareness campaign (June 15, 2010).

Internet survey

Also according to the pilot study, 84 percent of participants agreed that breast cancer public relations / fundraising campaigns address issues that are important to them, while 43 percent were neutral about a need for cancer campaigns to address different issues from what they currently address.
Depth interviews

Participant N said, “…awareness campaigns originate from advocates who are passionate and want to do something. And they seem to be primarily driven from female survivors” (June 3, 2010).

When asked about priorities for campaigns conducted by their national breast cancer non-profit organization, Participant J said:

… it’s just raising the funds in general. And then, two, educating and raising awareness for people about breast cancer. Because you know even though in the United States pretty much everyone knows the seriousness of breast cancer and even sometimes the specifics, there’s still a lot of misinformation out there. One, in the United States and then other countries like Africa and developing nations they are very much still where we were 30 years ago. The word breast cancer isn’t even mentioned aloud and in some cases people still think it’s contagious and husbands leave their wives and things like that after diagnosis. So providing that awareness and education piece is also critical for us (June 8, 2010).

Participant T said:

Definitely breast cancer is the easiest one to fundraise for…Again I think it goes back to two reasons: impact of funding. We can have a good impact on decreasing the incidence of breast cancer with prevention…it’s free from judgment in terms of ideology of the disease if you compare it to…lung cancer. Smoking is the number one reason people get lung cancer. Of course others can get it without smoking…people can have a judgment about that. Breast cancer is free of that…other than genetics, there’s not one particular defining reason why a woman gets breast cancer or a man. We are able to have a bigger impact with breast cancer as compared to lung cancer (June 14, 2010).

Participant D said:

…you do not see ads for men and prostate cancer on television or anywhere else. You don’t see much about lung cancer…it’s only cigarettes… you see ads to help people stop smoking, but those have sort of a commercial twist and not usually trying to address the fact that smoking causes lung cancer. So I think breast cancer is the most organized and the most aggressive and the most effective probably [in] campaigns (June 11, 2010).
Participant U said:

…when we had a women’s program that I participated in several years ago…mainly directed toward breast cancer, but I also tried to set up a booth to get people aware of the best thing you can do for your health is to stop smoking…because we know that in the long run, they are much more likely to be killed, more women being killed by lung cancer than they are by breast cancer, so we had a lot of women there. We were trying to get this message across. Nobody wanted to listen to that…they’re keyed into the breast cancer. They don’t want to listen to the other…there’s even [the influence of] the public’s receptiveness to listening to the message. People don’t want to change their behavior. They [will] change it when they are ready to (June 15, 2010).

Participant S said:

…they end up with these lung cancers. Not just smoking but environmental hazards…asbestos and chicken excrement and stuff like that…there is a stigma involved…Well, I think it’s sad. That you know if there’s research with lung cancer it’s also going to promote awareness. Because there are so many – I don’t know how many times a month I hear from lung cancer patients that are currently smoking. Or even people who are not diagnosed who say ‘hey I have heard that if they quit smoking that this cancer is going to grow faster.’ It’s like, they don’t know…or [they’ll say] ‘I was told it wasn’t caused from my smoking, you know, it was caused from pollution.’ I think if the awareness is out there it might change things. But I think sometimes the damage is done years in advance. A lot of ex-smokers – you see those old farmers who started smoking when they were 13, quit when they were 35, now they are 74 now with lung cancer (June 14, 2010).

Participant K said, “I mean cancer is now the number one cause of mortality in this country. It has now surpassed heart disease. And we’re making great strides in some areas and not in other areas. And, you know, now is not a time to be shy on funding cancer” (June 9, 2010).

Internet survey

According the pilot study, 71 percent of participants pay attention to breast cancer campaigns when they appear in the media.
Depth interviews

The power of the media was mentioned quite a bit during the interviews. For example,

Participant U said:

Particularly, things that have a lot of mortality and morbidity obviously things like lung cancer, should still require a lot of attention from us, because of the high morbidity and mortality associated with it. And unfortunately, part of the problem with that is a lot of it could be prevented but people won’t change their habits and so – that may be a part of the reason why it doesn’t get as much press…as other things like breast cancer for example (June 15, 2010).

Participant A said:

But when you look at the press and you look at women’s advocacy groups…and here’s somebody talking for breast cancer, do they show a 70-year-old? No, it’s always the 44-year-old mom who is going to get the spotlight.

And you understand quite clearly from a spin point of view why that person is in the spotlight and why the 74-year-old isn’t there. And yet numerically they are missing the point. From an emotive point of view so mom and her young children have more potential for doing things in their life are clearly the factors and they’re picked up by the press hungry for good tear-jerking emotive stories. So I think what it gets down to when these organizations sit down and strategize, they are really looking at how can we get the fire started out there among people who can give us money (June 10, 2010).

Participant O said:

…women are very concerned about breast cancer. They are becoming more and more aware…So that is increasing quite a lot in diagnosing it early – compared to other diseases like for example disease types for example prostate and lung…there has been lots of…media that was concentration on breast cancer…I haven’t heard of a man who said, ‘I am getting all this money for cancer research’ as much as you have in women….besides the Susan G. Komen Foundation we have many other foundations also for breast cancer (June 15, 2010).

Participant Q said, “You just go back and look at the incidents of cancer and there’s no doubt that breast is always the leading cause of cancer….And so that typically gets a lot of the attention and a lot of the press just in volume alone” (June 14, 2010).
Participant L said:

I think that we’re probably a little bit unrealistic to think that capitalism doesn’t play a role in this. It does, or whatever is the flavor of the day, that public opinion can wrap itself around kind of whatever the media feeds us. From that, we do seem to have an appetite for that. I just caution us to be aware of that. And then not to try to forget some of the more vulnerable patients that are afflicted with some of the less accepted, if you will, diagnoses from their choices (June 16, 2010).

RQ4: Why does breast cancer receive so much more federal funding and fundraising efforts than other types of cancers, particularly lung cancer – the leading cause of cancer related deaths?

Internet survey

According to the pilot study, 23 percent of all participants said that breast cancer was the most important type of cancer or cancer related issue, followed by lung cancer at 13 percent (Figure 4.5). Participants named many other types of cancers, along with research, funding, cures, and treatments, but nothing was named with the any degree of regularity, and especially not the same regularity as breast cancer and lung cancer.
Figure 4.5

Type of Cancer Most Important to Participants

Depth interviews

Cancer advocacy and awareness campaigns

One participant described how their organization determines which cancer type would benefit from an awareness campaign. Participant B said:

…most of them [awareness campaign decisions] are made in collaboration with what we call the Iowa Cancer Consortium. And this is not only the Cancer Center, but the Department of Public Health, the American Cancer Society, and other advocacy groups across the state where we get together and decide which areas of cancer control we think are best to fund (June 10, 2010).

The direct impact of the federal government

Participant L specifically discussed the role of the federal government in cancer advocacy: Participant L said:

I think the federal government ultimately controls cancer research with the FDA and also with the National Cancer Institute. And they definitely can be
swayed…from public opinion, from advocacy, from lobbyists, from large public organizations – and I think we’ve seen that in recent years. If there’s a new treatment, a new breakthrough for cancer diagnoses, we all know it has to be FDA approved. And the federal government has held the strings to that so they’re very much in the driver’s seat from my perspective in regards to funding… I think they’re very much impacted by public opinion or what they perceive as being public opinion and big business and lobbyists and ultimately votes (June 16, 2010).

When asked how the federal government impacts cancer awareness campaigns,

Participant C said:

You know the war on cancer started back in the 1970s. It’s a matter of whether or not the government decides to put cancer research and cancer awareness as a priority item. And do it through the CDC and its public health campaigns. You know we were active just recently in trying to establish a new law to create an awareness program for younger women. And we were successful in getting that enacted as part of the recent health care reform bill. But as a matter with public health campaigns, with getting into the schools, working with the CDC to write public programs where they talk about the importance of awareness and early detection and really explain to people through a variety of forms what their risk factors are and what to be aware [of] (June 10, 2010).

When asked about any concerns that advocacy groups might have more influence or attention than they should, Participant K said:

Well, yes. That always happens. There’s always perhaps a cancer or a health issue that’s getting a lot more resources than…the mortality or the morbidity than that issue deserves…But I think those tend to be for short times and they seem to balance out fairly quickly… That’s always a worry, are you putting more money in one area than you should. I think the same thing has happened in breast cancer. Is it getting more attention than it really should? And you know it’s hard to know. It’s an incredibly important cancer that needs lots of resources, but should we be putting some of those into colon or pancreas…? Those are hard questions to ask and hard questions to balance. But I think the public advocacy makes us aware of the issues and they need to be responded to. And the over time those need to be balanced with what is scientifically available to address the questions and what overall health improvements need to be made by addressing those specific questions (June 9, 2010).
Breast cancer advocacy

Many participants specifically discussed the power of breast cancer advocates.

Participant B said, “I think first of all, very importantly, it’s the strength of the advocate community. I think it’s the very personal nature of breast cancer to women. It’s an organ that’s slightly different than some of the others. And I think its frequency [of diagnoses]... (June 10, 2010).

Participant D said:

I think breast cancer is the most organized and the most aggressive and the most effective probably in campaigns...[breast cancer is] one of the big three cancers and next to lung cancer it is the leading cancer for women. Two is there are opportunities; there’s breakthroughs to at least explore. And, three, there’s a very powerful advocacy group (June 11, 2010).

Participant K said:

Public advocacy groups play a very important part in health research. Fortunately, public advocacy groups in the cancer area specifically, but in health care in general, tend to bring to light very important issues that need funding. There’s a great breast cancer public advocacy group, and many cancers have public advocacy groups of one form or another that do fundraising, but they also do advocacy...I think at all levels we want to pay attention to those needs. You know we want to treat them appropriately, but public advocacy groups tend to be pretty pristine themselves when it involves cancer. They’re interested in curing a certain type of cancer, so I think it’s important to consider their advocacy... (June 9, 2010).

Participant F said, “...Without question the advocacy community in breast cancer is very large, very vocal and quite active. There’s no question that that has some influence on it [breast cancer research funding]” (June 15, 2010).
Participant J said, “I just think it’s an easy way for people to show their support of the cause. All it takes is just a ribbon or a sticker or anything pink and then people associate that with the support of breast cancer” (June 8, 2010).

Many participants mentioned the sheer number of breast cancer survivors who become advocates. Participant U said:

… The other thing is it [breast cancer]…affects women of all ages although it’s more common in an older woman. The fact that younger women can be affected and sometimes are affected in a time where they may be in the prime of their life, they have young children, so the emotional impact is very strong. And therefore this brings out a lot of people, both breast cancer survivors – and there are large numbers of them…and it also brings out people who are being treated for breast cancer, and therefore are going through therapies. That’s a large number of people, and many of their relatives, who then may be at risk or feel that they are at risk…So this brings out a large number of people who are emotionally involved and committed. First, they have a strong voice and people hear it and they feel for them, and therefore they get involved and contribute in a variety of ways (June 15, 2010).

Participant X said:

…there are 2.5 million breast cancer survivors in the US – the largest number of cancer survivors of any type. Susan G. Komen for the Cure is leading the way related to the breast cancer movement, and many other organizations have successfully leveraged the passionate and commitment of survivors to address the significant problem of breast cancer (June 9, 2010).

Participant J contrasted the number of breast cancer advocates with lung cancer advocates:

But you know when you have a [breast cancer advocacy] group that large that is still living and able to have a passion for the disease and raise money for it, I think that lends itself to so much more awareness and attention as opposed to something like lung cancer that, it’s just caught in such a late stage, that unfortunately most of the people don’t live past a very long diagnosis, so that you don’t have very many people (June 8, 2010).

Participant V also contrasted the numbers of survivor advocates:
…For instance, lung cancer, we often don’t have survivors. Or if we have survivors they may not have the energy to walk on Washington or to sort of rally the troops. The same thing with colorectal cancer. It’s right up there as one that’s quite honestly preventable, but it’s not very romantic to talk about. There [are] still taboos about talking about colonoscopies, and so I think part of it is just the anatomy or the body site. Some things that we definitely need research money on are things like pancreatic cancer. Most people don’t even know where that is…(June 8, 2010).

Participant C carefully outlined their organization’s advocacy efforts:

The [large national breast cancer organization] Advocacy Alliance was founded in 2007. And really was a growing process. [Our organization] has always been active in all areas of the breast cancer movement, both in the awareness, the research, and advocacy both the state and federal level. And there are certain laws and IRS regulations that govern how much of your budget can be used for direct lobbying. And we had found that over the years as we were becoming much more active and [the] impact of our work was becoming much more needed, we found that we were starting to get close to but not surpassing those caps that they have for your traditional 501(C)3 organization. And so they developed the [501](C)4 and moved all of the public policy functions from the national organization into that separate organization so that they could be much more active and aggressive in their advocacy work (June 10, 2010).

When asked about their advocacy priorities, Participant C said:

One is advocacy support for the affiliates at the local level as they’re doing their own advocacy campaigns looking for, to protect and increase funding for state and local screening programs or a variety of other policy issues. And then it provides the direct lobbying at the national level on our national public policy priorities. Over the last year, that has been primarily focused on patient protections as far as the overall health care reform debate. But there’s also included the need for increased funding for cancer research at NCI, and also for the awareness campaign that I mentioned before for younger women. And right now we’re actually in an effort to help support the state programs pushing for an extension of the enhanced Medicaid match for the states to help provide an additional support for the state budgets, who are looking to cut breast cancer services because of their growing deficits (June 10, 2010).

When asked why their advocacy efforts had been so successful, Participant C said:

Well the number one reason is [our founder] and her power and drive and power of that promise that she made [to end breast cancer]. Number two is the power of the grassroots. I mentioned that we have 120 affiliates nationwide. There are
2.5 million breast cancer survivors living in the United States today. And we have really become the global voice for those survivors and the people that love them. And then I would say also that one of the things that has differentiated us and really has enabled us to have so much success from an advocacy standpoint is that we know that cancer does not discriminate based on political party or race or ethnicity and neither do we. We’ve been very nonpartisan in our approach and we’ve worked very closely with leaders of both political parties to get things done and that’s helped us along the way (June 10, 2010).

When asked if breast cancer advocacy groups make a difference, Participant N replied:

I would say that to be very clear, it is a categorical, unequivocal yes. There has been no force probably across the spectrum of advocacy whether it’s…cancer, or diabetes, or anything that is as effective as that organization. And so, you know, they’re just a force to be reckoned with. I don’t know that their actual dollars that they contribute change it, but their whole perception has forced a lot of people into the field, and it has changed their funders and I would say definitely influences how the federal government makes their decisions (June 3, 2010).

One participant praised the efforts of breast cancer advocates. Participant G said:

Well, I think it’s [breast cancer] been a focus of an advocacy group that’s just been extremely successful in getting that word out. They’re very dedicated and they’re very devoted and I think it’s just a blessing to have those people sort of on the job to do the lobbying and the fundraising and all that. It’s just unfortunate that some other types of cancer it hasn’t led to that kind of a focus group that is so avid and dedicated to raising funds and creating awareness. I think people look at the breast cancer community as an example of how they can…mobilize those resources and make it happen. And most others are just behind, you know, in terms of the time frame of being able to get all that together… I think that even in colon cancer and some other cancers it’s still not at that level as breast cancer, probably just because the level of expertise and effectiveness of the advocacy group is not at that point (June 15, 2010).

Internet survey

According to the pilot study, 77 percent of all participants believe that breast cancer receives the most public and private funding for research, while 15 percent believe that lung cancer receives the most funding (Figure 4.6). Also according to the study, 48 percent are
neutral when asked if they believe that public and private funders are properly allocating money to research the most important cancer issues.

**Figure 4.6**

*Perception of Top 3 Cancer Types That Receive Public and Private Research Funding*

Depth interviews

Cancer funding

The federal government was mentioned by interview participants as a factor in priorities for cancer research funding.

For example, Participant B said, “As with everything else [for funding] it’s a mixture of specific pet projects of senators and legislators, pressure applied by different advocacy groups, and many other factors” (June 10, 2010).

Institutional bureaucracies were also mentioned as funding road blocks. Participant N said, “You know I have not yet witnessed a strategic allocation process that’s felt like it was –
you know, made sense. If you pick a path, that path can sort of go on for a long time before it changes, because you are talking about institutional bureaucracy…” (June 3, 2010).

Other factors were mentioned regarding general cancer research funding, including the human element. Participant C said:

… it really is putting that human face on it. Whenever you’re trying to raise money for a disease, it’s important to not talk about it in the abstract. Not talk about it as much as far as numbers, but put that human face. The most powerful things that we have are our survivors and their stories and talking…what they go through. Whether it be the advances and the fact that it’s no longer a death sentence or the trouble that they’re having in access to the screening and treatment. The stories of people going through it are the most impactful, both advocacy and fundraising. And all those help energize and drive research (June 10, 2010).

In one case, the human element included the impact of the donor’s wishes. Participant B said, “If you do have a donor who provides support for a specific type of research, obviously you’re going to support, you’re going to honor the wishes of the donor, and so you use that money to support that type of research” (June 10, 2010).

Breast cancer funding

The federal government was specifically mentioned in regards to breast cancer research funding. Participant D said:

Well the Congress of course can always, and not just in health but in anything, they can always put strings attached to the money that they send up to NIH. They can say we’re gonna’ allocate 500 million dollars to breast cancer. They could do that, and they have done that in specific instances that some Congressman who had enough pull or clout got it through committee, got it through the floor for a vote. So they can always do that. I mean, Congress has a lot of flexibility (June 11, 2010).

And Participant Y thought advocacy should have influence on Congress, saying:
I believe that those groups, ACS, Komen…can have an impact on Congress. And from a lobbying perspective, it makes sense. It’s just logical that that many people charged with some passionate issue would go out and kind of raise the mantle and say look at all the people we have supported us here you should support us as well (June 14, 2010).

Another participant specifically addressed the role of breast cancer advocates and research funding. Participant H said:

…and this is really important, is that the advocates, the women who get breast cancer are much more likely to get much more involved in campaigning to either raise money directly or to get breast cancer research funded…I think that women tend to get engaged in these kinds of activities. A lot of them are women who had other jobs. A lot of it is that more women are not employed or don’t have as intense involvement in jobs. A lot of women who have gotten involved had very strong working positions…(June 3, 2010).

Breast cancer vs. other cancer types regarding advocacy and funding

Many participants compared and contrasted breast cancer funding vs. lung cancer funding. Participant B said:

I think one of the challenges of lung cancer fundraising is – there are two major challenges that I see. Number one is that fewer patients survive. And if you’re not alive you can’t advocate. The second issue is that many people view lung cancer as a self-inflicted disease. And that makes it a little hard to advocate for. So I think that despite the fact that lung cancer is most the most common cancer killer, advocating for lung cancer research is very challenging for those reasons…I think, it’s ‘you brought this [lung cancer] on yourself by your lifestyle, so be it,’ attitude that some people have. And that’s going to be hard to overcome (June 10, 2010).

When asked if this attitude affects the prioritization of research and research dollars spent by the federal government and large organizations, Participant B said:

I think it can…We don’t have anybody who goes out and raises funds specifically so we can support lung cancer research. We do have people doing that for breast cancer and leukemia and lymphoma and sarcoma, for example. So, I think it does impact on the type of research we are able to support, [though] I don’t think it has a direct impact on how we prioritize our research support… There’s a
distinction there. One is where the resources come from; the other is how we use our flexible resources (June 10, 2010).

When asked why breast cancer receives more attention and funding than lung cancer, Participant C said:

…people see breast cancer as something that they didn’t cause in any way. They got it because they were female and they were getting older and there was just a genetic mutation. There wasn’t something that they did to get this. And the same can’t be said about every other cancer, because there are some behavioral elements, whether it be with tobacco or what not that can be contributable. And that’s not to say that those particular cancers shouldn’t be funded because absolutely they should. But I think that’s one of the reasons why if I, Joe Blow, without a personal connection to any[one] who’s had cancer and try to make a decision about which one I’m going to give my surplus revenue to, I could see why some would choose that [breast cancer] over the other [lung cancer] (June 10, 2010).

Participant Y called it marketing, instead of advocacy, and said:

Some cancers, because of marketing, are much better known than others. Marketing works or it wouldn’t be used. And so breast cancer…Komen has done a wonderful thing. I can look at them and…wonder why does your money seem to go to certain areas, but not the areas where we are doing great work. But I can’t question the fact that their goal is to continue to fund research. So, they may have higher administrative expense than we do, but ultimately I have to applaud them because they are trying to cure breast cancer. They can’t apologize because other people have not done similar things, especially regarding marketing, for lung cancer, skin cancer, colon cancer. They are doing a great job. They should be applauded. Until breast cancer is gone, there’s the need for their research dollars (June 14, 2010).

When asked why the leading types of cancers annually diagnosed, nonmelanoma skin cancer and lung cancer, weren’t funded as well as breast cancer, Participant A said:

…You know it [breast cancer] probably is so decidedly gender specific. Those other ones are not so numerically – the concerns are diffused a little bit and then from a gender point of view melanoma doesn’t pick on a particular part of the population. So where you find cancers picking on part of the population like neuroblastoma, picks on pediatric patients…Oh boy, why isn’t that one up there? Because it’s a rather rare disease. So I think that the way that we process
this as a public and our national legislative folks, Surgeon General, NIH, NCI, I think all of those things are operative in the final analysis (June 10, 2010).

The theme that most lung cancer patients bring the disease on themselves as opposed to the victims of breast cancer was pervasive throughout the interviews.

Participant E said:

Well, I think that most of the lung cancer advocates say the reason they have not got the same commence for dollar for dollar funding that breast cancer has per number of people who have died, is because this is a disease that…clearly is linked to something that people do that gives them the disease. Whereas with breast cancer, so much less so. We know that diet and exercise could influence breast cancer, but it’s not the same as smoking two packs of cigarettes a day and giving yourself lung cancer and everyone else in your family, potentially from second hand smoke, exposure [to] lung cancer…

So who’s left to advocate? That makes a difference too. If you’ve got stage one breast cancer, you’ve got a 98 percent five year survival rate. If you’ve got stage one or two lung cancer you’re probably in the 50 to 60 percent range. So yeah, you’ve got fewer people and lung cancer advocates may…feel less empowered, because they’ve got to defend their smoking habits. Everybody understands it’s an addiction, but how that’s understood and how much blame or whatever else is associated with that I am sure plays a part (June 14, 2010).

Participant U said:

[With lung cancer], many people feel, and it’s not always true but to some extent it’s true, they feel like this is behavior-related, you know, ‘you caused this yourself.’ There [are] non-smokers who feel this way. You know, ‘we told you about it and you didn’t quit.’ So there’s a little bit of blame for the person involved. So there’s one aspect of that. The other aspect is that it [lung cancer] usually does not occur until somewhat later. Usually a person smokes for many years before they get lung cancer. There are a few young people who die from lung cancer, who are affected by lung cancer, but it’s not that many compared to breast cancer, where there is a definitely a young cohort that gets people’s imagination, heart, and everything else involved in it.

There is the aspect of people feel like…there is specifically something we can do for breast cancer. We can detect it early, we’ve got all these treatments that work in many cases, not in all cases, but in many cases. Even people who ultimately die will have some improvement in their quality of survivorship and their length of survival with treatment. So there’s people though like, ‘yes, this is something we
have a chance of attacking.’ Lung cancer on the other hand, yes there are ways of attacking, of prevention first of all, but many, many people don’t want to give up on their smoking habits although...we see more people who are able to do that. But unfortunately at the same time, many more young people are being sucked into it. So it’s kind of a big behavioral issue that many people feel hopeless to stop. They don’t feel like, ‘oh, I can really do something to help this either because I feel like I can’t make people stop,’ or the person, the smoker sometimes feels like, ‘I can’t stop.’

People feel like, ‘...you didn’t do anything to deserve breast cancer, you didn’t do anything to get breast cancer,’ and yet people feel like ‘blame the victim, you did it to yourself’ kind of thinking [with lung cancer] (June 15, 2010).

Participant G continued that rationale with:

There are some groups now that are developing but, you know, there is a certain stigma associated with lung cancer, because it commonly is contracted in individuals who smoke tobacco. I think there might be some negative connotation there but some think ‘wow you could have avoided that’ so we are not as dedicated. Whereas people who get breast cancer often times it just happens without...people doing something that’s going to increase their risk for it...but clearly we’ve got to get beyond that, because lung cancer is a huge problem for us (June 15, 2010).

Participant H also said:

...in the cases associated with lung cancer people were less sympathetic. You know, because of there being some sense of it being self – of there being some component you know, some kind of personal responsibility...colon cancer, it’s funny, there aren’t any major campaigns. My husband works in pancreatic cancer and there is a pancreatic cancer foundation that is a very active group. But still they haven’t captured public attention like breast cancer has...The other closest one is lung, which is connected to smoking, but there are so many people with lung cancer who have never smoked a day in their lives. So it’s not fair (June 3, 2010).

Participant N said:

I think if you were to step back and say this [lung cancer] is the prevalence, this is what...is likely to be cured or mitigated or improved based on drugs...There would be 90 percent less if we didn’t smoke...my gut feeling is I don’t understand why we are spending a lot of time developing drugs for something that is a behavior issue and a lifestyle issue. And breast is having a tremendous amount, probably too much investment... (June 3, 2010).
Participant Q said:

…breast cancer is typically thought of as a disease that you’re not necessarily or knowingly doing something to cause you to get cancer. Whereas in lung cancer, the stigma around smoking which is by far one of the leading causes of lung cancer, it does create a negative stigma around that because it’s a lifestyle behavior that’s detrimental. We all know it, but then some of us end up getting the lung cancer for it. It has a different stigma; it has more of a negative stigma than breast cancer does (June 14, 2010).

Participant Y said:

And they’ve [breast cancer advocates] been very successful in creating a model that is sympathetic to those who have suffered from breast cancer. And related to that the reason they are successful is because a woman with breast cancer is very sympathetic as she should be. And the numbers were very large and no reason for it. One of the reasons why I think it’s in contrast to lung cancer specifically is we in essence, we can cure lung cancer, it’s called not smoking. If smoking were ended, 95 percent of lung cancers and mouth cancers and bladder cancers would go away.

I don’t want anybody to be in pain. But that’s different than a woman waking up and going to an exam and finding out she has breast cancer through no fault of her own. So it’s certainly a more sympathetic disease (June 14, 2010).

Participant T said:

… we’re judgmental, we’re self-righteous …as far as some folks’ choices. And it seemed as if breast cancer was something there that we could just jump on to – ‘well, no one has a choice for that’ – within reason. And how horrible is that to have a woman’s breast removed. And it just seemed like it from a societal standpoint it was the right thing to do (June 14, 2010).

Participant R said:

I think lung cancer has a stigma associated with it that in some cases I think people are suspicious that the patients themselves were culpable in what happened to them. That they made a certain choice or lifestyle choice such as smoking that impacted their future health. So I think they’re more sort of a victim – a helplessness associated with breast cancer versus lung cancer for example (June 14, 2010).

Participant A said:
…breast cancer in large measure is something that is innocent people who have not done anything to contribute to the risk that they have of getting cancer. They’re innocent victims versus the clear connection between smoking and lung cancer – where despite good education, despite warnings right on the package, and 25 to 30 years of hard data to suggest a connection.

That we as a society lack sympathy for the lung cancer victim who is clearly walked into this saying at least implicitly this is a vice that may kill me and I know that but I am going to do it anyway. And then expect…people to go out and dump out their change and give money to fix a problem that you are causing yourself? I think there’s a lack of sympathy.

…We can talk about radon and other causes of non-smoking lung cancer, but it gets lost numerically. And I think from a cognitive point of view most lay people probably lose it too. There’s just not a depth of knowledge to know the causes of [lung] cancer away from the obvious and that is smoking causes lung cancer (June 10, 2010).

Advocacy and funding success due to the physical implications of breast cancer

Many interview participants discussed the physical looks of breast cancer survivors, as opposed to other types of cancers.

Participant U said:

It’s emotional from the viewpoint a woman can see her breast and what’s happening to it whereas like with lung cancer, for example, which kills many more women, they don’t see that… So it’s not as interesting to people…Something that you can see – and the breasts, which have value to them – that kind of gets people more interested in something than like in the lungs, which they don’t really see (June 15, 2010).

Participant R said:

I would say certainly one of the biggest areas that we are drawing momentum to right now is breast cancer. And candidly part of that decision-making was that we have a clear physical not fiscal, physical, need in terms of patient care there and I am sure that the baby boomer population has influenced that (June 14, 2010).

Participant S said:
I think it’s because it’s the breast. It’s what a lot of women feel is makes them part of who they are. You know, and ‘if something happens to my breast, what will my husband or if it’s a man my wife, what are they going to think about my mutilated body?’ It’s because most women take pride in their breasts. I think that’s why. And I think that’s why more and more women now are getting screened at earlier ages. If you have kidney cancer and you get your kidney removed, no one is going to notice unless you are wearing a bikini and you can see the scar. Verses if you have a mastectomy you know it’s a very visual type of surgical resection. You know and it’s scary to lose something that people can see…We even have people that we can tell them you know, ‘congratulations, we can actually surgically resect this [lung] cancer, you will be cured next week, we’ll have you cured of cancer’ and people say, ‘well, how big is my scar going to be?’

(June 14, 2010)

Participant V said, “...But there’s so much emphasis on breasts in American society that even T-shirts that say ‘Save the Girls’ or things like that, it’s just more culturally out there… there’s a lot of sympathy, and I think in America sex sells, and certainly boobs are a part of our sexuality” (June 8, 2010).

Participant O said:

…I think because for the breast it is outside. Women usually find it much easier. Much quicker. Where in lungs most of the time they wait until the patient starts spitting some blood and then they go check with the doctor – especially if they are heavy smokers, heavy drinkers…and whatever. They try to deny it. So they wait until it is a little bit late (June 15, 2010).

Success breeds success

Many participants commented that oncology researchers, funders, and doctors get into breast cancer because of the history of success with the disease.

Participant E said:

… success breeds success. So if there have been successes in breast cancer and there are more mouse models available in breast cancer, more clinical trials, more drugs to test, then in a very competitive field where only one in five grants on a good day get funded, you are going to go…where the success has been and where you can build on that success…
So again in a very competitive environment if you are going to try to achieve success, and it’s a paradigm that most researchers have, publish or perish. You have to have so many research articles to achieve tenure and et cetera, et cetera…you may very well go where you have the greatest chance of having success. And you may have the iconoclasts out there who don’t care about success who say ‘I want to find something new and different to go into the basic lung cancer research.’ And maybe those people are harder to find and ferret out (June 14, 2010).

Participant H said:

Once you accumulate a certain amount of baseline information that type of problem becomes a prototype. It’s like breasts just become prototypes for epithelial cancer. And so for instance I think a lot of people go into the field because there’s so much known already and there’s so many reagents available. That and for instance, the genomic databases for breasts, it’s probably 50 to one relative to other cancers, so you’ve just got a much better pool to get to derive really fundamental information about cancer (June 3, 2010).

Participant N said:

… scientists pursue their interests. So while you may…say, ‘well I want to get into this because it’s well funded, breast cancer is, it’s got a lot of support.’ Whatever the reason, once you get into it …you don’t switch. So you kind of commit very early. And then you’re an advocate for that just because that’s the position you took for the rest of your career (June 3, 2010).

Participant P said:

Nobody wants their money to be wasted…There’s been more advances [in breast cancer]. Advances promote advances. And so you want to feel like your money is doing some good…as we see more and more progress it makes people not only more aware but they’re thinking ‘wow, if I throw my money in that direction I am actually moving the needle. I am actually changing something rather than just tossing it in a bucket that’s going to – that doesn’t do any good.’ [Breast cancer targeted therapies] cause a lot of people to think, ‘oh gosh, if we’ve figured this out, what else can we figure out? So here, take $20 million and do something with it and keep going’” (June 10, 2010).

Participant Q said:

[Breast Cancer] cure rates are good. There is success there. People like to be associated with a winning team. They like to, you know, support and become
engaged with winners...And again, not that there’s not the success in other areas, but because of the volume and because it’s driven by health care decision makers and the future is bright. People like to get on that bandwagon (June 14, 2010).

Another depth interview participant commented on the success of breast cancer research. Participant F said:

Breast cancer has evolved now to pretty much what I call an outpatient specialty. And standard therapies really have become quite effective. There is still room for improvement, but we don’t have nearly as much room for improvement say as we do for lung cancer and some of these other types (June 15, 2010).

Other interview participants contrasted the success of breast cancer research with other types of cancers.

Participant D said:

Yes, we are doing much better at diagnosing and treating breast cancer than we did 20 years ago. For lung cancer, you know I can’t say that we have the same breakthroughs. I mean the best thing for lung cancer is prevention which is you know don’t smoke, don’t start and if you are stop. But that’s easier said than done. So, we don’t have the same breakthroughs in cancer and...some forms of lung cancer can be very aggressive (June 11, 2010).

Participant T said:

[Breast cancer] can be positively impacted, the outcomes can be. It responds well to fundraising, because we can make a difference with this particular disease. And we can’t necessarily with some of the other types of cancers.... You don’t see nearly that same level of fundraising around cervical cancer and again it goes back to impact. If you’re getting diagnosed with cervical cancer, it’s probably pretty late (June 14, 2010).

Some participants offered hope for the future. Participant R said:

I think there’s a perception of hope [around breast cancer], a perception that we are getting closer everyday because of dollars to a cure. As I said, I think it echoes that people feel that they, within one to two degrees of separation, have been touched by it. I think because it is a cancer that has the face of a victim on it. In other words that people have not made a lifestyle choice that created that disease in their body...I am confident that the fact that there is more than one
national organization focused on it also brings a great deal of momentum as well (June 14, 2010).

And Participant V said, “We have a large number of breast cancer survivors who are sort of growing up in an era of… there’s almost an expectation that if you have this disease presence you do something about it for the future. We have worked on prevention for breast cancer” (June 8, 2010).

Other findings

Several interview participants attributed the success of the breast cancer movement to other reasons than earlier discussed, including the belief that women are more vigilant about their own healthcare than men, the success of the National Organization for Women, HIV/AIDS activists, the power of celebrities, and the Department of Defense. Some interview participants also believe that this dialogue will soon change to a conversation about cancer at the molecular level, rather than cancer type. Each of these findings is discussed below.

Women are More Vigilant about Healthcare than Men

Some interview participants believe that women take better care of themselves than men, are more likely to seek the care of a doctor, and more likely to get screenings.

Participant T said, “Women make 95 percent of the health care decisions in their homes in the United States. And I think somehow that’s related to a focus on fundraising and a focus of breast cancer” (June 14, 2010).

Participant N said:

…It’s just ladies do that. I don’t go to the doctor. My wife insists that I go to the doctor. I get sick; she kicks me until I go. My wife makes appointments for me.
My wife goes to all her appointments. All the guys I know never go to their appointments. They never seek care; they don’t care. They ignore it…

…This is just me as a dude, not as a cancer researcher guy…I am blown away by the disparity between the prostate world and the breast world. And you know, my pastor is a…prostate cancer survivor and … it’s just a drop in the bucket compared to what the ladies have done. And what they’ve done is phenomenal, just phenomenal….

…I always say that the reason prostate doesn’t get any attention is the people in prostate haven’t figured out how to tap into women taking ownership of it…but to be honest, you know, guys don’t deal with this – with healthcare issues like women do.

And women are fierce advocates. They’ve gone out and done amazing work trying to sort of get mindshare…So you look at prostate cancer, you know, it’s a guy thing, and guys aren’t advocates for their own health (June 3, 2010).

Participant P said, “… and women are a little more – well, a lot more – prone to go see their doctor than men…and also just regular screenings and mammography and just regular check-ups with their physicians, [as a result] breast cancer has become highly treatable” (June 10, 2010).

**National Organization for Women and Feminism**

Some interview participants cited the timing of the victories of the National Organization for Women and the Feminist Movement as other reasons for the success of breast cancer advocacy.

Participant P said:

The National Organization [for] Women (NOW) back in the 70s and probably the 80s… brought breast cancer to heights that may never be met again by any organization. They kind of single-handedly started the foray into breast cancer awareness. Of course the mantle was taken up by the Susan B. Komen Foundation more recently. And you see pink ribbons everywhere.
…[NOW] would petition Congress on multiple levels for funding from the NIH. They sort of took off the, I don’t want to say stigma, but sort of the social barriers behind even thinking on a national level about breast cancer…in the 40s into the 1960s, it was probably a very private matter that women kept insular…just within their family. So this has brought it out into the world…I really do think advocacy groups like NOW and others and Susan B. Komen and the like really have just brought it out for public discussion. And that public discussion translates into federal funds (June 10, 2010).

Participant W said:

…what was the tipping point in breast cancer…was it at a time when feminism was on the rise – when women were taking charge of their own destinies, their own minds, that this [breast cancer] was a serious problem. I mean, breast cancer kills a lot of women…This was like ‘hell no, let’s do something about it.’ There wasn’t enough money in breast cancer research, but the truth is there wasn’t maybe enough for a lot of different cancers. And I think women mobilized and made it an issue. And I think the timing was good because it turned out also that there was a lot new stuff that was happening. And then you had the Komen Foundation which was….a very special experience. You had some very outspoken women who had breast cancer. And made it public, went public. And then they were successful (June 9, 2010).

Participant K said:

I believe breast cancer awareness, research, progress and treatment, all was coming about in a very positive way at about the same time the women’s movement became a substantial and important movement in our country. I think that although there may not be, or there may be I don’t know, a specific collaboration between [the] women’s movement and what it’s doing and breast cancer awareness, the two I think have run hand in hand.

I mean every hospital now has to have a women’s center as part of recognizing and dealing with women’s health. Women’s health issues and many other issues are now recognized as very important. And at the same time, major breakthroughs in breast cancer therapy and prevention were kind of simultaneously developed. So, it’s sort of been a natural alliance. And…I don’t know that that’s been an official alliance, that people that work for women’s issues outside of cancer are collaborating specifically with cancer campaigns, but it certainly is an issue that I think has worked together to raise public awareness, and government awareness, and congressional mandates, and therefore funding opportunities, that have just never been there before.
I think…our advances came along at the same time, as the women’s movement and they just blossomed together. I’ve observed the huge women’s awareness movements that have led to so many changes in our country, most positive…equal employment and equal salaries and equal opportunities and on and on…paralleled our discoveries and abilities to offer better care in breast cancer. So the women, that’s one of the reasons the whole women’s health issues arose as specific organizations and efforts…I think it’s much more the parallel rise of the women’s movement and women’s health awareness that has been able to get breast cancer really, really on the front page of advocacy and attention (June 9, 2010).

Participant W questioned if breast cancer advocates would have had the same results during a different time period, saying:

I think it would just seem like a perfect storm…a perfect situation for so many people and many things to happen at the same time. And if it had happened 100 years ago, the story might not have been so successful. Because we just didn’t have the technology and the biology for all the discovery that’s occurred (June 9, 2010).

Department of Defense

Several interview participants mentioned the unique situation that the Department of Defense funds breast cancer research.

Participant W explained:

The Department of Defense, they got Congress on board…The White House made a commitment of finding money for breast cancer research and went to the DOD. The Department of Defense has a ton of money, about 700 billion a year, and they were basically going to take 100 million dollars from the DOD or they would have to do breast cancer research…They [now] have grants for breast cancer research. You couldn’t get the money out of DOD, but they had to commit it to breast cancer research. So, the DOD sponsored breast cancer research (June 9, 2010).

Participant E compared the DOD funding with federal funding, “…When you talk about breast cancer research we certainly have the largest breast cancer research portfolio in the federal government, but actually the Department of Defense has a very large breast
cancer research component….” (June 14, 2010).

When asked why the Department of Defense got into breast cancer research, Participant E said:

…Well, I can’t speak for the DOD other than they feel that it’s a priority for their service members and it’s something that they’ve looked at and have their own research portfolio…Quite frankly and since this is off the record, nothing in the federal government is free of political influence. So, my understanding is there was a strong request. I don’t know if it was an earmark – how it was done from various members of Congress and certain constituencies that they should have funding components when they were funding DOD things that included these areas of research (June 14, 2010).

Participant G said:

…They’ve [breast cancer advocates] been able to raise funds directly and also to use political clout to get the government to provide funds from the Department of Defense and other resources, so that it has really boosted the amount of funding. And a lot of that’s driven by the advocacy group and their work to do direct fundraising through public efforts as well (June 15, 2010).

Participant H explained it further:

And then there’s as huge budget from the government that goes to the DOD for cancer…And you know this was originally, [I’m] not sure how they got this started, but from what I understand there were some breast cancer advocates that went to the DOD and argued that the wives of servicemen and national security was affected by women getting breast cancer. And now they’ve expanded it to all different kinds of cancer (June 3, 2010).

Participant H explained the advocacy influence on the DOD this way:

There’s this group run by Fran Vesco, who got the DOD to fund it and then they [the advocates] stayed in there with it. In fact, the advocates control who gets money. The breast cancer advocates are sitting there on the funding panel and have enormous influence. There could be the greatest grant in the world on something, but if the breast cancer advocates don’t feel like it’s really going to make a difference near term, then it’s, you know, it’s going to get a lower priority score (June 3, 2010).

Participant V added more information about the advocacy efforts regarding the DOD:
Now once the Department of Defense put the breast cancer funding in there…the advocacy groups wanted this to be peer reviewed. The Department of Defense already had in place a big peer review – they already had a peer reviewed mechanism in place. But you know, breast cancer research funding and the Department of Defense, really, does that go together? There’s Health and Human Services…there’s about three different places the government thought would make a better fit. But Fran [Vesco] knew if she could get it thought the DOD which she ended up doing actually because…even though they have peer review they weren’t peer reviewers on cancer. So I think that was a way…for a group of activists to retain some control over it. Because then they volunteered to be on the peer review panel. She was able to, that’s quite a coup to move it around. Number one to get the money dedicated and then to get it moved to where you felt like you had some control over it. In the federal government? That was an amazing thing (June 8, 2010).

HIV/AIDS

A few interview participants mentioned that they believed that the breast cancer advocates learned from the HIV/AIDS advocates regarding awareness campaigns and fundraising.

Participant V said:

When the AIDS epidemic began, and the AIDS activists began, and created funding opportunities for themselves, that was the breach in sort of the federal funding protective shell…you sort of had to know somebody almost. You certainly had to have a good research project, but you know the same researchers over and over got hundreds of thousands of dollars. With AIDS activism, it taught grass roots cancer patients how to have a voice in what happened to them and what happened to their descendants as far as getting more research dollars. That’s when breast cancer research really hit the ground running (June 8, 2010).

Participant E said:

There’s no question that breast cancer advocates have become more and more astute. That they copied and learned quite well from the AIDS episodes in terms of so much of what happened during the height of the AIDS epidemic and the way the advocates then used their power to influence funding for AIDS research and the walks and the marches and all that. That has been successfully copied and to some extent co-opted by breast cancer advocates (June 14, 2010).
Participant K questioned the HIV/AIDS advocacy efforts, saying:

It [HIV/AIDS] just became such a national, international plague that it required huge amounts of resource for a time. And so it gets a significant amount of resource. But questions were raised at some points; you know there are many more people dying of lung cancer and breast cancer and other cancers that aren’t getting half as much money. But I think that sorted itself out, because the AIDS research needed to have a quick infusion of large amounts of resources so that the problem could even be addressed (June 9, 2010).

**Power of Celebrities**

The advocacy impact of several celebrities was mentioned, including cancer survivors, people who lost loved ones to cancer, and people who succumbed to the disease.

Participant I said:

I think it all started back when Betty Ford had breast cancer…it was probably in the ‘70s sometime. I think before that it wasn’t talked about, it was pretty much hidden. I think breast cancer is for women and females it’s very – has a lot to do with their body image and their sexuality so I think they kept that pretty quiet until she spoke out about it. And I think that has brought it to the forefront. And then especially in the last few years where you have Melissa Etheridge and Christina Applegate and some of the other celebrities, who have had it [and are] participating in a lot of these functions (June 7, 2010).

 Participant W said, “It’s become much more public. Now you can see people, celebrities, having colonoscopies something like that that people didn’t do in the past” (June 9, 2010).

Participant E said, “So, I don’t think anyone doubts that the stigma attached to that [lung cancer] may very well make it difficult. The [Dana] Reeve story, you know, Christopher Reeve’s wife, is where it was really brought to the floor and got its most public exposure” (June 14, 2010).
Participant A said, “… for some women clearly can make the difference between catching it early and being cured versus Mrs. [Elizabeth] Edwards struggling, struggling and likely going to die from the disease” (June 10, 2010).

Participant Q admitted to using a celebrity cancer survivor as a marketing tool, saying:

For example, a couple years ago, for breast, we hosted Robin Roberts, an anchor for ABC, that presented to a bunch of our survivors who shared her experience with breast cancer. And so again that was an opportunity that fell in our lap and again this is something we did for the benefit of our survivors. And it is good information for that, for them, but is also a marketing opportunity for us (June 14, 2010).

Several celebrities sponsored a telethon, called Stand Up to Cancer, to raise money for cancer. Participant G said:

Well it [Stand Up to Cancer] evolved over a long period of time. It started probably about eight or nine years ago and it stemmed from the fact that her [Katie Couric’s] husband died of colon cancer when he was 42, 41 or 42 years old. And then she became very interested in developing a foundation that would support colon cancer research… and we partnered with the Entertainment Industry Foundation and the Stand Up to Cancer to try to put on that telethon… So, that was all part of that effort to get public interest for that funding drive. So, that was held in September of that year and I think it raised somewhere above 100 million dollars for cancer research (June 15, 2010).

Participant P said, “The fact that Lance Armstrong, an elite athlete, cycled through this [testicular cancer] and suffered through it, and built a foundation around it, and brought men to a place where they are comfortable discussing it, makes amazing impact” (June 10, 2010).

Participant L questioned the outcomes of the Lance Armstrong campaign saying:

I am thinking of Lance Armstrong and his campaign for testicular cancer and the organization that he has developed as a result of that, although I don’t have the financials in front of me, has become a huge money maker. I have to wonder though if we would take a step back and actually look at the outcomes from that are more men getting screened for testicular cancer or is it more of kind of a fad for athletes to be wearing his apparel and promoting his image?
...I think unfortunately we’re a society that’s very much driven for the most part by media messages. And we do seem to idealize our athletes and successful people and I think that unfortunately for the most part they seem to be able to send a strong message. Although it wasn’t [an] oncology diagnosis here in our own home state I think one of our greatest successes was Ryan White with AIDS and HIV awareness.

And I struggle to come up with a comparison from a cancer diagnosis similar to the Ryan White story which I think is unfortunate...we seem to have more of an appetite for that because it was through a blood transfusion and he had hemophilia... I wonder if just your average factory worker...or your average person that smokes cigarettes or a social drinker was to come out with a huge campaign in regards to whatever cancer, lung cancer, pancreatic cancer, which can be a result of lifestyle choice, if we’d have the same type of appetite for that. I doubt we would (June 16, 2010).

One depth interview participant speculated on the unlikely chance that cancers linked to behavioral choices will get the same celebrity attention as other cancers. Participant A said:

... no one is going to take on a cause for which there isn’t likely going to be a large recruitable following. So, people who get mouth cancer from chewing snuff, that’s probably never going to take hold out there. Will there be advocates who step forward with snuff in their mouths and [say] ‘you’ve got to help us, because some of us are going to get cancer and this is a disfiguring operation’ (June 10, 2010).

Cancer at the Molecular Level (Not Type) Will Soon Change the Dialogue

And finally, several interview participants mentioned that they believe the cancer type dialogue will soon change into a conversation about cancers at a molecular level.

Participant N explained:

... I think the model of, as the science evolves, it becomes molecular. The way that we’ve been structured around the disease site – prostrate, breast, lungs – is going to be less clear. And it’s going to be, ‘you know what there’s a genetic marker but it’s found across – it could be in prostate, it could be in lungs, it could be in breast, and as we look at this marker level, it’s a really new tool to sort of segment this based on breast or whatever, because cancer doesn’t think
like that. It doesn’t operate like that. The future is going to be at a molecular level and it may be people that you know as the language changes, I am a VEGF, I have a VEGF polymorphism and therefore I need to be aware of that. And that could strike and it could show up in lung, it could show up in prostate, and as we look at molecular markers people are going to be like, ‘man they used to do this by breast?’ And it’s going to seem so crude. And that’s actually – you know this is like a decade, maybe two decades...I’d say probably a decade if I heard correctly from Dr. Sledge and Dr. Einhorn at a recent event as we begin to get this data you are going to have this rapid sort of change in thinking. And so someone who is a breast doctor becomes a certain molecular marker doctor and then they start treating people with different disease sites...But I think that’s going to come sooner than most people are expecting (June 3, 2010).

Participant P shared similar remarks:

Pretty soon we won’t be using the terms breast cancer or lung or prostate cancer. We’ll be saying you have cancer and you are P-10 negative or you’re over expressing PI3 genes...That would be the only thing people care about.

And so you’ll send in a sample and for a few hundred dollars – eventually, we’re not there yet. Eventually a few hundred dollars you’ll have the entire cancer genome characterized. Your physician will get a ream of paper or the electronic equivalent of a ream of data and some sort of algorithm to walk him through and at the end of it he’ll say, ‘wow, 10 years ago I would have given you this and you would have suffered and died. And now, today, based on this information, I am just going to give you this one little pill you’re going to go off and you are going to live five more years.’

And you’ll have far less toxicity. You won’t be vomiting everyday and you won’t be on the toilet for 24 hours in the day – sorry to be graphic – and you are going to have a quality of life and you are going to live longer. That’s what cancer research and treatment is all about (June 10, 2010).

Participant K added:

It will boil down to genetic and molecular issues that are common to many cancers that we’ll be attacking. Now there may be some things that will always remain specific to particular types of cancer, but it’s expected that much of medicine will be the applied practice of genetics within the next several decades and cancer is in the center of that because it is a genetic disease. And many of the molecular and genetic pathways of cancer are common to a number of different cancers... (June 9, 2010).

Participant A agreed:
… The solutions to the cancers have been unraveled down to the understanding what the genes do and the mutations. So, I think if we were to scroll ahead, we are going to find that all cancers are the result of mutations that occur. And that the nastier a cancer gets over time is because of increasing mutations, because cancer cells we now know at a molecular level can’t repair mutations nearly as well as a normal cells can.

…this next generation of cancer researchers are going to be talking about probably less the name of the cancer that is ovarian or breast, but might very well be referring to the mutation that is known to cause that cancer and lead to progression and so forth (June 10, 2010).

Participant Q specifically mentioned the human genome project:

… I really think the future has to do with what will be called targeted therapies or individually tailored therapies and that’s really an outcome of the work that’s been done on the genome and understand why some drugs work for some people and they don’t for others. I think that’s really the future where funding and research is going is to really develop the therapies for patients that are customized and individualized. So that’s where I hope to see the future of that coming from (June 14, 2010).

Participant L shared some concerns about these particular cancer research paths:

I think on the one hand that’s exciting [cancer at the molecular level instead of by type]. But it also just scares the hell out of me, because really in order to be at that level of the pyramid…you really have to be dealing with a very highly educated, highly aware society. And…my fear would be almost a privileged society. If that’s the case, awesome, but so will everyone be able to afford that type of analysis? Will everyone be given the opportunity for that type of analysis? And will people, after they have that information, will people be judged? Because of…certain choices that they make after, perhaps being [genetically profiled] and you know it’s my genes have been typed and I’ve been informed I am at higher risk for breast cancer or for lung cancer or for pancreatic cancer. And I choose to drink or I choose to smoke. So then do we start down this slippery slope of, ‘well, you were informed, you were warned and now you are not going to be able to receive treatment?’ Or you have to go behind the line where you know someone said ‘someone who didn’t make these choices can move in front of you.’ So in the end, in all of this, that’s great news and I hope that that continues. But I also hope that we will be able to handle from an ethical standpoint the information that we learn. And again, not forget about our most vulnerable populations…(June 16, 2010).
Chapter 5
Discussion

This study considered four research questions regarding cancer campaigns, in particular breast cancer campaigns, and their affect on public awareness, fundraising, and cancer research funding:

RQ1: What is the public perception of cancer mortality rates by cancer type?

As discussed in the introduction, when adding statistics for both sexes together, lung cancer is the leading type of cancer death, followed by colon and rectal (combined), breast, pancreatic, and prostate. When just considering the statistics for women, lung cancer is again the leading type of cancer death, followed by breast cancer and pancreatic cancer.

More than half the Internet survey respondents replied correctly that lung cancer is the leading cancer killer, though 20 percent indicated that they believe it is breast cancer. Lung cancer deaths outrank breast cancer deaths nearly 3 to 1, so one could extrapolate that breast cancer campaigns have led some to believe that breast cancer is the number one leading cause of cancer deaths.

During the depth interviews, one participant made a very general statement that made it sound as though breast cancer was the number one cancer killer of women:

Participant V said, “Breast Cancer is the number one, it’s the most feared disease cancer that women have” (June 8, 2010).
And Participant C generalized, saying, “…the fact that everyone knows someone who has died of breast cancer” (June 10, 2010).

Both of these statements also lead one to believe that breast cancer campaigns have been effective at putting breast cancer at the forefront of people’s minds – even among experts in the cancer community. However, many other depth interview participants correctly stated cancer statistics, and many referred to lung cancer as the leading cause of cancer-related deaths. Many others mentioned other types of cancers and their mortality rates, though they didn’t talk about those diseases in the hopeful terms they used for breast cancer. These cancer leaders acted quite resigned that other types of cancers would continue to kill thousands of people each year.

**RQ2: What is the public perception of cancer diagnosis rates by cancer type?**

According to the pilot study, 32 percent of participants believe that breast cancer is the most common diagnosed cancer type, followed by nonmelanoma skin cancer at 30 percent, lung cancer at 17 percent, and melanoma at 12 percent.

As discussed in the introduction, when considering statistics added together for both sexes, nonmelanoma skin cancer actually tops the list of estimated new cancer diagnoses each year, followed by lung cancer, prostate cancer, breast cancer, and colon and rectal cancer (combined). Even when the statistics are considered just for women, the half million cases of nonmelanoma skin cancer (assuming half the cases are women) top the 182,460 cases of breast cancer diagnoses nearly 3 to 1.

This comparison of pilot study results with actual statistics shows that breast cancer advocates are making a significant difference in people’s perceptions. Breast cancer advocacy
campaigns are so pervasive, people don’t understand the significant numbers of nonmelanoma skin cancer that are diagnosed each year, as opposed to breast cancer.

Further, 89 percent of participants indicated that they, a family member, or friend had been impacted by cancer. The highest incidence reported by participants touched by cancer was breast cancer at 64 percent. So, apparently people aren’t talking about their diagnoses of nonmelanoma skin cancer with their family and friends, because the pilot study group believes that many more of their friends and family have been afflicted with breast cancer as opposed to skin cancer.

Consider the study referenced in the literature review regarding health communication channels. The study examined health communication channels for cancer prevention and found that publics should be reached through a variety of means including their social networks, doctors, workplaces, and the media. For example, for prostate exam promotion, more men had heard about the test from their doctors or a PSA (65 percent) in newspapers, magazines, and the Internet, than those men who relied most heavily on family, friends, and co-workers for health goal attainment. In order to reach more of the men who hadn’t heard about the prostate exam, the campaign needed to reach out to them through their social networks or workplaces.

The study also found that “people connecting to the Internet, health professionals, and/or family and friends for health goal attainment exercise fewer days per week on average than those who do not indicate that these are important health resources.” So, social networks, the Internet and health professionals are prime vehicles for information about exercise and its benefits for cancer prevention (Wilkin & Bell-Rokeach, 2007).
Many of the depth interview participants shared, in narrative form, similar beliefs about the pervasiveness of breast cancer, as opposed to other types of cancers.

Participant C said:

“It’s very relatable, it’s very personal, everybody has a mom, has a sister, has a daughter and many of them have been touched by breast cancer. I don’t know of a single person in my life that hasn’t been touched in some way by breast cancer. And so… the two biggest risk factors for breast cancer are being a woman and getting older (June 10, 2010).

And Participant J said something quite similar, “It’s really hard to find someone who doesn’t have a mother, a cousin, a daughter, an aunt, a sister who has been touched by breast cancer. So, unfortunately it just touches so many people” (June 8, 2010).

Throughout the depth interviews, none of the cancer experts mentioned nonmelanoma skin cancer when discussing cancer incidence rates.

**RQ3: Do breast cancer public relations / fundraising campaigns affect the overall perception of cancer mortality and diagnosis rates by type?**

While 95 percent of all pilot study participants were aware of breast cancer campaigns such as Komen’s Race for the Cure or the American Cancer Society’s Making Strides Against Breast Cancer, only 37 percent have participated in those campaigns. And while 79 percent were aware of fundraising or awareness campaigns for cancers other than breast cancer, only 39 percent have participated in any type of cancer campaigns to raise awareness or funding. So, awareness is high, but participation and action are low.

Even though it sounds like bravado, the number of people in the pilot study aware of breast cancer campaigns makes the following statement by Participant T seem plausible:

“[National breast cancer organization] has been a part, either a funder in full or a funder in-
part of every major breast cancer advancement in research over the last 20 years” (June 14, 2010).

And as Participant E said:

I think people still have a great fear of cancer, justifiably so – especially breast which affects one in three people in their lifetime. There will always be that desire to fund it so there is hope for treatment or cure. A cure is much more elusive in most people’s understanding, but for most people treatment for a prolonged cancer free life is what a lot of people would be shooting for (June 14, 2010).

Also according to the pilot study, 84 percent of participants agreed that breast cancer public relations / fundraising campaigns address issues that are important to them, while less than half were neutral about a need for cancer campaigns to address different issues from what they currently address. These numbers demonstrate that people are more interested in breast cancer and not likely to challenge the status quo for other types of cancer campaigns.

The sheer numbers of breast cancer survivors seem to be driving the interest in breast cancer campaigns. As Participant N said, “…awareness campaigns originate from advocates who are passionate and want to do something. And they seem to be primarily driven from female survivors” (June 3, 2010).

Also according the pilot study, 71 percent of participants pay attention to breast cancer campaigns when they appear in the media. Some depth interview participants took a cynical view of the media, “whatever the media feeds us,” while others blamed the media for agenda-setting, “part of the problem with that is a lot of it [lung cancer] could be prevented but people won’t change their habits and so – that may be a part of the reason why it doesn’t get as much press…as other things like breast cancer for example.”
However, Participant Q’s following statement, is the best example of how the breast cancer message is framed in the media, “You just go back and look at the incidents of cancer and there’s no doubt that breast is always the leading cause of cancer….And so that typically gets a lot of the attention and a lot of the press just in volume alone” (June 14, 2010).

Breast cancer is not the leading cancer by diagnosis or death, in men or women, nor in men and women combined. However, this interview participant conveyed what many of the pilot study participants believe – that breast cancer is the number one cancer by the numbers and that the media tell them so.

RQ4: Why does breast cancer receive so much more federal funding and fundraising efforts than other types of cancers, particularly lung cancer – the leading cause of cancer related deaths?

Even with the success of breast cancer campaigns, only 23 percent of all pilot study participants said that breast cancer was the most important type of cancer or cancer related issue, followed by lung cancer at 13 percent. Participants named many other types of cancers, along with research, funding, cures, and treatments, but nothing was named with the same, albeit limited, regularity as breast cancer and lung cancer.

Also according to the pilot study, 77 percent of all participants believe that breast cancer receives the most public and private funding for research and nearly half are neutral when asked if they believe that public and private funders are properly allocating money to research the most important cancer issues. In other words, Internet survey participants were right when it came to cancer funding – breast cancer does receive the most cancer funding
research dollars. And half the survey participants didn’t know or didn’t care whether or not funders were allocating money to the most important cancer issues.

Many depth interview participants either mentioned or acknowledged the federal government’s influence on cancer funding, either by way of Congress and advocates’ efforts to successfully lobby them for funding, or through the National Cancer Institute, the Food and Drug Administration, or the Centers for Disease Control and Prevention.

Participant L summarized it best:

I think the federal government ultimately controls cancer research with the FDA and also with the National Cancer Institute. And they definitely can be swayed…from public opinion, from advocacy, from lobbyists, from large public organizations – and I think we’ve seen that in recent years. If there’s a new treatment, a new breakthrough for cancer diagnoses, we all know it has to be FDA approved. And the federal government has held the strings to that so they’re very much in the driver’s seat from my perspective in regards to funding… I think they’re very much impacted by public opinion or what they perceive as being public opinion and big business and lobbyists and ultimately votes (June 16, 2010).

The simple fact that the Department of Defense has a fund for breast cancer research exemplifies the power of breast cancer advocates and the influence the federal government has on breast cancer.

By an overwhelming margin, breast cancer advocates were singled out as a major factor for breast cancer awareness and research funding. As Participant D said:

I think breast cancer is the most organized and the most aggressive and the most effective probably [in] campaigns…[breast cancer is] one of the big three cancers and next to lung cancer it is the leading cancer for women. Two is there are opportunities; there’s breakthroughs to at least explore. And, three, there’s a very powerful advocacy group (June 11, 2010).
Again, the thousands of breast cancer survivors that annually become advocates were mentioned as having a significant impact on breast cancer awareness and funding. It’s hard to argue with the 2.5 million breast cancer survivors who advocate for breast cancer awareness and research funding.

Another common theme in breast cancer research funding was that success breeds success. Many depth interview participants commented that oncology researchers, funders, and doctors get into breast cancer because of the history of success with the disease. One even referenced it as joining “a winning team.”

The antithesis of the successful breast cancer campaigns is the fight for lung cancer research funding. Participant J contrasted the number of breast cancer advocates with lung cancer advocates:

But you know when you have a [breast cancer advocacy] group that large that is still living and able to have a passion for the disease and raise money for it, I think that lends itself to so much more awareness and attention as opposed to something like lung cancer that, it’s just caught in such a late stage, that unfortunately most of the people don’t live past a very long diagnosis, so that you don’t have very many people (June 8, 2010).

And in the overwhelming majority of depth interviews, participants said that in nearly all cases of lung cancer, it was the patient who was at fault for contracting the disease. Some interview participants even went so far to question why lung cancer research should be funded at all.

Participant N said:

I think if you were to step back and say this [lung cancer] is the prevalence, this is what…is likely to be cured or mitigated or improved based on drugs…There would be 90 percent less if we didn’t smoke…my gut feeling is I don’t understand why we are spending a lot of time developing drugs for something that is a behavior issue and a lifestyle issue (June 3, 2010).
Another reason why breast cancer awareness and research funding campaigns have been so successful is the way breast cancer impacts a woman’s body. Some depth interview participants referred to it as the outside of the body (breasts) verses the inside of the body (lungs, prostate, etc.).

As Participant U said:

It’s emotional from the viewpoint a woman can see her breast and what’s happening to it whereas like with lung cancer, for example, which kills many more women, they don’t see that… So it’s not as interesting to people…Something that you can see – and the breasts, which have value to them – that kind of gets people more interested in something than like in the lungs, which they don’t really see (June 15, 2010).

The American culture dictates the physical qualities that women must possess to be beautiful. And it must be more important to have beauty than life, considering the fact that breasts don’t sustain life, but lungs do. This is further illustrated in the Results chapter when the depth interview participant commented that they would tell their patients that they could cure them of cancer, but the patients would be worried about how large the scar would be or where it would be located.

As Participant V said, “...But there’s so much emphasis on breasts in American society that even T-shirts that say ‘Save the Girls’ or things like that...in America sex sells, and certainly boobs are a part of our sexuality” (June 8, 2010).

This brings the research to the pivotal reasons why breast cancer campaigns have been so successful – the perfect storm.
The perfect storm

During the 1960s, when sexual issues were becoming less taboo, slowly too was the discussion of breast cancer. The literature review calls out the fact that women also began to question radical mastectomies in the 1970s. Many quotes from the depth interviews can be woven together to tell the story of breast cancer advocacy and why it has been so successful.

Some interview participants cited the timing of the victories of the National Organization for Women and the Feminist Movement as reasons for the success of breast cancer advocacy.

Participant P said, “The National Organization [for] Women (NOW) back in the 70s and probably the 80s… brought breast cancer to heights that may never be met again by any organization” (June 10, 2010).

And Participant K said:

I believe breast cancer awareness, research, progress and treatment, all was coming about in a very positive way at about the same time the women’s movement became a substantial and important movement in our country…the two I think have run hand in hand.

I think…our advances came along at the same time, as the women’s movement and they just blossomed together. I’ve observed the huge women’s awareness movements that have led to so many changes in our country, most positive…equal employment and equal salaries and equal opportunities and on and on…paralleled our discoveries and abilities to offer better care in breast cancer (June 9, 2010).

As a matter of fact, Participant W even questioned if breast cancer advocates would have had the same results during a different time period, saying:

I think it would just seem like a perfect storm…a perfect situation for so many people and many things to happen at the same time. And if it had happened 100 years ago, the story might not have been so successful. Because we just didn’t
have the technology and the biology for all the discovery that’s occurred (June 9, 2010).

The brewing storm of breast cancer also had perfect timing when it came to observing another advocacy campaign: HIV/AIDS.

Participant V said:

When the AIDS epidemic began, and the AIDS activists began, and created funding opportunities for themselves, that was the breach in sort of the federal funding protective shell... with AIDS activism, it taught grass roots cancer patients how to have a voice in what happened to them and what happened to their descendants as far as getting more research dollars. That’s when breast cancer research really hit the ground running (June 8, 2010).

Participant E said:

There’s no question that breast cancer advocates have become more and more astute. That they copied and learned quite well from the AIDS episodes in terms of so much of what happened during the height of the AIDS epidemic and the way the advocates then used their power to influence funding for AIDS research and the walks and the marches and all that. That has been successfully copied and to some extent co-opted by breast cancer advocates (June 14, 2010).

Breast cancer advocates learned so well from the HIV/AIDS advocacy, they even cracked the Department of Defense for breast cancer funding.

Participant H explained the advocacy influence on the DOD this way:

There’s this group run by Fran Vesco, who got the DOD to fund it and then they [the advocates] stayed in there with it. In fact, the advocates control who gets money. The breast cancer advocates are sitting there on the funding panel and have enormous influence. There could be the greatest grant in the world on something, but if the breast cancer advocates don’t feel like it’s really going to make a difference near term, then it’s, you know, it’s going to get a lower priority score (June 3, 2010).
Meanwhile, Betty Ford came out publicly about her breast cancer, followed shortly by Nancy Reagan. These two presidents’ wives became two of the first celebrity endorsers for breast cancer.

And after the stage had been set, Nancy Brinker made a promise to her dying sister, Susan G. Komen, in the early 1980s to end breast cancer. The Komen advocacy efforts started shortly after. And, as discussed in the literature review, Komen’s Susan Braun says that public health officials were the key to success by setting guidelines for and encouraging breast self exams and clinical exams. Braun also says that the media increased their coverage of the disease, and the Komen Race for the Cure began in 1983. She says that “Funds from these efforts enabled advocates to hold educational forums and produce educational materials in different media and tailored to different audiences and to become active in the funding of research.”

Their efforts at political action created the uprising of breast cancer advocates in the 1980s and 1990s to “work toward legislative, regulatory, and funding changes, such as passage of the Mammography Quality Standards Act and increased funding for the National Cancer Institute.” Braun says that these efforts quadrupled federal funding for breast cancer research in the 1990s.

The perfect storm also requires a favorable environment. Women needed to be receptive to the breast cancer awareness campaigns, and generally speaking they were. Some interview participants believe that women take better care of themselves than men, are more likely to seek the care of a doctor, and more likely to get screenings.
Participant T said, “Women make 95 percent of the health care decisions in their homes in the United States. And I think somehow that’s related to a focus on fundraising and a focus of breast cancer” (June 14, 2010).

Participant T wasn’t far off with the statistic about women and health care decisions. According to the U.S. Department of Labor, “Women make approximately 80 percent of health care decisions for their families” (U.S. Department of Labor).

Participant N shared this observation:

…it’s just ladies do that. I don’t go to the doctor. My wife insists that I go to the doctor. I get sick; she kicks me until I go. My wife makes appointments for me. My wife goes to all her appointments. All the guys I know never go to their appointments. They never seek care; they don’t care. They ignore it…(June 3, 2010).

Participant P said, “… and women are a little more – well, a lot more – prone to go see their doctor than men…and also just regular screenings and mammography and just regular check-ups with their physicians, [as a result] breast cancer has become highly treatable” (June 10, 2010).

The perfect storm of breast cancer advocacy included the right timing during the feminist movement and the advances of NOW, a great case study in the HIV/AIDS campaign, celebrity endorsers, and a passionate advocate who had just lost her sister to breast cancer. Throw in the advances in screening and surgical technology at that time, along with a receptive female environment, and breast cancer research and awareness benefited from the perfect storm.
Recommendations for public relations practitioners

Third-party endorsers

Third-party endorsement refers to “…the extra credibility that comes with the endorsement of an outside and unbiased agent…” (Smith, 2009). Celebrities, or third-party endorsers, were mentioned several times by depth interview participants. Clearly, celebrities have had much impact on cancer research funding and awareness campaigns.

For breast cancer, wives of politicians, including Betty Ford, a pioneer in breast cancer advocacy, and Elizabeth Edwards, were mentioned, along with Melissa Etheridge and Christina Applegate. Robin Roberts was even named for her marketing appeal as a breast cancer survivor.

It was also mentioned that now celebrities are having colonoscopies on television. One can assume they were referencing the famous colon of Katie Couric, who is a fierce advocate for colon cancer since she lost her husband to the disease.

Other celebrities and their cancer types were named, though none with as much regularity as Lance Armstrong. Some even question whether the awareness he brings to testicular cancer has now been overshadowed by the trendy Livestrong clothing line.

The only person mentioned for lung cancer was Dana Reeve, who succumbed to the disease. Again, this reinforces the poor survival rates of lung cancer. Not many survive long enough to advocate for the disease. And whenever Dana Reeve’s lung cancer is discussed, one of the first items disclosed is that she was a non-smoker. For smokers, the social stigma is that they deserve lung cancer.

Lung cancer advocacy and the associated stigma
These breast cancer and lung cancer case studies add more credibility to the body of knowledge that third-party endorsers do make a positive difference in a public relations campaign.

Lung cancer advocates must find survivors that they can lift up to help raise funds for research for the disease. It doesn’t appear as though they will ever be able to completely conquer the social stigma of smoking as it’s attributed to lung cancer, but they would have much more success if they could find a celebrity lung cancer survivor who is a non-smoker.

Lung cancer advocates should also explore and promote the framing of cigarettes as a habit-forming drug. Consider alcoholism and the perceived public acceptance throughout the last 20 years of alcohol as an addiction. It appears as though the public is much more understanding about the addictions associated with alcoholism as opposed to the addictions of smoking. Perhaps lung cancer advocates could learn something from advocates for alcoholics, just like breast cancer advocates learned from HIV/AIDS advocates.

Further research should be conducted to fully examine lung cancer campaigns and advocacy on their own. Specifically, one could study the stigma attached to lung cancer, and how that might be overcome through a public relations campaign. This study examined lung cancer campaigns as part of a larger discussion about breast cancer awareness and advocacy campaigns, but did not fully scrutinize lung cancer campaigns on their own merits.

The role of new media

New media was only mentioned once during all 25 depth interviews. One of the interview participants, a leader in the cancer field, mentioned that he hosts a blog to discuss
cancer awareness and prevention. When all the other interview participants were asked about awareness campaigns, none mentioned any type of social media.

The need to put a face on cancer survivors to raise funding and awareness was discussed several times by interview participants. New media would be a helpful communication channel to promote the stories of cancer survivors and raise awareness and research funding. One suspects that many of the non-profit organizations and for-profit companies that employ the interviewed participants actually do engage in social media, but it must not be so significant as to come to mind during the interviews.

**Limitations**

This study had a few limitations, which may have produced flaws in the research and reporting. The Internet survey was conducted as a pilot study to influence depth interview questions. The number of participants totaled only 109 people, with 75 percent being female. The surveyed population could be expanded to reach a total of 384 completed surveys with a more proportionate mix of genders, so that the data may be generalized across populations (Stacks, 2002, p. 167).

Further, since depth interviews are qualitative by nature, they are subject to bias. Interview bias may include the selection of information that the researcher wants to report. The interviewer’s feelings about the topic may also influence the discussion with the participant.

According to Stacks, “Most people wittingly or unwittingly bias their reporting according to their own beliefs and attitudes; thus they may fail to mention a particular study
or research program because it does not coincide correctly with their evaluation criteria” (Stacks, 2002, p. 57).

Participants for depth interviews were selected based on snowball sampling. The researcher found populations of experts in the cancer field that met certain criteria for knowledge related to federal funding, awareness campaigns, and/or advocacy. Initial interview participants were selected based on their knowledge, but referrals were requested from those participants and others in the medical field.

**Conclusion**

The main question this study sought to answer was: Why does breast cancer receive so much more federal funding and fundraising efforts than other types of cancers, particularly lung cancer – the leading cause of cancer related deaths?

While the majority of pilot study participants know that lung cancer is the leading cancer killer, when it comes to diagnosis by cancer type the study was split between those who believe breast cancer is most often diagnosed and those who believe lung cancer is most often diagnosed. And they believe that the majority of their family and friends are diagnosed with breast cancer above all others.

Even when the statistics are considered just for women, the cases of nonmelanoma skin cancer (assuming half the cases are women) top the cases of breast cancer diagnoses nearly 3 to 1. Lung cancer follows nonmelanoma skin cancer in national diagnosis rates, then breast cancer.

This comparison of pilot study results with actual statistics shows that breast cancer advocates are making a significant difference in people’s perceptions. Breast cancer advocacy
campaigns are so pervasive, people don’t understand the significant numbers of nonmelanoma skin cancer that are diagnosed each year, as opposed to breast cancer.

Breast cancer awareness and funding has benefited from a perfect storm. The open dialogue of sexuality began to occur in the 1960s, just shortly before women began to question radical mastectomies. Respected third-party endorsers like Betty Ford began to talk candidly about their breast cancer in the 1970s. The feminist movement and the National Organization for Women were advancing women’s rights. And breast cancer screening technologies were vastly improving.

The environment was favorable for the perfect storm of breast cancer campaigns. Women needed to be receptive to breast cancer awareness campaigns, and generally speaking they were. Advocates for HIV/AIDS were making great progress for awareness and federal funding of that killer disease. Breast cancer advocates learned much about how to capture public attention and crack the federal bureaucracy from these early health issue advocates.

And after the stage had been set, Nancy Brinker made a promise to her dying sister, Susan G. Komen, in the early 1980s to end breast cancer. The Komen advocacy efforts started shortly after.

It’s clear that Komen and other breast cancer advocates have made a huge impact on public perceptions of the disease and its research funding. Will other advocates be able to replicate it with the same degree of success, or will it take another perfect storm?
## Depth Interview Participant Codes

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<td>Senior Communications Advisor</td>
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<td>D</td>
<td>National Health Advisory Group and Major University</td>
<td>Medical Department Chair</td>
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<td>Senior Writer</td>
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References


