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CONTEXT: RACING AROUND THE WORLD FOR A CURE

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HEALTH SOCIAL MOVEMENTS IN A TRANSNATIONAL CONTEXT:
RACING AROUND THE WORLD FOR A CURE

By

Lori B. Baralt

A DISSERTATION

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ABSTRACT

HEALTH SOCIAL MOVEMENTS IN A TRANSNATIONAL CONTEXT: RACING AROUND THE WORLD FOR A CURE

By

Lori B. Baralt

Beginning in the 1990s, the two largest, most influential and well-known breast cancer advocacy organizations in the US, Susan G. Komen for the Cure and the Avon Foundation, began expanding biomedical breast cancer advocacy internationally. Focusing on these organizations' development within the US and subsequent expansion, particularly within Puerto Rico and Italy, within this qualitative intrinsic case study, I draw from medical sociology and social movement theory to analyze how and why these breast cancer advocacy organizations have expanded globally, how advocacy strategies and tactics have been incorporated into diverse political and cultural contexts, and how corporate sponsors, particularly pharmaceutical and medical technology companies, and medical professionals have participated in the organizations' expansion to shed light on the role of transnational health advocacy organizations in processes of biomedicalization and the political economy of health and illness on an international scale. I find that SGKC, as an elite advocacy organization, and the Avon Foundation, as the outgrowth of a corporation, expanded based on a corporate model of market expansion. These organizations socially constructed breast cancer as a critical global epidemic requiring increased awareness and education about breast cancer, thereby positioning their

approach to breast cancer as the solution to the problem and legitimizing their expansion efforts. To expand beyond the US, SGKC and the Avon Foundation developed transnational mixed actor coalitions, in which they partnered with governmental agencies, medical professionals and research centers, and corporations, blurring the boundaries between the non-profit social sector and various sectors of society. Implementing only minor political and cultural adaptations to their biomedical advocacy strategies, SGKC and the Avon Foundation, through their global events, campaigns and programs, are facilitating processes of biomedicalization through messages of awareness and education, the dissemination of medical information, the promotion of “surveillance medicine,” and the production of new “at-risk” and medical consumer identities. Finally, by promoting cause-related marketing and corporate sponsorship and involvement in advocacy events internationally, SGKC and the Avon Foundation are playing a significant role in the global political economy of health and illness by promoting corporate and consumer-oriented solutions to health problems.

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To my mom, my inspiration

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KEY TO ABBREVIATIONS

ABCC	Avon Breast Cancer Crusade
ACS	American Cancer Society
AF	Avon Foundation
BBCA	Biomedical Breast Cancer Advocacy
BCAM	Breast Cancer Awareness Month
BHGI	Breast Health Global Initiative
BSE	Breast Self-Examination
CFDA	Council of Fashion Designers of America
DTCA	Direct-to-Consumer Advertising
GBBCAO	Global Biomedical Breast Cancer Advocacy Organizations
FHCRC	Fred Hutchinson Cancer Research Center
FTBC	Fashion Targets Breast Cancer
GCRT	Global Connection Ribbon Tour
GBCAS	Global Breast Cancer Advocacy Summit
IARC	International Agency for Research on Cancer
IIE	Institute of International Education
INGO	International Non-Governmental Organization
LBCO	Local Breast Cancer Organization
LILT	Lega Italiana per la Lotta contro i tumori
MAC	Mixed Actor Coalition
MEPI	Middle East Partnership Initiative
NABCO	National Association of Breast Cancer Organizations

NBCC	National Breast Cancer Coalition
NGO	Non-Governmental Organization
NIH	National Institutes of Health
POS	Political Opportunity Structure
RFTC	Race for the Cure
SAC	Sociedad Americana del Cancer
SGKC	Susan G. Komen for the Cure
SLACOM	Sociedad Latinoamericana y del Caribe de Oncologia Medica
TAN	Transnational Advocacy Network
TSM	Transnational Social Movement
TSMO	Transnational Social Movement Organization
UAE	United Arab Emirates
US	United States
WAWBC	Walk Around the World for Breast Cancer
WHO	World Health Organization

CHAPTER 1

GLOBAL EXPANSION OF BIOMEDICAL BREAST CANCER ADVOCACY

In the advanced global capitalist economy of the 21st century, market-based solutions to social problems are increasingly becoming the norm. The global health system is no exception. While highly profitable medical endeavors such as genetic testing (Cowan 2008) and pharmaceutical development and rebranding (Peterson 2008) are thriving, the most recent World Health Organization Report emphasized the dire need for a shift in global health approaches toward primary healthcare, including universal healthcare coverage reforms to increase health equity and public policy reforms to advance public health interventions (WHO 2008, ix).

The fact that neoliberal governments and multinational pharmaceutical companies promote an increasingly market-based approach to health and illness, moving further and further away from promoting health equity and public health interventions may come as no surprise.¹ But, the potential role of transnational health social movements in the global political economy of health and illness may be more unexpected because transnational social movements have largely developed in resistance to globalizing neoliberal trends (Evans 2005; Khagram et al. 2002; Tarrow 2005).

While definitions of social movements vary in terms of specifics, social movements are generally understood as collectivities acting at least partially outside of formal institutional channels, with some degree of organization and continuity, for the purpose of “challenging or defending extant authority, whether it is institutionally or

¹ For my dissertation, I adopt Samantha King’s definition of neoliberalism as “a philosophy and a set of economic and political policies aimed at cutting expenditures on public goods such as education, health care, and income assistance in order to enhance corporate profit rates.” (King 2006).

culturally based, in the group, organization, society, culture or world order of which they are a part” (Snow et al. 2004, 11). Health social movements in particular have mobilized to challenge medical policy, public health policy and politics, belief systems, medical research and medical practices (Brown, 2005, 1). Within the context of globalization, transnational social movements are primarily noted for the challenges they have posed to neoliberal proliferation, environmental degradation, human rights’ violations, crimes against women, war, and misguided development programs (Reitan 2007; Keck 1998; della Porta 2005; Smith 2004). In most cases, therefore, transnational social movements position themselves in opposition to global neoliberal policies. In the case of health, however, it is possible that the priorities and activities of certain transnational health advocacy organizations, particularly those with biomedical orientations, may actually align with the neoliberal trend of market-based health solutions.

RESEARCH OBJECTIVES

The trend toward disease-specific biomedical health advocacy in the US² is now expanding globally. This form of advocacy, rather than addressing healthcare access and equity on a national or international level, raises awareness about a particular illness, placing it in competition with other illnesses for media attention, financial resources, and ultimately medical attention. As this form of advocacy expands beyond the US, members of such groups are joining other actors in shaping the global political economy of health and illness.

² With the financial success of biomedical breast cancer advocacy, other health advocates are embracing a similar form of disease specific advocacy and adopting similar programs of awareness-raising events and fundraising partnerships with corporate sponsors. Examples of this can be seen around such diseases as ovarian cancer, testicular cancer, spinal muscular atrophy and heart disease.

The overarching theoretical goal of my dissertation research is to develop an understanding of the role of transnational health advocacy organizations in the global political economy of health and illness and transnational processes of biomedicalization. To illuminate this issue, I use the case of the global expansion of biomedical breast cancer advocacy organizations to address the following objectives.

(1) To understand how and why biomedical breast cancer advocacy organizations are expanding beyond the US. To this end, the dissertation addresses how the decision to expand and the choice of countries within which to expand were made by Susan G. Komen for the Cure and the Avon Foundation. Specifically, were their decisions based on the global distribution of breast cancer incidence or mortality rates? If not, what was it based on? Also, how have these organizations expanded? What other actors, if any, played a role in their expansion?

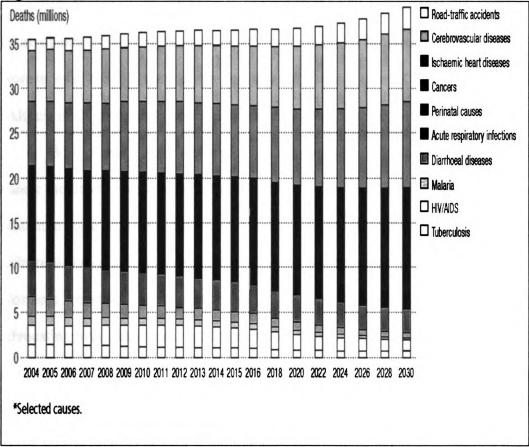
(2) To understand how forms of advocacy such as racing for the cure, cause-related marketing and breast cancer awareness month and symbols, specifically the pink ribbon, that are unique to biomedical breast cancer advocacy have been incorporated into, and possibly adapted to, other political and cultural contexts.

(3) To understand the role that corporate sponsors/partners, including, but not limited to, pharmaceutical companies, and medical professionals have played in the global expansion of biomedical breast cancer advocacy organizations. Addressing these objectives will contribute to our understanding of the potential role of transnational health advocacy coalitions in the global political economy of health and illness and transnational processes of biomedicalization.

PUTTING BREAST CANCER IN A GLOBAL CONTEXT

There has been a general shift in global health trends toward an increasing proportion of noncommunicable diseases, like cancer and heart disease, which has become more pronounced recently than heretofore. The World Health Organization predicts that by 2030, noncommunicable diseases will cause over three-quarters of deaths worldwide (see Figure 1.1). In response to this trend, global health organizations are increasingly shifting their attention from infectious diseases to noncommunicable diseases.

Figure 1.1. The Shift towards Noncommunicable Diseases as Causes of Death*



Source: The World Health Report (WHO 2008)

Based on these trends, cancer and heart disease will become increasingly prominent health concerns, not only in more industrialized countries, but in less industrialized

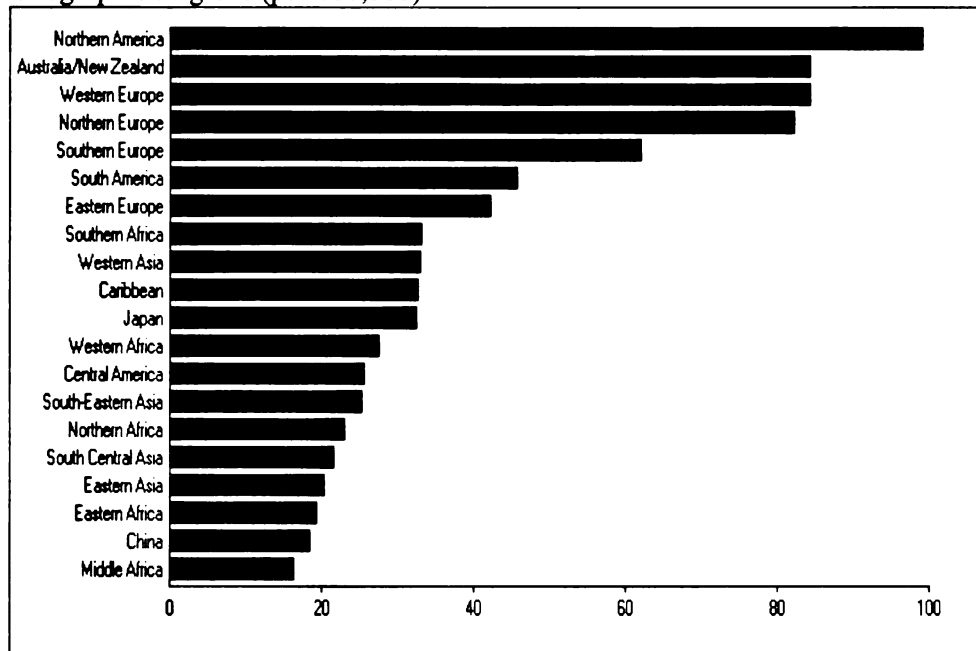
countries as well. Cancer, in particular, will be the cause of an increasing proportion of deaths globally.

Given the general trend in deaths from noncommunicable diseases and the fact that breast cancer is the second most common cancer in the world today and by far the most common cancer in women (Parkin et al. 2000, S17; Schwartzmann 2001), the disease may appear to be a logical candidate for a priority on any women's health agenda. Nevertheless, while breast cancer is the most common *cancer* in women, heart disease is the most common *disease* in women worldwide. Breast cancer is also the most common cause of cancer mortality among women, accounting for 16 percent of cancer deaths in women, even though heart disease remains the leading cause of women's mortality (Althuis et al. 2005; Parkin et al. 2000; Parkin 2006; Parkin et al. 2005).

While breast cancer incidence is increasing globally, the distribution of breast cancer incidence is very uneven (see Figure 1.2). The majority of breast cancer cases remain in more industrialized countries, even though rates are increasing in less industrialized countries as well. Given the high incidence rate of breast cancer in Northern America, it is not surprising that women with breast cancer in the US began advocating over thirty years ago for increased funding, more research, and better treatment to address the disease (Anglin 1997; Batt 1994). But, in other geographic regions, breast cancer may not be a pressing health priority for women given its prevalence in relation to both infectious and other noncommunicable diseases and in many cases the need for basic access to primary healthcare (WHO 2008).³

³ Incidence refers to the number of new cases of breast cancer occurring in a given geographic location during a specified amount of time, usually reported by year. Prevalence refers to the number of persons who have been diagnosed with a breast cancer, and who are still alive in a given geographic location.

Figure. 1.2. Age-Standardized Incidence of Breast Cancer in Females according to Geographic Regions (per 100,000)



Source: IARC, Globocan 2002

BREAST CANCER AS A “CONTESTED ILLNESS”

Given the prevalence of breast cancer, particularly in the US, it may seem intuitive that advocacy developed around the disease, but it is important to interrogate the development of breast cancer advocacy. While heart disease is the primary cause of death for women worldwide, only recently have heart disease awareness campaigns, similar to those for breast cancer, emerged in the US. Additionally, diseases like diabetes, which may be less fatal, but are more prevalent, and affect quality of life, have also lacked the type of advocacy that has developed around breast cancer. It is therefore necessary to understand why breast cancer became a contentious disease, one that spurred so much advocacy and attention, in the US.

Mortality is the number of deaths occurring due to breast cancer in a given geographic location during a specified amount of time, usually reported by year (IARC Globocan 2002).

According to Brown and his colleagues (2004, 52-53), “contested illnesses” are conditions that are either unexplained by current medical knowledge or have purported environmental explanations that are often disputed by medical professionals and scientists. People concerned with these illnesses may collectively organize to achieve medical recognition, treatment, and/or increased medical research. In some cases, where environmental factors are suspected, advocacy groups may strive to shift attention away from strictly medical explanations of the disease and call for research into environmental causes and prevention of the illness (Brody 2003; Brody et al. 2005; Brown et al. 2006; Eisenstein 2001; Krimsky 2000; McCormick et al. 2004; Steingraber 2000).

Breast cancer is a contested illness due to the lack of a definitive explanation of its etiology. Despite the discovery of the BRCA-1 and BRCA-2 gene mutations, genetic predispositions account for up to only ten percent of all breast cancer cases (Klawiter 2002; Wade 2007). Additionally, these genetic mutations are not particularly prevalent in the population and cannot explain the international or interethnic variation in breast cancer risk. Medical professionals tend to explain the increasing rates of breast cancer, particularly among women in industrialized countries, by citing changing reproductive behaviors (Aronowitz 2007). Delayed childbearing or lack of childbearing, birthing fewer children, not breastfeeding (or breastfeeding for only a short period of time), and using hormone replacement therapy all increase a woman’s lifetime exposure to estrogen, which is associated with increased breast cancer risk (Aronowitz 2007). Thus, in contrast to a disease like lung cancer, where a clear link has been drawn between smoking and lung cancer risk and only a limited number of cases remain unexplained, breast cancer remains an elusive disease despite much medical research.

Finding medical explanations of the disease unsatisfactory, many breast cancer patients in the US became frustrated and joined together in search of answers regarding breast cancer, with the ultimate goal of eradicating the disease. But despite sharing the same goal of eradicating breast cancer, breast cancer advocacy has not been a monolithic phenomenon. Rather, distinct forms of breast cancer advocacy have developed within the US.

TYPES OF BREAST CANCER ADVOCACY

Breast cancer advocacy, as it has developed in the US, can be divided into three distinct, though not entirely mutually exclusive, categories. In her extensive case study of breast cancer advocacy in the San Francisco Bay Area, Klawiter (2008) developed a typology of three distinct forms of actions taken to confront the disease, which I have adapted for the purposes of this chapter (see Table 1.1). While her research focused on dynamics within a particular geographic area, this typology is applicable to the broader US, which has seen all of these forms of breast cancer advocacy over the past twenty to thirty years.

Biomedical screening and early detection advocacy is the most prominent form of breast cancer advocacy in the US. Biomedical breast cancer advocates focus on the problem of lack of awareness of and access to screening for breast cancer. Given the biomedical focus of this type of advocacy, biomedical breast cancer advocates have a positive view of the medical establishment, seeing them as allies in the quest to conquer breast cancer. These organizations had elite and often professional origins, frequently being initiated by corporations (e.g., Avon, Estee Lauder) and celebrity or wealthy families who formed organizations after losing a member of their family to breast cancer. Drawing on the rhetoric of the 1970s women's health movement, these organizations in

practice often function more as philanthropic charities, but have self-identified as social movements.

Table 1.1. Types of Breast Cancer Advocacy in the US

	Biomedical Screening and Early Detection	Patient Empowerment/Feminist Treatment	Environmental/ Cancer Prevention
Definition of the Problem	Lack of awareness of and access to screening	Entrenched, male-dominated cancer establishment committed to “business-as-usual”	Profit-driven global cancer industry
Public Culture	Race for the Cure	Women and Cancer Walk	Toxic Tour
Privileged Identity	Breast cancer survivors	Women living with cancer	Victimized communities
Representative Symbol	Pink ribbon	“Cancer sucks” pins	Skull and crossbones
Emotion Culture	Hopeful, grateful, upbeat, positive, celebratory	Public anger but private compassion and support for women with cancer	Unmitigated anger targeted at the cancer industry
Attitude toward Science	Trusting, respectful, committed	Critical, unintimidated, participatory	Critical; strategic use of science
Ideological and Organizational Origins*	Philanthropic organizations; 1970s women’s health movement	Feminism; 1970s women’s health movement, lesbian communities, AIDS activism	Environmental justice movements; feminism
Organizational Identity*	Advocacy	Activist	Activist
Organizational Form*	Hierarchical; national network; global network	Local organizations; participation in national network (National Breast Cancer Coalition)	Local organizations; participation in national network (NBCC); some international networking with Canadian affiliates
Organizational Origins*	Elite; professional	Grassroots	Grassroots

Table 1.1 (Continued)

Corporate Sponsorship*	Unproblematic widespread use of corporate sponsorship	Limited use of corporate sponsorship with companies whose products complement the goal of eradicating breast cancer	Limited use of corporate sponsorship with companies whose products complement the goal of eradicating breast cancer
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Source: Adapted from Klawiter (2008, 47)

*Categories that I added to the typology based on interviews, participant observation, and documentary analysis

In stark contrast to biomedical breast cancer advocacy, patient empowerment and feminist treatment activists often have grassroots origins, developing out of communities of women who are dealing with breast cancer. These activists focus on the problem of the male-dominated cancer establishment and advance participatory approaches to scientific research whereby people with the disease in question would play a role in defining the research priorities. In addition to drawing on the 1970’s women’s health movement, these activists also have a distinctly feminist orientation. Rather than working toward gaining greater access to biomedical screening and treatment in its current state, they advocate a new inclusive scientific paradigm.

Finally, similar to patient empowerment and feminist treatment advocacy, environmental and cancer prevention advocacy takes a critical stance toward science and medical professionals. These activists focus their attention on the profit-driven global cancer industry. With grassroots origins, these activist organizations often develop in communities where cancer clusters appear to exist. They often strategically partner with scientists to investigate the increased cancer incidence rates in their communities. In addition to drawing on feminism, these organizations have strong connections to environmental health and justice movements.

While all three types of breast cancer advocacy organizations remain active in the US today, biomedical breast cancer advocacy is the form that is expanding globally. Therefore, in what follows, I will provide a more detailed account of its development in the US and then discuss the recent global expansion of biomedical breast cancer advocacy organizations.

DEVELOPMENT OF BIOMEDICAL BREAST CANCER ADVOCACY IN THE US

In the 1970s in the US, the public announcements of personal experiences with breast cancer by several famous women such as Betty Ford and Happy Rockefeller (Batt 1994, 269; Lerner 2003) paved the way for breast cancer activism. Babette Rosmond, for example, wrote about her experience, thereby contributing to changes in informed consent laws so that surgeons have to discuss treatment options with breast cancer patients prior to performing a mastectomy (Lerner 2003). Personal testimonies and reports have continued from the late 1970s until today (Rosenbaum 2000; Batt 1994). Initially shocking, and then widely read, these testimonies have had a major impact on the public, bringing breast cancer more fully onto the social landscape.

In the 1980s, making the public aware of the most frequent killer of middle-aged women was a difficult and distant goal. Nevertheless, during the 1980s breast cancer support groups began to form across the US. These support groups provided a transitional space for women with breast cancer to transform their personal experience with the disease into a politicized view of the illness (Altman 1996; Brenner 2000). Groups supplying information and assistance to women with breast cancer proliferated. Women with breast cancer began to see themselves as part of a community, a sisterhood (Brenner 2000). Drawing on the women's health movement of the 1970s, these women

attacked the sexism of the health research system in the US (Altman 1996; Anglin 1997; Brenner 2000; McCormick 2003; McCormick 2003). They worked to transform breast cancer into a mainstream area of research.

Prior to the emergence of grassroots breast cancer advocacy in the US, the American Cancer Society sponsored programs for women with breast cancer such as “Reach for Recovery” and “Look Good, Feel Good,” that provided breast cancer patients with limited, one-on-one support from women who previously had breast cancer (Love 1997). The programs were primarily focused on returning women to a feminine beauty standard (thereby making them “feel good”) by encouraging them to wear temporary breast prostheses and put on make-up everyday. This disguising of breast cancer was partially in response to the social stigmatization of the disease that resulted from strong cultural perceptions of the breast as related to vitality, sexuality and motherhood (via the act of breastfeeding) (Olson 2005). Thus, breast cancer was not just a threat to a woman’s health but also a threat to her femininity.

Due to the work of breast cancer activists in countering the stigma, billboards, advertisements, radio and television programs, and books openly discuss most aspects of the disease today. Breast cancer advocates use these fora to encourage women to perform monthly breast self-exams and start getting yearly mammograms once they reach 40 years of age. By speaking out about breast cancer publicly, breast cancer activists reduced the stigma and shame surrounding the disease in the US (Anglin 1997; Casamayou 2001; McCormick et al. 2003).

The pink ribbon became the culturally ubiquitous symbol of breast cancer throughout the US in the 1990s (Fernandez 2005; Moffett 2003; King 2006). Developed

in 1992 by Evelyn Lauder, a breast cancer survivor and Senior Corporate Vice-President of Estée Lauder, in conjunction with *Self Magazine*, it is currently being promoted by biomedical breast cancer advocates globally. Pink ribbons serve as reminders for women to tend to their health as well as symbols of public support for finding a cure for breast cancer. The pink ribbon campaign has successfully created a deeper sense of public concern and awareness about breast cancer.

Biomedical breast cancer advocacy has also advanced unique forms of advocacy. Instead of more conventional forms of social movement activity such as protests, boycotts, and marches, breast cancer advocacy organizations have developed practices such as racing and shopping for the cure that are geared toward raising awareness and funding breast cancer research. “Race for the Cure,” through partnerships and sponsorships, and “Shop for the Cure” promotions and products are largely tied to corporations. In the US, “Race for the Cure” events taking place throughout the country have been sponsored by companies such as Ford, Yoplait, Avon, American Airlines, BMW, and Kellogg, along with pharmaceutical companies such as AstraZeneca and Johnson & Johnson. Shopping for the cure has taken place through various corporate promotions such as Yoplait’s “Save Lids, Save Lives,” BMW’s “Test Drive for the Cure,” KitchenAid’s “Cook for the Cure,” and Republic of Tea’s “Sip for the Cure,” that donate percentages of their sales to breast cancer organizations. These forms of advocacy, as well as ties to corporations, and particularly to pharmaceutical companies, are expanding beyond the US as the biomedical breast cancer movement redefines its mission as the “global eradication of breast cancer” (Komen website 2008).

A series of powerful, professionalized breast cancer organizations and foundations emerged from this movement. One of the largest breast cancer foundations, the Susan G. Komen Foundation, was established in 1982 by Nancy Brinker when her sister died of the disease (Klawiter 2000; Casamayou 2001). In 1984, National Breast Cancer Awareness Month was established by AstraZeneca, Cancer Care, Inc. and a group of oncologists (Brenner 2000; Zones 2000; King 2006). The following year Amy Langer's National Alliance of Breast Cancer Organization (NABCO) in New York became one of the first national organizations to provide information and support to women across the US (Brenner 2000; King 2006).

The National Breast Cancer Coalition (NBCC) was founded in 1991 (Brenner 2000; Weisman 2000; Casamayou 2001). At that time, other organizations were working determinedly to get women mammograms, access to services, and more humane treatment. None had yet attempted to shape research or policies. NBCC activists' efforts were groundbreaking, gaining the group's advocates participation in government health research proposals and opening up funding mechanisms for breast cancer. The founders conceived of the organization as a new kind of breast cancer organization meant to influence politics and gain more funds for research (Stabiner 1997). The first concern of many breast cancer advocates was the small amount of funding devoted to the disease.⁴ These advocates pushed for more money and for influence regarding how it would be spent. In 1993, the work of NBCC and other advocates led to the passage of the first governmental plan for breast cancer, the National Action Plan on Breast Cancer (Weisman 2000; Brenner 2000; Steingraber 2000; Casamayou 2001). Due to the work of

⁴ See Klawiter (2008, 6-7) for figures on the National Health Institute's and National Cancer Institute's allocation of funds for research on various cancers and other diseases. Klawiter (2008) argues that, in fact, breast cancer was not financially marginalized by these government institutions.

advocates who urged legislators to support new research, the US government established the Breast Cancer Research Program, housed in the Department of Defense, in order to provide federal funding specifically on research about breast cancer prevention, detection, diagnosis, and treatment (Brenner 2000; Rosser 2000; Weisman 2000; King, 2006).⁵ As of fiscal year 2009, over two billion dollars have been appropriated for this program (Department of Defense 2008; NBCC 2009).

Further, by 2008, breast cancer organizations spanned the US, and research was increasingly well-funded by the US government. In 2005, NBCC encompassed more than 500 groups across the US. These organizations have major political influence and have exercised their sway in the legislative arena (Weisman 2000). Advocates from the organization sit on the President's Cancer Panel and the National Cancer Policy Board, among other panels, and they testify in front of the House, the Senate, the President's Cancer Panel and other governmental agencies. As biomedical breast cancer advocacy organizations gained legitimacy and success in the US, some organizations have begun to set their sights on expanding to other countries.

GLOBAL EXPANSION OF BIOMEDICAL BREAST CANCER ADVOCACY

Increasingly, biomedical breast cancer advocacy is being promoted globally by Susan G. Komen for the Cure (SGKC), the Avon Foundation, the Breast Health Global Initiative, pharmaceutical companies (e.g., Johnson & Johnson and AstraZeneca) and other corporations through "cause-related marketing" and sponsorship of advocacy events.⁶

The Breast Health Global Initiative (BHGI) is an initiative founded by the Fred

⁵ The budget was housed in the Department of Defense in order to safeguard it from potential budget cuts.

⁶ "Cause-related marketing" refers to a mutually-beneficial partnership between a for-profit business and a non-profit organization in which the for-profit business financially supports the non-profit organization by donating a portion of its proceeds from the sale of a cause-related product (King 2006).

Hutchinson Cancer Research Center (FHCRC) and SGKC to “develop, implement and study evidence-based, economically feasible, and culturally appropriate ‘Guidelines for International Breast Health and Cancer Control’ for underdeveloped nations to improve breast health outcomes” (BHGI 2008). These actors are promoting a biomedical model of breast cancer advocacy that focuses on raising awareness about breast cancer, promoting breast self-exams, clinical exams and mammography, and raising funds to support medical research geared toward improved treatment options, pharmaceutical interventions, and ultimately finding a cure. Environmental causes, prevention, and feminist critiques of the political economy of breast cancer are largely absent from this globally expanding form of advocacy.

The literature on the global aspects of breast cancer advocacy is very limited. Klawiter (2000) addressed breast cancer advocacy on a global scale in her analysis of diverse strands of breast cancer activism. She argues that while the First World Conference on Breast Cancer in Kingston, Canada in 1997 was indeed a “worldwide” conference in terms of delegates who were present, it was made possible by grassroots activism in North America and framed in terms of North American women’s experience and history with breast cancer. In her analysis of breast cancer advocacy, King (2006, 81) frames the expansion of US-based breast cancer advocacy, primarily through the Avon Foundation and SGKC, as “imperial charity” in which, after successfully capturing the US market, these philanthropic foundations seek market expansion through neoliberal projects in the guise of advocacy for women’s health. In particular, she argues that US breast cancer advocacy organizations do not expand internationally independent of long-standing corporate backers, such as AstraZeneca. Therefore, the goal of the expansion of

these advocacy organizations is not merely to advance some form of social good, but also to initiate “techniques for market penetration and retention” (King 2006, 84).

While scholars are beginning to address the global expansion of biomedical breast cancer advocacy, it is largely un-theorized. Why have biomedical breast cancer advocacy organizations expanded globally? How have decisions been made regarding which countries to expand to? How have advocacy activities, symbols and structures been incorporated into, and possibly adapted to, other political and cultural contexts? These questions remain largely unanswered by the current literature. King (2006, 145), who has provided the most in-depth analysis of the global expansion of breast cancer advocacy, notes that her analysis is “necessarily speculative” given that her data are exclusively drawn from Avon Foundation literature. Therefore, the global aspects of biomedical breast cancer advocacy require further attention.

Furthermore, while the literature largely refers to the “breast cancer movement,” “advocates,” and “activists,” it fails to engage with social movement literature as a whole and, more specifically, with literature on transnational social movements and health social movements. Examining the global expansion of breast cancer advocacy in light of social movement theories has the potential to provide a deeper understanding of this particular situation, as well as make useful contributions to the definition of social movements, understanding of transnational social movement processes, global health social movements, and social movements as globalizing forces. My research focuses on the role of transnational biomedical breast cancer advocacy organizations in order to better understand the role that these un-examined organizations play in the global political economy of health and illness and processes of biomedicalization.

OVERVIEW OF CHAPTERS

Drawing principally on health and illness and social movement theories, in Chapter 2 I provide an explanation of my chosen theoretical framework. I utilize a diagram to visually represent the theoretical perspectives informing my research. My theoretical orientation draws on the broad area of feminist health studies that has provided critical appraisals of global processes of biomedicalization as well as the capitalist political economy of health and illness, particularly as they relate to diseases affecting women. To answer my research questions, I utilize theories from the sociology of health and illness and have attempted to integrate the political economy of health and illness, the social construction of illness, and processes of biomedicalization, which are often presented as distinct theoretical pursuits in the existing literature. Within the realm of social movement theory, I primarily draw on health social movement and transnational social movement theories, also attempting to integrate them into an examination of transnational health advocacy organizations, an effort previously lacking in the literature. Finally, I also explore the overlap between social movements and health and illness, by integrating transnational health advocacy organizations into understandings of the political economy of health and illness, the social construction of illness, and processes of biomedicalization.

In Chapter 3, I discuss the methodology and methods used in this study. The study utilizes an intrinsic case study approach, with my research centering on globally expanding biomedical breast cancer advocacy organizations. The purpose of this approach is to understand how and why biomedical breast cancer advocacy organizations are expanding globally. The global expansion of biomedical breast cancer advocacy provides a unique and interesting case in which (1) US-based biomedical breast cancer

advocacy organizations are expanding to other countries, (2) transnational health advocacy coalitions may be playing a significant role in the global political economy of health and illness and processes of biomedicalization, and (3) theoretical conceptualizations of health social movements and transnational social movements are challenged.

After presenting the rationale for an intrinsic case study approach, I discuss feminist research methodology as it relates to my dissertation. I then address the selection of the organizations that I focus on in my dissertation as well as the selection of the research sites. Finally, I discuss the qualitative research methods that I employed for this study, focusing on the particular role that each method played in addressing my research objectives.

In Chapter 4, I present my findings regarding the reasons for Susan G. Komen for the Cure's and the Avon Foundation's global expansion as well as the trajectory of each organization's global expansion. SGKC and the Avon Foundation, despite their differences, both "went global" to expand their brand to new markets. For both organizations, global expansion was the logical extension of a general pattern of organizational growth. Both organizations globally expanded based on a corporate model of market expansion.

While I address the reasons for the organizations' expansion in Chapter 4, in Chapter 5 I present the ways in which SGKC and the Avon Foundation socially constructed breast cancer on a global scale in order to legitimize their expansion. Susan G. Komen for the Cure and the Avon Foundation have purportedly expanded globally in order to confront the global epidemic of breast cancer. In Chapter 5, I challenge the claim

that breast cancer is a global health crisis in need of a global *biomedical* breast cancer movement. I do this by examining how biomedical breast cancer advocates have actively constructed breast cancer as a global epidemic and crisis in light of actual global breast cancer incidence and mortality rates. Additionally, I argue that advocates from both organizations frame the global breast cancer problem as being caused by lack of awareness of and education about breast cancer leading to low levels of early detection, thereby positioning their biomedical brand of advocacy as the appropriate solution to the problem.

In Chapter 6, I describe how SGKC and the Avon Foundation are expanding internationally. The findings that I present in this section indicate that biomedical breast cancer advocacy organizations have formed transnational mixed actor coalitions (MACs), in which they are the central organizations, but other non-state actors, such as local NGOs, as well as government agencies, medical professionals, medical research centers, and corporations are also included. While Khagram and his colleagues (2002, 11), like many other social movement scholars, argue that the non-governmental sector, and specifically, social movements, represent a distinct sector of society, I found that in their effort to globally expand, biomedical breast cancer advocacy organizations are intricately tied to governmental, medical, and corporate sectors in ways that blur the boundaries between their identities, thereby blurring the boundaries between the various social sectors.

In Chapters 4, 5 and 6, therefore, I provide a broad picture of the SGKC's and Avon Foundation's global expansion. In Chapter 7, I draw on my findings regarding how forms of biomedical breast cancer advocacy have been incorporated into, and adapted to,

other political and cultural contexts to argue that the diffusion of biomedical breast cancer advocacy activities are furthering processes of biomedicalization globally. With only minor cultural and political adaptations, SGKC and Avon Foundation events, campaigns and programs in other countries are strikingly similar to their events in the US. By raising awareness about early detection, disseminating medical information, promoting “surveillance medicine”, and creating new risky subjects and biomedical breast cancer advocate identities among women across the globe, biomedical breast cancer advocacy organizations are playing a significant role in establishing a biomedical understanding of breast cancer outside of the US. The foci of SGKC and Avon Foundation events, campaigns, and programs are twofold: raising awareness and raising funds. Chapter 7 addresses the former of these two.

In Chapter 8, I move on to examine the role of fundraising in the global expansion of biomedical breast cancer advocacy organizations in the context of the global political economy of health and illness. I argue that through their collaboration with corporations and specifically pharmaceutical and medical technology and equipment companies, biomedical breast cancer advocacy organizations are creating economic opportunities for corporate market-expansion, particularly in health-related fields. Additionally, with regard to cause-marketing, biomedical breast cancer advocacy organizations are introducing this form of corporate/advocate hybridization in political and cultural contexts where it previously did not exist.

In the final chapter, I propose theoretical and practical implications based on my research. I first present the challenges posed by globally expanding biomedical breast cancer advocacy to the existing definitions of social movements, and transnational social

movements in particular. I then elaborate on the role of globally expanding biomedical breast cancer advocacy in processes of biomedicalization and the global political economy of health and illness. Finally, I discuss SGKC's and Avon Foundation's corporatized and individualized approach to health problems with regard to the future of health advocacy.

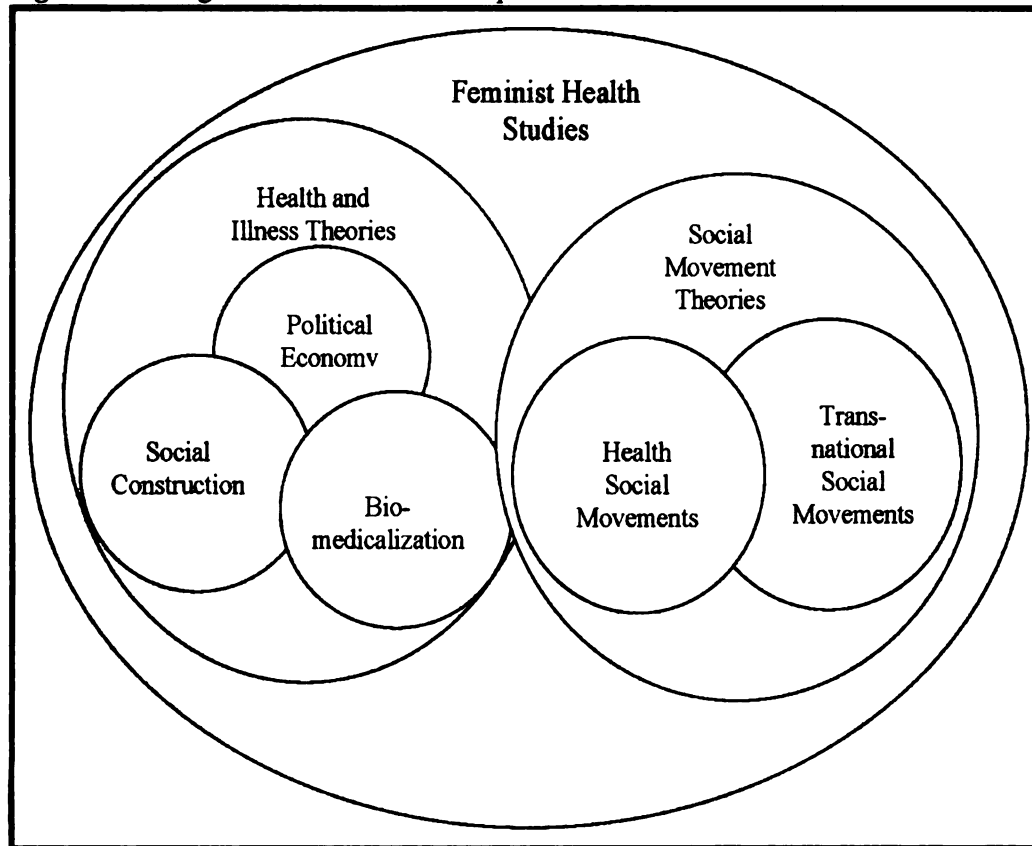
CHAPTER 2

THEORETICAL PERSPECTIVES

My research questions arose out of my feminist health theoretical orientation, which has informed my critical approach to the capitalist political economic context of health and illness and accelerating processes of biomedicalization. Additionally, my research questions developed out of my engagement with social movement theory, which informed my approach to the role of agents of “change” in effecting issues of health and illness. Within this broad oeuvre, I draw on strands from the sociology of health and illness literature and social movement theory. Within these broad theoretical fields, I utilize insights from the literature on social construction, political economy, biomedicalization, health social movements and transnational social movements.

In Figure 2.1, I provide a visual representation of the theoretical perspectives that inform my research. Feminist health perspectives contributed to the formation of my overarching research question regarding the political economy of health and illness and processes of biomedicalization. I depict feminist health perspectives as the encompassing circle in my diagram because these perspectives informed the overall project. In answering my research questions, I draw from two bodies of literature: health and illness theories and social movement theories. These areas are theoretically distinct; however, I present them as overlapping because I am interested in the intersection between the two areas where social movements engage with issues of health and illness. Within the expansive field of health and illness, I focus on the social construction of health and illness, processes of biomedicalization, and the political economy of health and illness.

Figure 2.1. Diagram of Theoretical Perspectives



While these areas are often theorized separately, I am interested in the interconnections among them, which is why they are presented as overlapping. Among theories of social movements, I am particularly interested in health social movements, transnational social movements, and more specifically, their intersection in transnational health social movements. By drawing on these theories, I seek to illuminate the ways in which transnational health social movements, specifically transnational biomedical breast cancer advocacy organizations, contribute to the social construction of health and illness, processes of biomedicalization, and the political economy of health and illness on a global scale.

FEMINIST HEALTH STUDIES

My research questions were prompted by my feminist health theoretical orientation.

Feminist health scholars have critiqued the biomedical model of women's health as being removed from the social, political, and economic realities of women's lives that affect their health and well-being (Ruzek et al. 1999; Ruzek 1999). This critique is not an attempt to completely abandon biomedical perspectives of women's health. On the contrary, feminists have also made significant contributions to biomedicine. According to Ruzek et al. (1999, 13), feminist perspectives "have spurred recognition of how gender affects etiology, natural history, and treatment of disease." Nevertheless, the biomedical model of health and illness fails to interrogate the underlying dynamics of what actually "*produces* health for different groups of women" (Ruzek et al. 1999, 13). Feminist health scholars argue for a model of health that is more inclusive. This requires recognizing and dealing with complexities and differences in women's lives. Multiple factors produce health or, conversely, contribute to disease and illness for women. These social, economic, political, occupational, educational, and environmental factors must be central in the quest to improve women's health.

In addition to critiquing a strictly biomedical model of health, a number of feminist health scholars also have scrutinized processes of biomedicalization that are spreading globally through the medical industrial complex. Feminist health scholars argue that processes of biomedicalization, in concert with companies that produce various health-related commodities, are promoting the Western biomedical worldview. "Part of the new biomedicalization includes what is now being termed 'surveillance medicine,' the creation of *potentially* diseased persons through risk analyses of individuals, communities, and populations" (Clarke et al. 2005, 22). Globalizing processes of

biomedicalization encompass the shift toward “surveillance medicine,” which dissolves previous categories of “healthy” and “ill” persons in favor of new categories of “at-risk- individuals, communities, and populations, using strategies of pathologization and vigilance” (Clarke et al. 2005, 22). As argued by Clarke and Oleson (1999, 14), “new processes of biomedicalization extend science, technology, and medicine further into our lives. Surveillance medicine is creating a new culture of risk and new burdens of health care consumption that particularly implicate women” (Clarke and Oleson 1999, 14). Being “at risk” is now being transformed into “requiring biomedical prevention/intervention” (Clarke et al. 2005, 22). Feminist health scholars question to what extent these globalizing processes of biomedicalization actually improve women’s health on a worldwide scale, versus simply increasing profit by the proliferation of medical technologies, treatments, and pharmaceuticals.

In addition to critiquing the global expansion of processes of biomedicalization, feminist health scholars have also examined the current advanced capitalist political economy, in which health and healthcare are commodities, rather than basic human rights for all people. They are critical of the inherent inequality within this system, in which people who can afford it are granted the “Cadillac” of medical care and preventative and elective medical treatments, while others struggle to survive, lacking the most basic of healthcare services (Clarke 2005). The concept of a “biomedical industrial complex” has been adopted by Clarke and Oleson (1999, 20) to describe the current political economic structure of capitalist health systems. Originally put forth by Relman and colleagues (1987, as cited in Clarke and Oleson 1999, 20), the concept of a “biomedical industrial complex,”

denote[s] a parallel politico-economic institutional sector to the military industrial complex (and not unrelated to it). Moreover, this medical industrial complex is globalizing. By and large, the Western biomedical worldview is exported along with companies which can produce many commodities—many of them technoscientific—which are requisite for proper health care within this worldview.

Feminist health scholars are critical of processes of biomedicalization and the economic interests that are increasingly defining the political economy of health and illness within a narrow biomedical model on a global scale. Nevertheless, empirical investigations of how processes of biomedicalization are globalizing, and specifically, what role advocacy organizations that are comprised of mostly women and are theoretically acting in the interest of women's health, such as biomedical breast cancer advocacy organizations, may play in these processes are sparse.

Finally, like other feminist health scholars, and feminists more generally, I am committed to social movements and political solutions that are aimed toward improving the health and well-being of all women, not just a select few. As aptly stated by Clarke and Oleson (1999, 15),

How can we analyze the breast cancer activism of very elite women and physician's wives that made that disease the "cause" of the year 1996 for corporate as well as individual charity, sending the funds raised to a biomedicine that refuses to address cause and prevention?

Through my research, I seek to address some of the large issues that feminist health scholars are currently grappling with related to processes of biomedicalization, the political economy of health and illness, and the globalizing of biomedical models of advocacy, that are purportedly acting in the interests of all women's health, but may actually steer global health agendas, financial resources, and medical attention to the benefit of a minority of women, at the expense of broader health reform.

Health and Illness Theories

The sociology of health and illness has made significant contributions to our understanding of the critical role that social factors play in determining the health of individuals, social groups, and entire societies (Cockerham 2004). While the World Health Organization defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”, sociologists have found that medical, lay, economic, and environmental perspectives of health vary from this definition (Cockerham 2004; WHO 2009). Additionally, sociologists of health and illness differentiate between disease, a biophysiological state, and illness, a social state in which particular meaning is assigned to a physical or mental state (Conrad 2005). In attempting to better understand the maintenance of health and the production of disease and illness, sociologists have explored these topics through social psychological, inequality, institutional, and environmental perspectives, which I briefly outline before turning to the areas within the sociology of health and illness that I use to explain my findings.

Drawing on social psychology, sociologists of health and illness have explored the ways in which social interactions affect understandings and experiences of health and illness. In particular, sociologists have used a social psychological approach to understand the dynamics of doctor-patient relationships as well as the dynamic between doctors and other healthcare workers (e.g., nurses, physician assistants) (Cockerham 2004). Sociologists have found that the social interaction between various groups is shaped by race, class, and gender power dynamics, although there is an increasing trend toward mutual participation in these interactions, in which all parties involved are heard in what becomes a process of negotiation regarding medical treatment (Cockerham 2004).

In addition to drawing on social psychological perspectives, sociologists of health and illness have drawn attention to the ways in which social inequalities with regard to race, class and gender have largely shaped the social distribution of disease and illness. While the biomedical perspective, the predominant lens through which people understand health and illness, emphasizes health and disease in individuals, sociologists have found social inequalities to be significant predictors of health and disease in both industrialized and developing countries (Brown 2000). By examining the impacts of poverty, income inequality, racial and gender inequality, sociologists of health and illness have demonstrated the need for political, social and economic efforts to promote health and reduce the occurrence of disease (Brown 2000). This perspective challenges the notion that biomedical interventions are solely responsible for health and illness outcomes.

Institutional perspectives within the sociology of health and illness primarily focus on the medical profession, hospital organization, and healthcare systems. From this perspective, sociologists of health and illness have studied the rise of medical power through the professionalization and consolidation of medical knowledge and expertise, largely through the establishment of the American Medical Association (Annandale 2002; Conrad 2005) as well as the current decline of medical professional's power in light of the rise of government regulation, managed care, and corporations in the health care business (Conrad 2005). Additionally, institutional perspectives on health and illness have documented the development of hospitals as a social institution as well as the changing organization of hospitals over time. Finally, from this perspective, sociologists of health and illness have explored health care delivery systems in the US as well as globally (Conrad 2005).

Finally, sociologists of health and illness and environmental sociologists have joined together in addressing issues of health, illness and the environment as integrated phenomena. The field of environmental health that has developed through the collaboration of environmental and medical sociologists has posed significant challenges to the biomedical paradigm. Environmental health perspectives provide a broader, contextualized definition of health and illness. According to Brown (2002, 7), the broadest definition of environmental health

would include the totality of unhealthy living and working conditions: bacteria and viruses in human waste; animal vectors for infectious diseases; surface water and groundwater pollution; air pollution from fires, vehicle exhaust, and incineration; chemical and petroleum product spills and explosions; and disasters, such as floods, hurricanes, and fires (which may be either natural, human caused, or human exacerbated).

Because this definition is particularly broad and all-encompassing, Brown (2002, 7) suggests that environmental health researchers, activists, and policy makers have rightly focused on “the health effects caused by toxic substances in people’s immediate or proximate surroundings (soil, air, water, food, and household goods).” Even with a narrower focus on health effects caused by chemical-related, air-pollution-related, and radiation-related symptoms and diseases, the field of environmental health challenges the myopic biomedical definition of health.

While all of these perspectives have been useful in addressing various issues of health, illness, and disease, for the purposes of my dissertation, I draw on the social construction of health and illness, the political economy of health and illness and processes of biomedicalization, which I now discuss in turn. Although I do not draw on environmental health perspectives directly, this approach to understanding health and

illness informs my dissertation as well, in that I have adopted an environmental understanding of health and illness, which in turn, has influenced my critique of solely biomedical perspectives of health and illness.

Social Construction of Health and Illness

Foucault's theorizing of knowledge and power as they related to changes in medical practices over time in *The Birth of the Clinic* (1973) presented a radical challenge to previous approaches to health and illness that conceptualized disease as the biophysical state and illness as the social state (Annandale 2002, 34). Foucault's social constructionist approach argued that what we know as diseases are themselves fabrications of powerful discourses, rather than discoveries of 'truths' about the body. Drawing on social constructionism, many feminist health and illness scholars have argued that various health problems (e.g., menopause, PMS) exclusive to women have been socially constructed within a male-dominated medical establishment in ways that reinforce gender inequality (Ferguson 2000; Casper 1998; Figert 1995; Lorber 1997; Ehrenreich 1978; Leysen 1996).

While breast cancer is a medical disease, medical issues surrounding breast cancer have been socially constructed. Breast cancer movements have played significant roles in socially constructing breast cancer issues. Lantz and Booth (1998) argue that the US media discourse on breast cancer, supported by many breast cancer advocates out of a desire to "raise awareness," has socially constructed breast cancer as an epidemic in a way that medical professionals did not. The rhetoric of the breast cancer movement has now moved beyond national borders and is striving to socially construct breast cancer as a global epidemic.

Related to the social construction of breast cancer as an epidemic, moreover, breast cancer advocacy has played a significant role in socially constructing breast cancer risk discourse. Because medical knowledge regarding the causes of breast cancer is very limited, breast cancer is a “contested illness,” allowing breast cancer movements to socially construct breast cancer causes and risk in ways that strengthen their movement. Breast cancer risk has been constructed by breast cancer advocates in the US so that all women are “at risk” (Fishman 2000; Klawiter 2002; Fosket 2004; Simpson 2000). Within the category of “at risk,” some women (i.e., those with a family history or genetic predisposition to breast cancer) are constructed as “high risk,” while other women are placed along a continuum down to “low risk” (Klawiter 2002). By constructing risk in such a way, the biomedical breast cancer movement has increased its constituency, from women who had already experienced breast cancer or were personally affected by breast cancer (e.g., lost a family member to breast cancer) to all women. With the global expansion of this breast cancer movement, breast cancer advocates are also expanding this risk discourse on a worldwide scale.

Biomedicalization

As the biomedicalization of society increases, the biomedical paradigm continues to gain strength, despite its inability to address many people’s concerns about health and illness (Clarke et al. 2005). Peter Conrad (1992; 2007) argues that medicalization is a process through which aspects of life previously understood as existing outside of the medical realm, come to be narrowly constructed as medical problems (e.g., menopause, ADHD, erectile dysfunction). It is often medical professionals who redefine sets of behaviors or feelings in medical terms. But, groups of laypeople experiencing certain symptoms (e.g.,

Gulf War veterans) or pharmaceutical companies trying to rebrand existing drugs (e.g., advertising birth control pills for mild acne treatment or PMS symptoms) also participate in these processes of medicalization (Peterson 2008; Brown 2005).

With regard to diseases, like breast cancer, which never existed completely outside of the medical realm, Maren Klawiter (2008, 313) provides an additional understanding of medicalization. She argues that medicalization theories have tended to ignore the

practices through which conditions that are already commonly viewed as medical are shaped, managed and contested by and within medicine and the way the practices through which medical conditions are continuously reproduced as medical conditions can change over time.

Prior to the strengthening of medical power, consolidated by the organization of medical professionals through the American Medical Association in 1847, diseases were treated in multiple ways by different types of healers (Klawiter 2008; Conrad 2005). According to Klawiter, breast cancer was medicalized in a variety of ways. Cancer treatment was moved from the home to the hospital. Surgeons became the sole breast cancer experts. Medical professionals constructed breast cancer as a curable disease. The Halsted radical mastectomy became the “hegemonic treatment” for breast cancer (Klawiter 2008). Breast cancer patients took on the passive “sick role,” which reinforced the paternalistic role of the surgeon and the role of the patient as the compliant child (Klawiter 2008; Conrad 2005, 30). In order to escape the confines of the “sick role” after radical mastectomy surgery and chemotherapy, women could wear wigs, have reconstructive breast surgery or breast prostheses implanted and return to their normal lives and duties (Klawiter 2008, 37). The formation of disease-related identities, solidarities, and social networks was heavily constrained by processes of medicalization, which discouraged patients from

identifying with their disease, in order to focus exclusively on recovery and a return to normalcy (Klawiter 2008).

Breast cancer was further reconstructed within the medical field, as medicalization gave way to intensified processes of biomedicalization beginning in the 1970s and 1980s and continuing today. Adele Clarke and her colleagues (2005, 442) argue that “recently, medicalization is intensifying in new ways. Biomedicine is being reorganized through the remaking of the technical, informational, organizational, and hence institutional infrastructures of the life sciences and medicine, largely via the incorporation of computer and information technologies.” Biomedicine, which Clarke and her colleagues (2005, 442-42) define as “the increasingly technoscientific, complex, multi-sited, multi-directional processes of medicalization,” is transforming the practices of medicine and understandings of health and illness in the twenty-first century.

Building on the “medical industrial complex” concept developed in the 1970s, Clarke and her colleagues (2005, 446) argue that the “Biomedical TechnoService Complex, Inc.” typifies the political economy of the current era of biomedicalization. The corporatized and privatized research, products, and services made possible by technoscientific innovations that further biomedicalization are emphasized by this complex concept. “Through its sheer economic power, the Biomedical TechnoService Complex, Inc. shapes how we think about social life and problems” (Clarke et al. 2005, 446). Within the political economy of biomedicalization, which consists of multinational corporations that are spreading the biomedical paradigm and processes of biomedicalization around the world, solutions to health problems are increasingly corporatized and commodified.

Processes of biomedicalization also transform the concepts of health, risk and surveillance, bringing discourses of risk to the forefront of medical attention. Whereas processes of medicalization redefined social problems as medical illnesses, disabilities and/or diseases, processes of biomedicalization have redefined health so that the lack of symptoms does not necessarily indicate the lack of disease or potential disease. Therefore, health must be maintained through biomedical surveillance and risk assessment (Clarke et al. 2005, 446). Individuals who may otherwise appear and feel healthy are defined as “at risk” based on family history, personal behaviors, and/or results from genetic testing. Risk is then managed through “processes of surveillance, screening, and routine measurements of health indicators” (Clarke et al. 2005, 448). Through biomedical screening, breast cancer was “reinvented as an invisible risk and symptomless disease that required continuous bodily vigilance and surveillance” (Klawiter 2008, 38). According to Klawiter (2008, 38),

Breast self-exam, clinical exam, and mammographic screening were heavily promoted and discursively constructed as the moral duty of every woman. As this occurred, the temporary sick role for symptomatic women was replaced by a permanent “risk role” for all women. Biomedicalization thus reconstituted healthy, asymptomatic women as risky subjects and transformed the disease from an either-or condition to a breast cancer continuum.

Processes of biomedicalization have also transformed information, knowledge production, and distribution of medical information (Clarke et al. 2005, 450). Information on health and illness “is proliferating in all kinds of media, especially newspapers, on the internet, in magazines, and through direct-to-consumer prescription drug advertising” (Clarke et al. 2005, 450). Multiple sources create and distribute health-related information and “non-expert” individuals are increasingly expected to navigate and make sense of various health-related messages (Clarke et al. 2005, 450). While the proliferation

of sources of information, knowledge production and distribution has implications for democratizing biomedicine, the interests of the pharmaceutical industry still predominate (Clarke et al. 2005, 450).

Finally, processes of biomedicalization have transformed bodies as well as identities (Clarke et al. 2005, 451). The body, once viewed as immutable and the focus of control, is reconceptualized as “flexible, capable of being reconfigured and transformed” (Clarke et al. 2005, 451). “Technoscientific identities” also are created through processes of biomedicalization (Clarke et al. 2005, 452). These identities were not available prior to certain developments in biomedical technologies. For instance, with the availability of genetic testing, identities may shift from “healthy” to “ill,” “healthy” to “genetic carrier,” or “low risk” to “high risk,” with the arrival of test results. These individual identities can also develop into collective identities. For example, in the case of the breast cancer gene, people who find out that they are “high risk” for breast cancer may take on that illness identity and become involved with breast cancer advocacy or join a support group for “high risk” women. In this sense, these identity transformations can be quite profound.

My research explores processes of biomedicalization, as they are expanded to a global scale by biomedical breast cancer advocacy organizations. Much of the literature on biomedicalization has focused on the role of medical professionals and the pharmaceutical industry in promoting processes of biomedicalization in order to increase profits by monitoring “at-risk” individuals, communities, and populations. By examining biomedical breast cancer advocacy organizations, I am contributing to this literature by examining the role of health advocacy in these processes. Furthermore, I am examining how these processes are translated to other political and cultural contexts via biomedical

breast cancer advocacy organizations. Previously, the discussion of processes of biomedicalization focused primarily on the US.

Political Economy of Health and Illness

The central tenet of the political economy of health and illness perspective is that there is a clear contradiction between the pursuit of health and the pursuit of profit (Annandale 2002, 15; Doyal 1979). I take this to signify a couple of things that are relevant to understanding health and illness in advanced capitalist society. First, if profit is the ultimate goal in capitalist society, industrial processes will proceed with regard to the maximization of profit, while disregarding any harmful health effects of the processes. Second, if the pursuit of profit permeates all social institutions in capitalist society, then the medical field is also motivated by the pursuit of profit, not (solely) by the pursuit of health. As Landry and MacLean (1993, xii, as quoted in Annandale 2002, 17) state, “now the market is ‘in’ everything and nothing is incapable of being commodified.”

Related to both of these aspects of the political economy of health and illness, McKinlay (2005, 561) argues that,

In the past, it has been common to advocate the education of the public as a means of achieving an alteration in the behavior of groups at risk to illness. Such downstream educational efforts rest on “blaming the victim” assumptions and seek to *either* stop people doing what we feel they “ought not” to be doing, *or* encourage them to do things they “ought” to be doing, but are not. Seldom do we educate people about the activities of the manufacturers of illness and about how they are involved in many activities unrelated to their professed area of concern.

Although McKinlay situates “downstream educational efforts” in addressing ill health as “in the past,” these types of educational campaigns remain quite common, while the “upward stream” of educating people about manufactures of illness in order to create social change remain relatively rare. Even when educational campaigns no longer “blame

the victim” by calling for changes in personal behaviors, health advocacy increasingly involves the promotion of biomedical research and pharmaceutical and medical technological solutions to disease, rather than seeking changes in the disease-producing social structures.

A key player in the political of health and illness in terms of the commodification of solutions to disease, the pharmaceutical industry has become a central concern among scholars within the political economy of health and illness. Pharmaceutical companies once known for competing over the best scientists in order to create the next and best drug (or so they told us), now spend most of their resources hiring the “most creative and aggressive marketers” (Peterson 2008, 4). While the drive for profit in medical research has long been associated with little to no medical research on disease causes and prevention, according to Peterson (2008) pharmaceutical companies are not interested in finding the cures to such widespread ailments as cancer and heart disease either. From a profit-driven perspective, pharmaceutical companies are interested in marketing products that can “manage” chronic diseases if taken for the duration of a patient’s life. In addition to creating drugs to manage illnesses, pharmaceutical companies also focus on expanding their market by “creating” new diseases, expanding the understanding of who needs a certain drug or how that drug can be used, and finally, expanding geographically to new markets.

One way that pharmaceutical companies seek market expansion is through the legalization and expansion of direct-to-consumer pharmaceutical advertising (DTCA).

DTCA via openly persuasive publicity slogans—mostly on television—or industry-funded “educational” campaigns on the identification and lifelong drug treatment of various troubles, is a harbinger for a major transformation in the significations and roles of medications in society—moving them even further out

of the domain of medical mystique and into the *mass market as lifestyle products* {my emphasis, Cohen et al. 2005, 280).

The pharmaceutical industry, largely through shifting its efforts to marketing drugs and particularly through the expansion of DTCA, is increasingly promoting commodified solutions to health problems.

In addition to analyzing the pharmaceutical industry, scholars have applied the concept of political economy specifically to breast cancer (e.g., Zones 2000), arguing that the disease has become a source of economic gain, particularly for the pharmaceutical and medical technology industries. In Zones' (2000, 137) view, "once a product or service has made its way into the marketplace, sales may be increased by appealing to new customers." She refers specifically to the targeting of more and more women as "at risk populations." Similarly, Klawiter (2002, 313) discusses breast cancer in terms of the "pharmaceuticalization of medicine." She argues that AstraZeneca, a large pharmaceutical company, played a crucial role in redefining breast cancer risk to include larger numbers of women in order to market and sell their breast cancer drug, tamoxifen (Klawiter 2002). While some women's health movements were concerned about the direct-to-consumer advertising of this potentially dangerous drug to women in the US, biomedical breast cancer organizations began to incorporate risk assessment discourse in their informational materials (Klawiter 2002, 339). I utilize this work on the political economy of breast cancer to examine the role of globally expanding biomedical breast cancer advocacy organizations in the political economy of health and illness.

Finally, while not a health and illness sociologist, King's (2006) understanding of the neoliberal political economy in which health-related advocacy engages is very

relevant for my research. According to King (2006, xxvi), neoliberalism is “a philosophy and a set of economic and political policies aimed at cutting expenditures on public goods such as education, health care, and income assistance in order to enhance corporate profit rates.” She argues that Avon Foundation events focus on developing “consumer-oriented, private, and individual responses to breast cancer in locations across the globe,” which complements neoliberal projects, like IMF and WB structural adjustment programs that are requiring public sector cutbacks and private sector alternatives (King 2006, 98).

I will utilize political economy of health and illness perspectives in my research by examining the way in which biomedical breast cancer advocacy organizations globally promote medical technology and pharmaceuticals as solutions to illness, globalizing, as argued by King (2006), privatized and corporatized solutions to health problems. In partnering with medical technology and pharmaceutical companies, biomedical breast cancer organizations may expand these companies’ abilities to advertise directly to consumers, via breast cancer events, in locations where they otherwise would not be able to. Additionally, by creating new at-risk identities related to breast cancer, biomedical breast cancer advocacy organizations are creating potential medical consumers for medical technology and pharmaceutical companies. Finally, I will utilize a political economic perspective to understand the role of SGKC’s and Avon Foundation’s elite connections, power and influence with regard to their ability to expand globally.

Social Movement Theories

Social movements, as Buechler (2000) argues, pose challenges to the social order and, along with many other social forces, have shaped the current context of many social institutions within advanced capitalist society. Social movements, therefore, provide an

opportunity to examine human agency with regard to social change in conjunction with the social structures (e.g., political, economic, educational, religious, medical) that contextualize their struggles. Snow and his colleagues (2004) provide a definition of social movements that is useful for the context of my dissertation research. According to Snow and his colleagues (2004, 9),

In order to have an understanding of social movements that is both more inclusive in terms of what gets counted as social movement activity, and yet more tightly anchored institutionally and culturally, we argue that movements be considered as challengers to or defenders of existing institutional authority-whether it is located at the political, corporate, religious, or educational realm- or patterns of cultural authority, such as systems of beliefs or practices reflective of those beliefs.

Globally expanding biomedical breast cancer advocacy organizations challenge non-biomedical understandings of disease that rely on alternative or non-traditional medical practices or rely on medical intervention for symptomatic individuals only. Regardless of the political or cultural contexts to which they are expanding, biomedical breast cancer advocacy organizations promote breast cancer awareness, biomedical screening of non-symptomatic populations, and individual responsibility for one's health. Given that this form of advocacy does not challenge existing governmental, medical, or corporate authority, globally expanding biomedical breast cancer advocacy organizations are able to partner with the US government, governmental and non-governmental medical organizations, medical professionals, and corporations. Because of these partnerships with institutional authorities, biomedical breast cancer advocacy organizations often diverge from what are often considered social movements. Furthermore, biomedical breast cancer advocacy organizations' activities are not particularly disruptive, which is often included by social movement scholars as a definitive element of social movement

activity. Biomedical breast cancer advocacy is also culturally significant in that it is promoting activities, such as athletic events and consumer spending to fundraise, which have been developed within the US, and are now being deployed to other cultural and political contexts in which these activities are often unfamiliar.

To understand how and why biomedical breast cancer advocacy is expanding globally, I will utilize social movement perspectives from resource mobilization, political opportunity structures, and framing theories. The notion of resource mobilization is particularly useful in understanding how social movements emerge or, in this case, how they expand. In answering the question of how social movements emerge and expand, the resource mobilization approach focuses on “group access to and control over the various resources necessary for effective social movement activism” (Buechler 2000, 35). According to McCarthy and Zald (1977, 1216), “study of the aggregation of resources (money and labor) is crucial to an understanding of social movement activity.” Furthermore, mobilizing resources requires that social movements exhibit some level of organization. McCarthy and Zald (1977, 1218) define a social movement organization as “a complex, or formal, organization which identifies its goals with the preferences of a social movement or a countermovement and attempts to implement those goals.” Resources are not merely indigenous to social movement actors and organizations; rather they must be sought from elite individuals and institutions from outside of the movement (McCarthy 1977). Elites control large amounts of resources and are therefore needed by social movements. Resource mobilization will therefore be useful in explaining how biomedical breast cancer advocacy organizations have attained the organizational structure and financial resources to expand beyond the US.

In addition to resource mobilization, the political process model, with its focus on political opportunity structures (POS), will be useful in understanding the broader environment in which the biomedical breast cancer movement has expanded. Using this perspective helps shed light on why advocacy organizations expanded at the particular time that they did and to the particular countries that they did. The political process model is generally concerned with the ways in which the political environment shapes the development, trajectory and outcomes of social movements. In the case of biomedical breast cancer advocacy, I am particularly interested in the trajectory of biomedical breast cancer advocacy with regard to its expansion beyond the US. While there are various definitions of what constitutes the political opportunity structure, Tarrow (1998, 76-77) provides a broad definition that captures the meaning of the concept by stating that political opportunity refers to “consistent—but not necessarily formal or permanent—dimensions of the political environment that provide incentives for collective action by affecting people’s expectations for success or failure.”

Some scholars have critiqued the political process model for having a structural bias and being overly reliant on the role of the state in explaining social movements (Goodwin 1999; Van Dyke et al. 2004; Morris 2000). According to Goodwin and Jasper (1999), the political process model, through the use of the popular concept of political opportunity structures, over-emphasizes the structural aspects of political opportunities, while downplaying or ignoring all together the ways in which political opportunities are subjective and dynamic. Furthermore, both Goodwin and Jasper (1999) and Van Dyke and her colleagues (2004) problematize the state-centered aspect of the political process model. “While it is undeniably true that many social movements direct their grievances

and concerns to the state or state institutions, it is also the case that modern movements target other entities, such as religion, medicine, educational organizations, professional associations, and private employers” (Van Dyke et al. 2004, 28). While the political process model may be useful for explaining movement mobilization that is directed at the state, it is much less potent in its ability to explain movements that are not primarily state-oriented. Political process theorists have tended to avoid this issue by focusing primarily on movements that, at least to some extent, target the state.

To apply this perspective to explain biomedical breast cancer advocacy, I will implement a broad understanding of “political environment,” that includes the medical establishment and economic actors, such as multinational corporations and pharmaceutical and medical technology companies. I will also pay attention to governing bodies on national and international levels (e.g. the EU) as they may also play a role in expanding or limiting the opportunities for this movement to expand to particular countries.

Political opportunity scholars also have addressed the ability of social movements to produce political opportunities. That is, in addition to responding to exogenous political opportunities, collective action also creates opportunities. “Once collective action is launched in part of a system, on behalf of one type of goal, and by a particular group, the encounter between that group and its antagonists provides models of collective action, master frames, and mobilizing structures that produce new opportunities” (Tarrow 1998, 87). The opportunities created by social movements can expand or contract the opportunities of unrelated social movements, allied social movements, countermovements, as well as elites (Tarrow 1998, 87-89). In the case of biomedical

breast cancer advocacy, given their organizational and financial successes in the US, it is possible that they were able to create opportunities for expansion without too much concern for the cultural and political contexts into which they were moving. Additionally, by expanding biomedical health advocacy to diverse political and cultural contexts, they are likely to affect the political and economic opportunities of other health-related advocacy organizations as well as elites, such as the corporations with which they partner.

The notion of framing within social movement theory will also be useful in explaining my research findings. Framing is the process of meaning construction performed by social movement organizations (Benford 2000). By shifting their language to the global realm, biomedical breast cancer advocacy organizations have reframed breast cancer from a domestic to an international concern. Within the US, biomedical breast cancer advocates framed breast cancer as a threat to all women, and therefore, by extension as a threat to everyone through the potential illness and loss of a daughter, wife, mother, or friend (Kolker 2005). Instead of placing blame on medical professionals, polluting companies, or the government, biomedical breast cancer advocates framed breast cancer itself as their enemy or target, and enlisted medical professionals, corporations, and the government as allies in the fight against breast cancer. In order to defeat breast cancer, biomedical breast cancer advocates framed the solution as individual vigilance (e.g., monthly self-exams, regular clinical exams and mammograms) and increased funding for breast cancer research focused on detection and treatment, with the ultimate goal of finding the cure.

According to Benford and Snow (2000), frame diffusion is the dynamic process by which a social movement transmits its construction of an issue to another political and/or cultural context. In some cases a social movement may “strategically select” and adopt particular framing of an issue to another context or culture. In other cases, a movement may “strategically fit” its framing of an issue to another political and/or cultural context (Benford and Snow 2000, 627). In the case of the expansion of biomedical breast cancer advocacy, I am interested in how biomedical breast cancer advocacy organizations have, or have not, altered their framing of breast cancer to “strategically fit” it to other political and cultural contexts in order to expand this form of advocacy beyond the US.

Health Social Movements

Theorizing and research on health social movements has burgeoned in the past few years, exploring how diverse health-related movements emerge and function (Allsop et al. 2005; Brown et al. 2004; Hess 2005; Klawiter 2005; Kolker 2005; Brown 2005; McCormick et al. 2003). Theorizing these movements is critical to this new body of literature that is attempting to account for interlocking and overlapping interest groups. Most important to these theoretical developments has been the work of McCormick et al. (2003), Brown et al. (2004) and Brown and Zavestoski (2005) who defined health social movements as organized around three main foci: (1) access to health services; (2) health inequality; and (3) the experience of illness.

Within the body of literature on health social movements, breast cancer movements have been conceptualized as “embodied health movements,” which address illness experience by challenging science on etiology, diagnosis, treatment, and/or

prevention (Brown 2004). Embodied health movements, such as breast cancer movements, often respond to “contested illnesses” that are either unexplained by current medical knowledge or have purported environmental explanations that are often disputed (Brown 2004; Brown 2005). As is the case with breast cancer movements, embodied health movements may include constituents who are not ill, but who perceive themselves as vulnerable to the disease (Brown 2005; Brown 2004).

Brown and his colleagues (2004) also acknowledge the diverse tactical and organizational forms that health social movements may embrace. They present a spectrum of tactical and organizational forms spanning from “advocacy-oriented” to “activist-oriented.” “Advocacy-oriented” movements include groups working within the current political economic system and the biomedical model, using tactics other than direct, disruptive action (e.g., education), and tending not to push for lay involvement in scientific and medical expert knowledge systems; “activist-oriented” movements, in contrast, include groups engaging in direct action, challenging current scientific and medical paradigms, and pursuing democratic participation in scientific or policy knowledge production by working largely outside the current political economic system and the biomedical paradigm (Brown 2004). While a range of breast cancer organizations exist, spanning advocacy-oriented to activist-oriented, the globally expanding biomedical breast cancer movement is advocacy-oriented in its approach.

The concept of “boundary movements” emerging out of the health social movement literature is also relevant to my research. Health social movement scholars have described many embodied health movements as “boundary movements” due to the fact that they transcend various boundaries including boundaries between movements,

science and non-science, laypeople and experts, movement insiders and outsiders, and movement organizations and corporations (McCormick et al. 2003; Brown et al. 2004; McCormick and Baralt 2006).

Through my research, I expand on this concept of health social movements as boundary movements, arguing that through their collaboration with the US government; medical professionals, medical research centers, corporations, and pharmaceutical and medical technology companies, biomedical breast cancer advocacy organizations are actually creating “hybrid” organizations and events on a global scale. This means that in many cases, to be discussed in detail in Chapter 5, the organizations and events within the transnational biomedical breast cancer advocacy coalition are not strictly advocacy organizations, events and activities, but rather advocate/diplomatic, advocate/medical, and advocate/corporate organizations, events and activities. Given the financial success of this hybrid form of biomedical breast cancer advocacy, it is important to include it in the conceptualization of forms of health social movements, as it may become an increasing trend in health advocacy.

Additionally, health social movements have played a role in processes of biomedicalization (Conrad 2007), participating actively in the medicalization of certain diseases and the de-medicalization of others. The processes of medicalizing alcoholism, post-traumatic stress disorder, Alzheimer’s disease, and most recently Gulf War Illness⁷ were led by social movements (Conrad 2007). In some cases, social movements have been less successful in their attempts to medicalize illnesses, as in the case of multiple

⁷ After years of pressure from Gulf War veterans suffering from health problems, in 2008, a U.S. congressionally mandated panel, the Research Advisory Committee on Gulf War Veterans’ Illnesses, confirmed that Gulf War illness, as reported by veterans since the war in 1991, is a real disease that should be treated as such by doctors and funded by veterans’ health and disability benefits (Maugh 2008).

chemical sensitivity disorder (Kroll-Smith 1997). With regard to women's health issues such as menopause, menstruation and childbirth, women's health movements have sometimes butted heads with each other, with some supporting increased medicalization as a means of legitimating illness symptoms, and others challenging medicalization, emphasizing these processes as "natural" parts of women's lives, not in need of medical intervention (Westfall 2004; Leysen 1996; Ferguson 2000).

In the case of biomedical breast cancer advocacy, advocates working in the US have promoted a biomedical model of the disease to the exclusion of environmental factors that may contribute to breast cancer incidence (Eisenstein 2001; Zavestoski et al. 2004). Having achieved great financial success in the US (King 2006; Klawiter 2008), these advocacy organizations are now expanding globally and playing a role in processes of biomedicalization on an international scale. While breast cancer is, without dispute, a disease that needs to be addressed by the medical establishment, both within the US and globally as well, it is also a disease whose increasing incidence is largely unexplained by sole reliance on medical science.

My research will expand current understanding of the role of health social movements in processes of biomedicalization by examining biomedical breast cancer advocacy organizations on a global scale. These organizations promote a biomedical understanding of breast cancer, emphasize all women's status as "at-risk" for the disease, and encourage medical surveillance in the form of clinical breast exams and regular mammograms. Working collaboratively with medical professionals, medical research centers, hospitals, and pharmaceutical companies, biomedical breast cancer advocacy organizations play an integral role in creating awareness about biomedical breast cancer

screening and treatment and creating new medical consumers. Finally, health social movements, currently, have been examined within individual countries, primarily within the US and the UK. Therefore, the examination of transnational biomedical breast cancer advocacy will expand the examination of these organizations beyond national borders, contributing to our understanding of how health advocacy, particularly biomedical health advocacy, translates to other political and cultural contexts.

Transnational Social Movements, Networks, and Coalitions

Given the rapidity with which international political, economic and socio-cultural inter-connections are proliferating through processes of globalization, social movements are increasingly transcending national borders in order to confront issues that are not confined by national boundaries. According to transnational social movement scholars, in the context of an increasingly globalizing political economy, we can expect that “collective actors in transnational space will be a feature of the contemporary world and will continue to expand in number and importance” (Khagram et al. 2002, vii).

Transnational movements, networks, and coalitions, are significant social actors in that they have the potential to transform both domestic and international politics by creating issues, mobilizing new constituencies, and altering understandings of interests and identities (Khagram et al. 2002, vii). To investigate this trend, social movement scholars have amended state-centric social movement theories, which largely theorized social movements confined within national boundaries, to better understand the increasingly transnational nature of much social movement activity (Eschle 2001; Farro 2001; Keck, 1998; Khagram et al. 2002; Sikkink 2002; Moghadam 2001; Tarrow 2005; Farro 2001 ; Keck 1998; Khagram 2002; Sikkink 2002; Moghadam 2001; Tarrow 2005).

Transnational social movement (TSM) scholars are careful to acknowledge multiple forms and meanings of “globalization.” Globalization refers to a diversity of economic, political, and socio-cultural trends of increasing inter-connections among economic institutions, governing bodies, and cultural phenomena (McCarthy 1997; Pieterse, 2001). TSM scholars have primarily focused on what they variously refer to as “neoliberal globalization”, “economic globalization” or “corporate-dominated globalization” (Evans 2005; Bennett 2005; Eschle 2001), given that this is the form of globalization that many contemporary TSMs are challenging (Bennett, 2005). According to Pieterse (2001, 22), “to distinguish contemporary globalization from long-term trends it may be appropriate to speak of accelerated globalization. Accelerated globalization coincides with the prominence of neoliberalism and the drive to free markets.” Similarly, della Porta and Tarrow (2005, 2) argue that there is a “shift in the axis of power from politics to the market, with neoliberal economic policies increasing the power of multinational corporations and reducing the capacity of traditional state structures to control them.” To counter neoliberal globalization, Evans (2005, 655) argues that social movements have “harnessed the growth of transnational connections” to construct “more equitable distributions of wealth and power and more socially and ecologically sustainable communities.” This trend in social movements is often referred to as “counterhegemonic globalization” or “globalization from below” (Evans 2005; Khagram 2002; Pieterse 2001). Much TSM scholarship thus far has been biased toward progressive movements countering globalization. This scholarship has fruitfully explored how these social movements have “harnessed” transnational connections, using them as opportunities to counter current neoliberal economic trends. At the same time, research is

lacking on how transnational social movements may actually utilize neoliberal economic institutions and trends to further their goals. My research will help fill this gap.

TSMs, via their respective organizations (TSMOs), work toward a variety of social change goals. Nevertheless, social movement scholars have tended to focus on the most populous transnational movements. The issues that have generated the most transnational activity are “also those that have achieved wide support among national groups in Western democracies” (Smith 2004, 320). The transnational movement for human rights has consistently been the most populous TSM. Other large TSMs include the “anti-globalization” or “global justice” movement, women’s rights movements, peace or anti-war movements, and the environmental movement. In some cases, claims originally defined within national boundaries are “reframed” in order to fit within transnational discourses (Smith 2004, 321). The literature on TSMs is lacking in terms of research on transnational health social movements. My research on transnational biomedical breast cancer advocacy, utilizes concepts from TSM literature, while broadening the types of movements that have been studied.

In addition to the diversity of issues addressed by TSMs, there are a variety of forms of transnational collective action. Many TSM scholars have focused their attention on transnational advocacy networks (TANs), which consist of informal connections between non-state actors linked across national boundaries. Network participants are bound together by “shared values, dense exchanges of information and services, and common discourses” (Keck 1998; Khagram et al. 2002, 7). While TANs primarily exist for the exchange and shared use of information, transnational coalitions involve a greater level of transnational coordination than is present in transnational networks.

Transnational coalitions are sets of actors linked across national boundaries who coordinate shared strategies or sets of tactics to publicly influence social change (Khagram et al. 2002). Transnational campaigns are shared strategies or sets of tactics utilized by transnational coalitions and they can include so-called “non-institutionalized” tactics (e.g., boycotts, protests, civil disobedience) or a combination of institutionalized and non-institutionalized tactics, as is often the case with domestic social movements (Tarrow 1998). Finally, transnational social movements (TSMs) are “sets of actors with common purposes and solidarities linked across country boundaries that have the capacity to generate coordinated and sustained mobilization in more than one country to publicly influence social change” (Khagram et al. 2002, 8).

In addition to these “pure” forms of transnational collective action, consisting solely of non-state activist or advocacy organizations, TSM scholars have also noted the existence of mixed actor coalitions (MACs). Although NGOs and social movements are the primary actors within these transnational coalitions, (parts of) states and intergovernmental organizations, as well as other non-state actors such as foundations, research institutions, and/or corporations could also be included (Khagram et al. 2002). This definition is more expansive and inclusive, as opposed to transnational coalitions and networks, which only include domestic and international NGOs and social movements. According to Khagram and colleagues (2002, 11), the non-governmental sector, of which TSMs and NGOs are a significant part, represent a third sector of society: “distinct from, but interacting with, government and business, in which the characteristic form of relation is neither authority or hierarchy, nor the market, but rather the informal and horizontal network.” Additionally, while Khagram and his colleagues

(2002, 11), like many other social movement scholars, argue that the non-governmental sector, and specifically, social movements, represent a distinct sector of society, I have found that in their efforts to globally expand, biomedical breast cancer advocacy organizations are intricately tied to governmental, medical, and corporate sectors, in ways that blur the boundaries between their interests, identities, and activities.

Transnational social movements and INGOs are increasingly emerging as significant actors in the global political economy. TSMs and INGOs are “transforming global norms and practices” (Khagram et al. 2002). Scholars of TSMs and INGOs stress the increase in new non-state actors, new arenas for action, and the blurring of distinctions between domestic and global levels of politics (Khagram et al. 2002). Rather than theorizing TSMs as completely new phenomena, social movement scholars tend to view transnational movement dynamics as extensions of national social movements. As stated by Smith (2004, 320), “while global integration has altered dramatically the arenas of political struggle, there are tremendous continuities in how social movements operate and interact with authorities.” Social movement scholars have also noted that there is a trend in which national groups are increasingly participating more in transnational networks and coalitions “as they discover that achieving their organizational aims require engagement at the transnational level” (Smith 2004, 320).

Structures of opportunities for transnational advocacy are similar to those for state-based advocacy, in that the potential for influence is affected not only by governmental structures, but also by social and cultural contexts including values, beliefs, and patterns of behavior that movements seek to change (Smith et al. 1997, 70). Many studies of TSMs, however, focus exclusively on social movement activity in explicitly

“political” arenas. As stated by Smith and colleagues (1997, 70), “the ‘deep politics’ of shaping individuals’ thinking and action on environmental, peace, development, and other issues clearly occupy much, if not most, social movement energies.” Nevertheless, it is these efforts that are often neglected by social movement scholars. My research will contribute to this literature by examining how globally expanding biomedical breast cancer advocacy organizations work to shape how women in other countries think and act regarding breast health, cancer risk, medical surveillance, and health advocacy.

Biomedical breast cancer advocacy organizations have not shifted to a global scale primarily to influence transnational governing bodies (e.g., the European Union), to challenge transnational economic organizations (e.g., IMF, WTO), or to confront multinational corporations. Rather they are committed to the “deep politics” of shaping women’s understandings of health and illness by promoting a global biomedical breast health agenda.

Transnational social movements often attempt to draw upon preexisting institutional structures in mobilizing around particular issues. TSMOs usually draw on preexisting organizations that are tackling similar issues, rather than reinventing the wheel by trying to recruit individuals who are unaffiliated with any organization. At the same time, social movement scholars have noted that social movement organizations also “have strong incentives to compete with one another for resources, constituents, and legitimacy” (McCarthy 1997, 250).

Transnational arenas of engagement frequently involve global conferences and meetings. These annual or bi-annual conferences provide opportunities for advocates from different countries to meet in person to strategize for their transnational campaign.

These types of meetings are obviously expensive and resource-intensive in terms of planning and coordination. Therefore, in addition to global conferences and meetings, transnational social movements conduct most of their organizing over the internet. Many transnational advocacy organizations also sponsor formal training sessions “to help reduce the costs of mobilizing around transnational issues” (Smith 2004, 326).

In pursuing their goals, transnational advocacy organizations, networks, and coalitions employ mobilizing and action strategies. According to Smith and her colleagues (1997, 71), mobilizing strategies “attempt to attract new activists and resources for the cause.” Action strategies, on the other hand, are the “activities that social movements employ in order to influence policy” (Smith et al. 1997, 71). TSMs, like national movements, have to make decisions about their repertoires of contention, or which types of strategies they will employ. Strategic repertoires “can be conceived of as some mix of public education, direct aid to victims of injustice, and attempts to change structures directly” (McCarthy 1997, 257). In the case in which movements are not focused on influencing policy, per se, action strategies are employed in order to influence potential allies, participant identities, socio-cultural norms, and/or various priorities or values (e.g., economic, educational, religious, health).

Transnational social movements also engage in strategic framing processes. As stated by McCarthy (1997, 245), “if the work of strategic framing is difficult at the national level, it is far more difficult at the transnational level.” Transnational movements must attempt to construct frames that resonate in diverse cultural settings and to promote frame bridging, which is “the linking of new mobilizing frames with existing cultural materials” (McCarthy 1997, 245). According to social movement scholars, one of the

most successful transnational framing efforts in the recent period has been the “creation of a common transnational conception of human rights” (McCarthy 1997, 245).

An important question regarding transnational social movements is what leads advocates to globalize their struggles. Scholars of transnational advocacy campaigns and movements have identified “important linkages between social movement actors and global institutions, such as the United Nations or European Union, that encourage transnational activism” (Smith 2004, 325). Additionally, “modeling” or “diffusion” refers to the adoption of norms or forms of collective action or organization in one setting that have been developed or used in another (Smith 2004, 325). Finally, national social movements are likely to expand transnationally if they have reason to believe that doing so will further their goals (Reitan 2007).

According to Bennett (2005), diffusion is the oldest form of transnational contention. Diffusion involves advocates in one country or region adopting or adapting the organizational forms, collective action frames, or targets of those in other countries or regions. Diffusion processes may, but need not, involve connections across borders (Bennett 2005). Tarrow (1998) describes a variant of diffusion, called “brokerage,” through which groups or individuals deliberately connect actors from different sites of contention. In general, social movement research indicates that “sustained diffusion processes both require and help to produce transnational networks and identities” (Della Porta 2005).

Transnational social movements are not only shaped by globalizing forces, they also are agents affecting current political, economic and socio-cultural trends. Transnational social movements can be important agents of global change in a variety of

ways (Kriesberg, 1997; Pieterse 2001). While transnational social movements, networks and coalitions, like their national counterparts, are rarely “successful,” if success is strictly defined as achieving specific policy changes, there are several ways transnational advocacy can and does influence transnational politics, economics, and culture.

Transnational advocacy often focuses the attention of elites and the general public on particular global issues or problems (Smith et al. 1997, 73). In many cases, transnational social movements foster new transnational identities among their constituents.

Additionally, transnational social movement organizations provide a network of relations for “the diffusion of ideas and practices, thereby facilitating mobilization for movement goals” (Kriesberg 1997, 14). Transnational social movement organizations also affect global change, in some cases, by establishing intergovernmental institutions, placing different people in decision-making offices, and “providing particular goods or services through the market place or through public or private nonprofit organizations” (Kriesberg 1997, 15). Nevertheless, TSMOs are “only one of many global actors, and they are often relatively powerless when compared to other global actors such as governments, multinational corporations, and international banking institutions” (Kriesberg 1997, 16).

Transnational social movements “help shape transnational policies in ways such as mobilizing support, broadening participation, sustaining activity, framing issues, and implementing policies” (Kriesberg 1997, 16). In some cases TSMOs try to influence international governmental organizations and other international non-governmental organizations by direct contacts. They usually also work at the national level to influence officials, national organizations, and the public at large. Transnational social movements shape global policy by “helping mobilize support for particular policies, helping sustain

attention on critical global problems, helping frame issues and setting the policy agenda and some carry out transnational policies” (Kriesberg 1997, 17-18). Finally, within TSMOs and transnational campaigns, there is evidence to suggest that new leadership skills and advocate identities are generated (Smith, 2004, 326).

While the transnational social movement literature has expanded significantly over the past decade, it remains limited in some significant ways. There is a bias in the literature toward progressive TSMs that are countering neoliberal globalization. Additionally, there remains a bias in the TSM literature, similar to that in the literature on national social movements, focusing on movements that are directed toward political (e.g., EU) and economic (e.g., WTO, IMF) institutions. Finally, the literature is completely lacking with regard to analyses of transnational health advocacy. My research, therefore, will contribute to this literature in a number of ways. By examining transnational biomedical breast cancer advocacy, I will employ concepts from transnational social movement theorizing to understand how health advocacy develops on a transnational scale. Rather than positioning themselves against neoliberal globalization, biomedical breast cancer advocacy organizations play a role in neoliberal trends by promoting individual responsibility for one’s health and promoting a consumer model of health advocacy and health-related behavior. Finally, biomedical breast cancer advocacy does not focus on political and corporate targets; instead, these advocacy organizations align with government agencies and corporations to further their goals.

CHAPTER 3

THE RESEARCH PROCESS

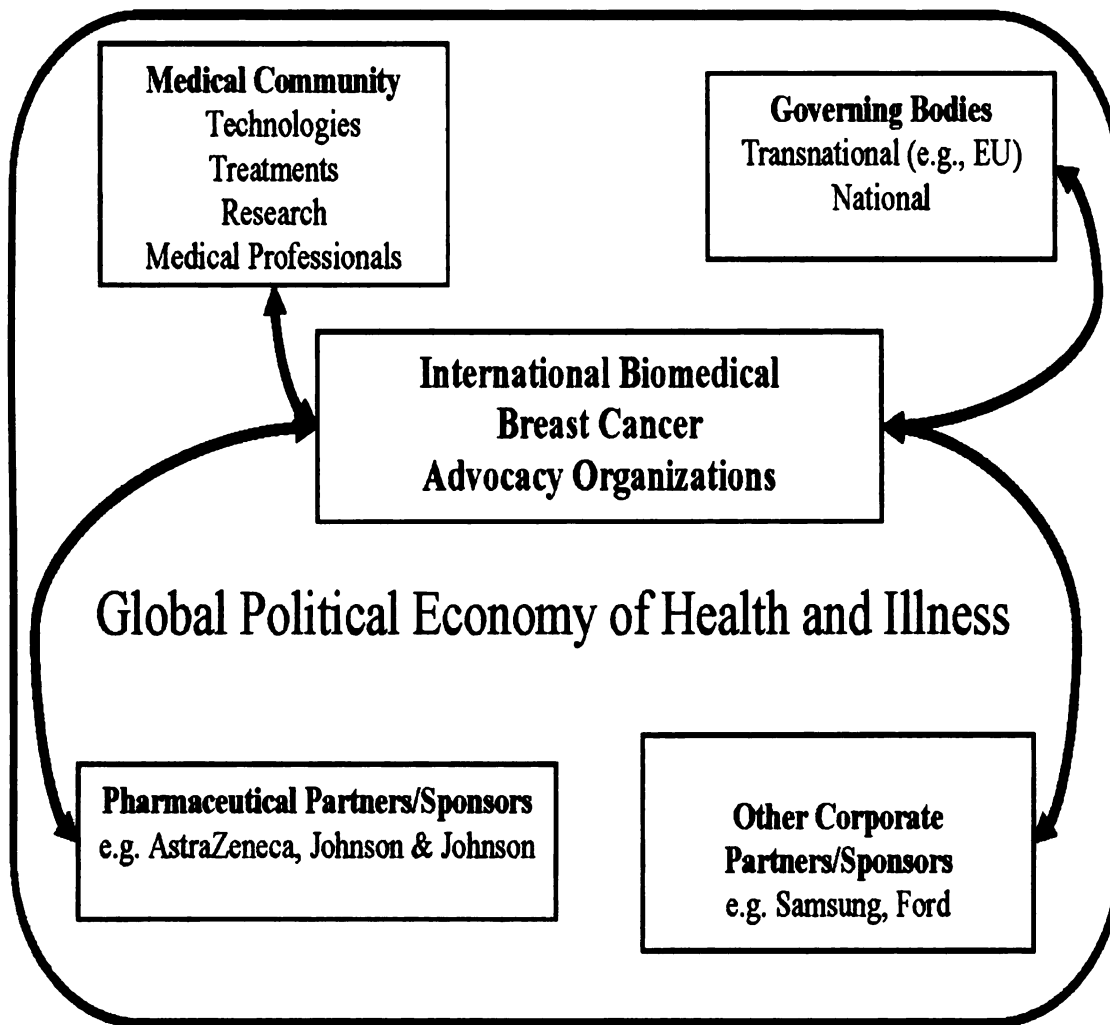
The findings presented in this study are based on twenty-four semi-structured interviews, qualitative content analysis, and participant observation. In this chapter I begin with a discussion of my research design as it relates to my research objectives. I then discuss the principles of feminist research methodology that I drew on for this project. Next I discuss the rationale behind the selection of organizations and research sites for this project. Finally, I discuss my entry into the research sites and conclude by elaborating on my particular research methods and data analysis techniques.

RESEARCH DESIGN

The methodological approach taken in my research is that of an intrinsic case study (Berg 2004). By this I mean that I am utilizing the global expansion of biomedical breast cancer advocacy because it presents a unique and interesting case in which (1) US-based biomedical advocacy organizations are expanding to other countries, (2) transnational health advocacy coalitions may be playing a significant role in the global political economy of health and illness and processes of biomedicalization, and (3) theoretical conceptualizations of health social movements and transnational coalitions are challenged. By better understanding this particular case, I will be able to contribute to theoretical understandings of the social construction of health and illness, processes of biomedicalization, the political economy of health and illness, health social movements, and transnational advocacy coalitions. While findings based on this case will not be generalizable to other health social movements, there does seem to be a trend in the US

toward single-disease advocacy organizations that rely on fundraising and awareness campaigns.⁸ Biomedical breast cancer advocacy organizations led this trend, and therefore, may be the precursors to an internationalizing shift to this form of advocacy as well. Therefore, the results of this case study speak to a growing pattern among health advocacy organizations.

Figure 3.1. Conceptual Framework



⁸ The single-disease biomedical model of advocacy, like that of biomedical breast cancer advocacy, is proliferating, developing around such illnesses as autism, testicular cancer, ovarian cancer, spinal muscular atrophy, and heart disease. While other forms of health advocacy organized around universal healthcare and environmental justice issues remain present, single-disease biomedical advocacy organizations, by engaging in fundraising and awareness campaigns often through partnerships with corporations, utilizing "cause marketing" as well as public walking, running and racing events, are often publicly in the forefront of disease advocacy.

In Figure 3.1, I provide a visual representation of the conceptualization of my dissertation research. I depict therein the global political economy of health and illness, as I understand it for this study, as encompassing multiple actors, including the medical community, governing bodies, multinational corporations, both directly and indirectly related to health and illness, and health advocacy organizations. Within the global political economy of health and illness, I am interested in transnational health advocacy organizations, with particular emphasis in this study on the interconnectedness of globalizing biomedical breast cancer advocacy organizations with other actors in the global political economy of health and illness. These organizations are intricately linked to the international medical community, national and transnational governing bodies, and multinational corporations, thereby forming transnational health advocacy coalitions. With regard to the medical community, there are intersections between breast cancer advocacy organizations and medical professionals, who often have been involved on the boards of advocacy organizations, thereby becoming an integral element of the transnational biomedical breast cancer coalition. In the case of the global expansion of biomedical breast cancer advocacy in particular, medical professionals have been involved in establishing international affiliates of SGKC in Italy, Puerto Rico, and Germany. The BHGI is another example in which medical professionals are involved with global advocacy organizations, as the initiative was established through a partnership between SGKC and the Fred Hutchinson Cancer Research Center.

In addition to the intersection among medical professionals, research centers and biomedical breast cancer advocacy organizations, a mutually beneficial relationship also exists between these organizations and the medical community for the development of

new breast cancer technologies and treatments. Biomedical breast cancer advocacy organizations, through their global expansion, are increasing funding for medical research, spreading awareness about the medical treatments and technologies that currently exist, and trying to expand their reach to additional populations. Therefore, globally expanding biomedical breast cancer advocacy organizations have the potential to increase and/or accelerate processes of biomedicalization through their relationships with the medical community.

Governing bodies also play a role in the global political economy of health and illness and interact with globally expanding biomedical breast cancer advocacy organizations. Governing bodies, on national and transnational levels, have been targeted by biomedical breast cancer advocacy organizations to increase funding for breast cancer research and to enact legislation to ensure proper treatment of all women with breast cancer (Casamayou 2001; Love 1997). Governing bodies are significant, therefore, with regard to their role in financially supporting the global expansion of biomedical breast cancer advocacy organizations as well as their role in establishing breast cancer and other health-related policies.

Finally, corporate partners/sponsors are also part of the global biomedical breast cancer coalition. In this model, I have separated non-medical corporate partners/sponsors and pharmaceutical and medical equipment partners/sponsors. While both play a role in the global expansion of biomedical breast cancer advocacy, I look at them separately because the pharmaceutical industry and producers of medical equipment have clearer ties to biomedical breast cancer advocacy organizations' agendas than do cosmetics or automobile companies, for example. All corporate sponsors play a role in the

transnational coalition by financially supporting the expansion of biomedical breast cancer advocacy organizations. In addition to financially supporting the global expansion of biomedical breast advocacy organizations, pharmaceutical and medical equipment partners/sponsors also participate in global biomedical breast cancer advocacy events, promoting breast cancer awareness along with their relevant treatments and technologies (King 2006).

Conceptualization and Operationalization

As discussed in Chapter 1, breast cancer advocacy is complex and multi-faceted. To differentiate forms of breast cancer activism and advocacy, scholars have used terms such as “environmental breast cancer movement,” “political breast cancer movement,” and “mainstream breast cancer movement” (McCormick 2006; Zavestoski et al. 2004). I will use the term “biomedical breast cancer advocacy” throughout my dissertation. This is the type of advocacy that is expanding globally. In the US, it is more often known simply as the breast cancer movement, the pink ribbon movement, or mainstream breast cancer advocacy. Nevertheless, using the term “biomedical” specifies the actual form of advocacy that the organizations promote.

While I draw on the social movement literature to theorize the expansion of biomedical breast cancer advocacy organizations and the development of transnational biomedical breast cancer coalitions, I will refer throughout my dissertation to “advocacy organizations” and “advocates,” rather than to social movement organizations, social movement actors, and activists. The distinction among interest groups, social movements, and nonprofit organizations, and even their corporate sponsors/partners is becoming increasingly blurry (McCormick 2006; Andrews 2004). Given that this is the case, I will

adopt Andrews and Edwards' (2004, 481) definition of advocacy organizations as organizations that "make public interest claims either promoting or resisting social change that, if implemented, would conflict with the social, cultural, political, or economic interests or values of other constituencies and groups." Biomedical breast cancer advocacy organizations, therefore, will include SGK, which defines itself as "the leader of the global breast cancer movement," but is seen by some as a fundraising or philanthropic nonprofit organization (King 2006). This definition will also encompass the Avon Foundation and its breast cancer-related projects, even though it was established by a corporation. A strict definition of social movement organizations would not be able to encompass these organizations; however, it is crucial that they are both included because they play important roles in the furthering of global biomedical breast cancer advocacy.

With regard to my overarching theoretical question, I will rely on Brown and Zavestoski's (2005, 1) definition of health social movements as "collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organizations, supporters, networks of cooperation and media." In referring to global health social movements, I mean that the health social movements to which I refer may be active primarily within national boundaries, but they have created transnational coalitions and are global in the sense that the organizations originated in the US, but are expanding to other political and cultural contexts.

My use of processes of biomedicalization draws on the work of Conrad (1992; 2007) and Clarke and her colleagues (2005). Conrad (2007, 5; see also 1992) defines medicalization as a process in which a problem is defined "in medical terms, using

medical language, understood through the adoption of a medical framework, or ‘treated’ with a medical intervention.” Clarke and her colleagues (2005, 444) describe biomedicalization as an extension of medicalization in which medicine is no longer only capable of exerting clinical and social control over particular conditions. Processes of biomedicalization are capable of transforming bodies and lives through the expansion of biomedical organizations, infrastructures, knowledges, and clinical treatments. Specifically, I am concerned with processes of biomedicalization that redefine what it means to be healthy or ill (e.g., creating “risky subjects”) and that promote risk assessment, medical technology and treatment options as the necessary responses to dealing with previously-defined healthy populations.

My understanding of the global political economy of health and illness is based on Clarke and her colleagues (2005, 446) concept of the “Biomedical TechnoService Complex, Inc.” According to Clarke et al. (2005), multinational corporations are spreading the biomedical paradigm and processes of biomedicalization around the world with solutions to health problems that are increasingly corporatized and commodified, as opposed to public health- or prevention-oriented interventions. My model, however, focuses on the role of globally expanding biomedical breast cancer advocacy organizations in order to better understand the role that these under-examined organizations may play in the global political economy of health and illness.

Definition of Terms

Medical Community: This refers to facilities, treatments, and technologies that are designed to treat disease as well as professionals who work within such facilities (e.g. doctors, physician’s assistants, registered nurses, researchers).

Governing Bodies: These are formal national and transnational political structures that define health priorities, fund health advocacy organizations, partner with health advocacy organizations, and are targets of health advocacy organizations. For the purposes of this study, I am concerned only with the Puerto Rican government, US government, Italian government, and the European Union.

Globally expanding Biomedical Breast Cancer Advocacy Organizations: These are formal groups that are established in more than one country and work to promote breast cancer awareness through the promotion of breast self-exams, clinical exams and mammographic screening and raise funds to support breast cancer research focused on detection, treatment, and finding a cure.

Pharmaceutical and Medical Equipment Partners/Sponsors: These are pharmaceutical and medical technology companies that have publicly and financially supported a globally expanding biomedical breast cancer advocacy organization through direct contributions, cause-marketing, and/or event sponsorship.

Non-medical Corporate Partners/Sponsors: These are companies that are not part of the medical community but that have publicly and financially supported a globally expanding biomedical breast cancer advocacy organization through direct contribution, cause-marketing, and/or event sponsorship.

Transnational Biomedical Breast Cancer Advocacy Mixed Actor Coalitions: These include the interconnections among biomedical breast cancer advocacy organizations, the medical community, governing bodies, pharmaceutical partners/sponsors, non-medical corporate partners/sponsors, and any other nongovernmental organizations partnering with biomedical breast cancer advocacy

organizations in more than one country. These collaborators work together for the shared purpose of increasing breast cancer awareness through the promotion of breast self-exams, clinical exams and mammography and raising funds to support breast cancer research focused on detection, treatment, and finding a cure. Actors in the coalition may benefit from their participation in other ways as well.

FEMINIST RESEARCH METHODOLOGY

My research design is based on principles of feminist research methodology, particularly with regard to the relationship between research and advocacy and researcher reflexivity (DeVault 1996). I view myself as a feminist researcher/activist. While I have not been directly involved in breast cancer activism, I support feminist- and environmentally oriented approaches to breast cancer prevention. I view breast cancer as one chronic disease among many both chronic and infectious diseases that affect women globally, thereby demanding attention, but not necessarily the disproportionate amount of concern that it has received to the marginalization of other diseases. Given this perspective, I hope to use my research not only to inform theory, but to inform practice. I will share my findings with the organizations that have contributed to my research as well as any other organizations that may be interested in them. I would also like to publish some of my findings in outlets such as *MAMM: Women, Cancer and Society*, a magazine dedicated to breast cancer for a lay audience, and *The Breast Journal*, an academic journal that addresses breast cancer primarily from a medical perspective, with some articles on advocacy. In this respect, I hope that my research will contribute to breast cancer advocacy in particular, and to women's health advocacy in general.

As a self-reflexive researcher, I am aware not only of my views on particular forms of breast cancer advocacy, but also on the motivation behind my chosen research agenda. Given that my mother was diagnosed with breast cancer when she was 38 years old, and I was eight, and died when she was 42, in a significant way breast cancer has shaped my life. With the discovery of the link between BRCA I and BRCA II gene mutations with susceptibility to breast cancer in the early 1990s, I was confronted by the predominant rhetoric of genetic risk that surrounded the disease. Frustrated by the emphasis on genetic factors that were found to only account for about five to ten percent of breast cancer cases (Steingraber 2000; Simpson 2000; Eisenstein 2001), I became increasingly interested in breast cancer activism and particularly in critiques of biomedical breast cancer advocates' sole reliance on biomedical explanations of breast cancer incidence.

During my research, almost all of the people I interviewed asked about my interest in breast cancer advocacy. The fact that my mother died of breast cancer seemed to legitimate my interest in this area of research and allowed the participants to treat me as an "insider" in the sense that they seemed more willing to talk to me and invite me to more of their events than they might otherwise have done once they knew about this aspect of my history.

Situated Knowledges

My research is also informed by Haraway's (2004) notion of "situated knowledges."

Evolving out of standpoint theory, situated knowledge provides yet another approach to feminist conceptions of knowledge creation. Like standpoint theory, situated knowledge is based on the notion that knowledge is socially located. Haraway (2004) argues that

knowledges are localized and embodied and that they are not simply about a single static identity, as standpoint theory suggests, but rather that they are complex and changing all the time. According to Haraway (2004: 173), “feminist objectivity means *situated knowledges*. Feminist objectivity is about limited location and situated knowledge, not about transcendence and splitting of subject and object.” Haraway argues that the notion of complete vision, or seeing everything, is not possible and what really occurs is partial vision. In advocating situated knowledges, Haraway critiques Harding’s notion of standpoint theory’s privileging of subjugated standpoints (Haraway 2004; Harding 2004). She argues that it is more important that all knowledges be viewed as partial and accountable, and even subjugated standpoints need to be subject to evaluation and deconstruction.

An important aspect of situated knowledge is that the researcher or “knowing self” is partial. In other words there is not a solid consistent identity in which any person is completely privileged or subjugated (Haraway 2001). Haraway argues that it is very important that the researcher be accountable for her or his particular social location by acknowledging the partiality of the knowledge produced. Indeed, according to Haraway “we do not seek partiality for its own sake, but for the sake of the connections and unexpected openings situated knowledges make possible. The only way to find a larger vision is to be somewhere in particular” (Haraway 2004, 180).

Based on this understanding of “situated knowledges,” I have chosen to use three qualitative methods, in the hope that while they all offer partial perspectives, they will jointly contribute to illuminating the answers to my research questions. As noted below, in the section on interviews, I also attempted to interview a wide-range of advocates from

different organizations, including ones who are not directly engaged with global biomedical breast cancer advocacy organizations, in order to better understand this phenomenon from multiple partial perspectives.

SELECTION OF ORGANIZATIONS AND RESEARCH SITES

To explore the case of the global expansion of biomedical breast cancer advocacy, I chose to focus my research on Susan G. Komen for the Cure and the Avon Foundation. As discussed in Chapter 1, Nancy Brinker founded SGKC, formerly the Susan G. Komen Foundation, in Dallas, Texas in 1982 after her sister, Susan Komen, died of breast cancer at the age of 36 (Brenner 2000; Casamayou, 2001). It is the largest breast cancer advocacy organization in the world to date (King 2006). In 1955, the Avon Company established the Avon Foundation as a nonprofit organization “dedicated to the betterment of the lives of women and their families” (Avon Foundation 2008). Thirty-seven years later, the Avon Foundation launched the Avon Breast Cancer Crusade in order to target their mission toward a disease that almost exclusively affects women. These two organizations are leading the global expansion of biomedical breast cancer advocacy.

I conducted my research in the US, the US Commonwealth of Puerto Rico, and Italy. Within the US, I conducted interviews with advocacy leaders within SGKC, Avon Foundation, and the Breast Health Global Initiative (BHGI), which was co-founded by SGKC and the Fred Hutchinson Cancer Research Center (FHCRC), who were directly involved in decision-making and program development regarding the global expansion of their respective organizations. In September 2007, SGKC sponsored *Ignite the Promise* Global Advocate Summit, the first global breast cancer advocacy summit of its kind, in Budapest, Hungary. The event was closed to the general public. Participants in the event

included the organizers from SGKC, representatives from the BHGI, advocates working with SGKC in the US who applied to attend the summit as delegates and who were selected by SGKC to attend the event, as well as international breast cancer advocates selected as delegates by SGKC based on their desire to work with SGKC internationally. I tried to gain access to the summit for my dissertation research through SGKC and the BHGI, but was not granted access, nor would they provide me with a list of delegates attending the summit. I therefore conducted interviews with delegates whose names I found on the SGKC website in reports from the summit. I contacted the six delegates who I was able to find contact information for using a Google web search and received responses from two international delegates who I was able to interview over the phone.

I also collected the majority of documents for my content analysis in the US. Press releases, news stories, summit reports, annual reports, financial reports, and published articles from SGKC, the Avon Foundation, and the BHGI websites supplied a great deal of information regarding the global expansion of these organizations. Finally, I also conducted participant observation at three RFTC events in Lansing, MI between 2006 and 2009.

I selected the US Commonwealth of Puerto Rico and Italy because they are two of the three current SGKC international affiliate locations and also have Avon Foundation offices and host Avon Foundation events.⁹ The third location that I could have selected because it also has both SGKC and Avon Foundation offices and events was Germany;

⁹ At the time that I began my research, the BHGI did not have any international locations in which it was working. The BHGI, a partnership between SGKC and the Fred Hutchison Cancer Research Center, is working to develop best practices for breast cancer care in limited resource countries. They are currently developing programs in South America, information about which I was able to include in my documental data.

however, because I would have needed to hire a translator to conduct research in Germany, I chose to omit it from my study. Additionally, my research funds were limited and I was only able to work in two research sites outside of the US. Puerto Rico and Italy are significantly distinct from each other, as well as from the US, thereby allowing me to adopt a comparative perspective (see Table 3.1).

In Table 3.1, I have highlighted some of the relevant ways in which my research sites vary, allowing for a comparative perspective. The US, Puerto Rico and Italy are distinct in a variety of ways that are useful for a comparative perspective regarding biomedical breast cancer advocacy. They are located in three different geographic regions, allowing me to draw comparisons between North America, the Caribbean, and Southern Europe. With regard to healthcare coverage and access to mammography specifically, which is one of the main foci of biomedical breast cancer advocacy, they also vary.¹⁰ Breast cancer incidence rates are also significantly different among these three countries, with the US having a comparatively high incidence rate, Italy having a moderately high rate, and Puerto Rico a decidedly low rate. With regard to breast cancer advocacy, in particular, they also represent unique cases.¹¹ While my dissertation is

¹⁰ The US and Puerto Rico both have privatized healthcare systems with limited government assistance in the form of Medicaid and Medicare. Puerto Rico has a higher percentage of people lacking health insurance as well as a higher percentage of people with government assistance. When people are covered by private or public health insurance in the US and Puerto Rico, the large majority of insurance plans cover yearly mammograms for women aged 40 and over. Younger women can also have mammograms covered if they have evidence of a significant family history of breast cancer or a history of other benign breast disease. In Italy, there is a national health plan, so everyone has healthcare. The healthcare plan covers bi-annual mammograms for women between the ages of 50 and 69. Women outside of this age range or who want to be screened annually have to pay out of pocket.

¹¹ As discussed in Chapter 1, the US has over a 30 year history of diverse forms of breast cancer advocacy. Puerto Rico has a number of small patient support oriented breast cancer advocacy organizations, which existed prior to the arrival of the Avon Foundation and SGKC. An international affiliate of the American Cancer Society, which has a breast cancer-specific campaign, is also active in Puerto Rico. Italy has its own history of breast cancer advocacy dating back to the early 1980s. In addition to a number of patient support organizations that function in Italy, there is also a strong *Europa Donna* chapter in Italy. *Europa Donna* is a pan-European breast cancer advocacy group that pressures both national European governments and the

primarily an intrinsic case study of biomedical breast cancer advocacy organizations, including these three diverse locations has allowed me to adopt a comparative perspective as well.

Table 3.1. Comparison of the US, Puerto Rico, and Italy in Relevant Categories

	US	US Commonwealth of Puerto Rico	Italy
Geographic Region	North America	Caribbean	Southern Europe
2007 GDP per capita¹	45,800	18,400	30,900
Relevant Governing Bodies	US Government	Puerto Rican Government; US Government	Italian Government; European Union
Healthcare system²	Privatized healthcare system, with limited government assistance	Government-based healthcare system prior to 1994; Health Reform in 1994 privatized healthcare, with limited government assistance	National health plan
Placement in WHO ranking of countries' quality of health care services³	37 th	No data available	2 nd
Incidence Rate of Breast Cancer in 2000 (per 100,000)⁴	143.8	63.8	124.2

European Union to implement standardized best practice guidelines for breast cancer detection, treatment, and care.

Table 3.1 (Continued)

Access to Breast Cancer Screening⁵	Dependent on health insurance coverage and ability to pay	Dependent on health insurance coverage and ability to pay	Covered by national health plan for all women between ages 50-69; prior to age 50 and after age 69 dependent on ability to pay
Existing breast cancer advocacy⁶	Variety of types of breast cancer advocacy; well established	Few small, local breast cancer advocacy organizations; International Affiliate American Cancer Society	Transnational European advocacy network; well established; medical professionals involved in advocacy

Sources: 1. Available at <https://www.cia.gov/library/publications/the-world-factbook/geos/.html>.

2. Pan American Health Organization (2007), available at <http://www.paho.org/hia/archivosvol2/paisesing/Puerto%20Rico%20English.pdf>; Giorgi et al. (2007)

3. WHO Health Report (2000)

4. Globocan (2002)

5. Giorgi et al. (2007)

6. Interviews and documentary analysis

ENTRY INTO THE FIELD

My research is largely based on data collected during two trips to Italy and the US

Commonwealth of Puerto Rico, as well as data collected in Lansing, MI. I made my first

trip to Italy in September 2007, followed by my first trip to Puerto Rico in October 2007.

I strategically planned my trips around SGKC and Avon Foundation-sponsored events so

that I could conduct interviews as well as engage in participant observation at events. The

primary purpose of the 2007 trips was to gather first-hand information that would help

me clarify my research questions and research proposal and to develop a feasible research

design. Prior to these trips, I had corresponded with a number of biomedical breast cancer

advocates affiliated with SGKC and the Avon Foundation in each location who were very helpful and agreed to meet with me during my visit. I also used these initial trips to begin to collect documents and statistics on or related to the expansion of biomedical breast cancer advocacy to Puerto Rico and Italy.

During the first research trip to Italy in 2007, I was primarily based in Rome since this was where SGKC and Avon Foundation offices were located, making it convenient to conduct interviews (see Figure 3.2). Rome was also the location where I collected *The Metro*, a free widely available newspaper, on a daily basis for the content analysis component of my research.

Figure 3.2. Map of SGKC and Avon Foundation Office and Event Locations in Italy*



Source: www.eeri.org

* Note: While I never visited Milan, it is on the map as the location of Avon Foundation “Walk around the World for Breast Cancer” events in Italy.

I conducted participant observation in Rome, in terms of experiencing the day-to-day operations of the SGKC office; however, the majority of the participant observation took place north of Rome, in Bologna, for the Race for the Cure events. In 2007, *Komen Italia*, the Italian affiliate of SGKC, decided to expand their events to northern and southern Italy, in Bologna and Bari, respectively (see Figure 3.2). Due to the timing of my visit, I was able to participate in the initial Bologna RFTC event. I participated in the preparation for the event, *Villaggio della Prevenzione* (Prevention Village), the volunteer gathering that evening, and then the RFTC the following day. During these events, I met a volunteer from Rome who offered to let me stay with her family for the rest of my visit. This was wonderful, as she was not one of my interview participants, but knew a great deal about the formation of SGKC in Italy. She was a US expatriate who had married an Italian and had lived in Rome for many years, so she had experience with SGKC in the US and was involved with *Komen Italia* from its inception. Her mother had breast cancer at the time of my visit, which led us to discuss our experiences dealing with a mother with breast cancer and made our relationship more intimate than might usually be the case during research. When I returned from my visit to Rome, before leaving for Puerto Rico, I conducted four telephone interviews with people who I was unable to meet with during my visit.

I first visited Puerto Rico in October 2007, shortly after my visit to Italy. I stayed with family members in San Juan, Puerto Rico, who lived within walking distance from the SGKC Puerto Rico Affiliate office (see Figure 3.3). I was able to conduct interviews in San Juan with members of SGKC as well as with Avon representatives. I found research in Puerto Rico a little more difficult than in Italy. Most people would not return

my calls or e-mails. I would therefore have to physically stop by without a scheduled appointment and meet people face-to-face in order for them to meet with me. Then I usually had to make an appointment and return at a later time or date.

I also found Puerto Rican advocates to be more hesitant about participating in my research. Further, I had trouble communicating with some participants about the purpose and content of my research project, particularly via e-mail and phone conversations prior to meeting them in person. I found that because my research focus is breast cancer, people often thought I was a medical student or a medical doctor, and did not understand why I would be conducting sociological research on the disease. I also had some trouble with participant observation in Puerto Rico. After my first visit in 2007, I had developed relationships with key informants. Upon my return in 2008, one of my participants drove me to an Avon event in Yauco, PR (see Figure 3.3). I found that I was quite conspicuous among the crowd, given that I was asking lots of questions, taking pictures, and collecting pamphlets and other written information. At one point, a man working at one of the informational tables at the day's events called me over to ask me what I was doing there. He seemed very skeptical at first, especially when I said I was a student doing research and was there from Michigan. We began speaking in Spanish and then he shifted to English. He asked about my research, why I choose to come to Puerto Rico to study, and for whom I worked. After talking for about ten minutes, he asked me my surname and when I told him, he recognized it and began asking about members of my family who still live in Puerto Rico. The tone of the conversation completely changed at that point, and he said "Why didn't you tell me that you are Puerto Rican?" He then informed me that he was the president of a large medical association in Puerto Rico and helped me

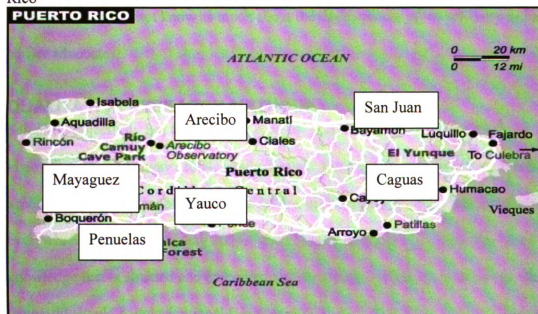
contact other participants for my research. From that point on, research in Puerto Rico became much easier.

None of the Puerto Rican participants told me why they were initially uncomfortable with me or my research project. I spoke about this issue with a colleague who is from the US as well, does not have a Puerto Rican background, and conducted research on the politics of language in Puerto Rico. She had a similar experience, in that participants only opened up to her once she informed them that she was engaged to a Puerto Rican man and would be moving to Puerto Rico permanently once her research was completed. Based on our similar experiences and some articles I had previously read on medical research conducted by US doctors in Puerto Rico between the 1940s and 60s, I pursued this issue further to better understand my experience. Puerto Rico has a colonial history, first as a colony of Spain and then as a colony of the US. Currently, Puerto Rico remains in a state of limbo regarding its sovereignty, as a territory of the US. Between the 1940s and 1960s social scientists used Puerto Rico as a “social laboratory,” viewing it as an easily accessible Third World country (Lapp 1995). At the same time, medical doctors from the US promoted sterilization among married Puerto Rican women and tried to alter the reproductive practices of Puerto Ricans by encouraging reduced fertility (Trombley 1988). Given this history with US social science and medical researchers, it is not surprising that participants questioned my motivation for researching breast cancer advocacy in Puerto Rico or that once I disclosed my Puerto Rican family history they became more comfortable with my interest in conducting research there.

Despite the initial problems in Puerto Rico, my research experience was overwhelmingly positive. Almost everyone I contacted was willing to meet with me and

the majority of participants were extremely helpful and generally forthcoming, although I found that the higher up a person was in an organization, the less forthcoming he or she seemed to be. This did not appear to be an attempt to withhold information from me; rather it seemed that the more established participants had stock answers regarding the expansion of their organizations that they reported often to the media or via their websites. Other participants, who were not as embedded in the organizations, seemed to spend more time thinking about my questions and then responding. The main challenge that I faced, as mentioned above, was arranging interviews with breast cancer advocates in Puerto Rico during my first visit in 2007. Additionally, due to the limited amount of time that I was able to spend in each location, primarily due to financial constraints, I had to settle for phone interviews in instances where, due to scheduling conflicts, I was not able to meet with certain people during my visits.

Figure 3.3. Map of SGKC and Avon Foundation Office and Event Locations in Puerto Rico*



Source: www.puertorico.eu

* Note: While I did not visit all of the locations marked on the map, the pink dots represent locations where Avon Foundation “Walk around the World for Breast Cancer” events were held. SGKC events were held primarily in San Juan. Clockwise, starting at

the northeastern part of the island, the locations are San Juan, Caguas, Peñuelas, Yauco, Mayagüez and Arecibo.

Another challenge that I confronted during this research is that because I am studying an expansion process that is occurring right now, getting up-to-date information has been challenging. When I first proposed doing this research, SGKC only had three international affiliates. Over the course of the last year, however, they have expanded to ten additional international locations, establishing global initiative pilot programs, which are distinct from affiliates in that they do not take on the name of Susan G. Komen for the Cure, but involve local advocates, medical professionals, and other interested groups who are trained in Susan G. Komen for the Cure fundraising and awareness-raising advocacy techniques. Similarly, Avon's programs and events also have evolved over the two-year period of time that I have been following the expansion process. Even visiting two locations just a year apart, there was some turn-over in terms of advocates and the new advocates often did not know as much about the development of the affiliates as had the earlier advocates.

QUALITATIVE RESEARCH METHODS

Scientific objectivity has traditionally assumed that researchers can have “infinite vision,” or what Haraway (2004, 128) calls the “god trick.” On the other hand, relativist accounts are equally problematic since it “is a way of being nowhere while claiming to be everywhere equally” (Haraway 2004, 129). Rather, all research accounts are based on knowledge that is situated and embodied and the struggle is always over whose view of the world should count as rational (Haraway 2004, 130). Harding's (2004, 136) concept of ‘strong objectivity’ requires that we question the notion of independence in science

and instead demand methods that allow us to examine the range of social values and situations that shape the research process. To accomplish this, it is necessary to include the perspectives of those actors who are generally marginalized from the scientific process. Nevertheless, while recognizing the social situatedness of all knowledge, strong objectivity requires from researchers “a critical evaluation to determine which social situations tend to generate the most objective knowledge claims” (Harding 2004, 134).

A qualitative research approach is useful for accomplishing these objectives. In particular, qualitative research is valued for its commitment to viewing the social world from the perspective of participants involved in the phenomenon being studied (Blaikie 2000). Qualitative methods provide a means to understand the social, political and economic situation of participants. Situation is important because it influences how people understand particular events or actions and how they act in relation to them. Additionally, it provides a way to incorporate meaning, that is, how participants – as well as the researcher – understand, view, or interpret the situation of participants, the situation of those around them, and the effects of particular events on their circumstances. This approach also allows researchers to describe the processes through which particular events or actions take place.

For this study, I have utilized several qualitative data-collection techniques including semi-structured interviewing, participant observation, and content analysis, that have allowed me to build a holistic, multi-dimensional, complex account of the answers to my research questions. By incorporating the voices of participants who are involved in and, therefore, proponents of SGKC’s and Avon Foundation’s global expansion together with alternative sources of data from government documents, members of breast cancer

organizations that are unaffiliated with SGKC and Avon Foundation, and international representatives from the Global Advocate Summit, I seek to arrive at a more inclusive and comprehensive understanding of the global expansion of biomedical breast cancer advocacy.

It is reasonable to wonder what value, if any, does this case study involving a small number of individuals primarily representing two organizations that address a specific health issue have beyond this particular case. It is generally accepted that in contrast to quantitative studies, it is not possible to generalize qualitative research results to the general population (Babbie 2004). Nevertheless, there is a growing concern with the issue of generalizability and how it might be achieved, as researchers become interested in making statements about other sites or populations based on their own research results (Blaikie 2000).

Rather than generalizability, some scholars emphasize concepts such as ‘transferability’ or ‘comparability’ (Goetz and LeCompte 1984 cited in Blaikie 2000, 255). The argument here is that study results can be extended to other cases on the basis of theory development and by using comparable data collection methods and analyses across research sites. On this basis, “similarities and differences can then be taken into account in any judgment about the relevance of findings obtained from one site for some other sites” (Blaikie 2000, 253). The aim in such comparisons is generally “to establish whether the research site is typical of other sites” (Blaikie 2000, 255). Researchers conducting studies about the global expansion of breast cancer advocacy in other sites as the coalition continues to expand, who incorporate similar theoretical frames and

methodological techniques, should be able to make comparisons between this study and research sites with their own.

DATA COLLECTION AND ANALYSIS

As stated above, in order to answer my research questions, I utilized three qualitative research techniques: (1) semi-structured interviews; (2) qualitative content analysis of SGKC, BHGI, and Avon Foundation documents, newspaper articles, government documents, and corporate sponsor documents, and global health documents and statistics; and (3) participant observation.¹²

Interviews

Interviews have been shown to be effective in gaining nuanced information on values, perceptions, and motivations behind actions. My overarching goal with the interviews was to identify how and why biomedical breast cancer advocacy organizations are expanding globally. That is, why did people working within SGKC and the Avon Foundation decide to expand beyond the US, how was the decision to expand made, and how were the expansion locations selected? How did SGKC and Avon Foundation advocates in Puerto Rico and Italy incorporate biomedical breast cancer advocacy into their distinct cultural and political contexts? How were local breast cancer organizations in Puerto Rico and Italy, not affiliated with SGKC or Avon Foundation, affected by the expansion of SGKC and Avon Foundation? And how did international breast cancer advocates, who attended the 2007 Global Advocate Summit in Budapest, Hungary, perceive the global expansion of SGKC and the Avon Foundation?

¹² This research protocol was approved by Michigan State University's Institutional Review Board, IRB #07-836 on August 24, 2007.

I made no attempt to obtain a random sample of interviewees; rather, the sample was purposive (Berg 2004). Participants were seen as key informants and the intent of the interviews was to ensure organizational representativeness and maximize variation in responses so as to obtain as complete an understanding as possible of the informant's views of issues related to the global expansion of biomedical breast cancer advocacy (Berg 2004; Creswell 1999; Maxwell 1998). I began the interview process by identifying several key informants within SGKC in the US, the Avon Foundation in the US, SGKC and Avon Foundation affiliates in Puerto Rico and Italy, and the BHGI in the US. Names of informants came from the organizations' websites and publications. I expanded my informant pool using the snowball technique where participants were asked to recommend other key actors for me to interview (Berg 2004, 36). I stopped conducting interviews once I reached a saturation point, at which time I was receiving information that I had already heard from other interviewees (Berg 2004).

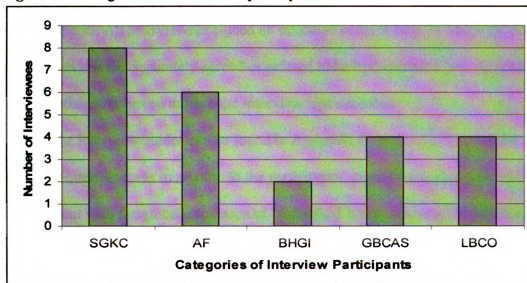
I utilized snowball sampling (Berg 2004) by asking those whom I interviewed for names of other organizations that are relevant to global breast cancer advocacy or to breast cancer advocacy in the context in which they are working (e.g., other breast cancer organizations in Puerto Rico or Italy). Through snowball sampling, I developed a better understanding of global breast cancer advocacy coalitions and interviewed breast cancer advocates from organizations such as the BHGI, *Europa Donna* (the European Breast Cancer Coalition), and *Mujeres sin Tiempo* (a Puerto Rico-based, breast cancer advocacy group). *Europa Donna* is an international non-governmental organization (INGO) operating throughout Europe that consists of a membership that is aware of, but not associated with, SGKC and the Avon Foundation. *Mujeres sin Tiempo* (Women without

Time) is an organization that works exclusively in Puerto Rico dealing with breast cancer, and it also is not affiliated with SGKC or Avon Foundation programs. By including interviews with actors such as these who are not directly involved in the global expansion of biomedical breast cancer advocacy, but may affect and/or be affected by this type of advocacy expansion, I sought to add additional perspectives to my understanding of the global expansion of biomedical breast cancer advocacy.

The result was that semi-structured, on-site and telephone interviews were conducted with a total of 24 participants (see Figure 3.4). It is important to note that while I have categorized each participant according to his or her primary organizational affiliation or conference attendance; some participants could have been included in more than one category. For example, some of the key informants from SGKC and the BHGI who I interviewed were also organizers of and participants in the Global Breast Cancer Advocate Summit (GBCAS). In these cases, I categorized participants according to their main role in relation to our interview.

Participants included key decision-makers in SGKC and the Avon Foundation who specifically worked with the global initiatives within their organization, leaders of the BHGI, leaders within Komen Puerto Rico and *Komen Italia*, leaders within local breast cancer organizations who were not affiliated with SGKC or the Avon Foundation, and international delegates who attended the 2007 Global Advocate Summit in Budapest.

Figure 3.4. Categories and number of participants involved in formal interviews*



Source: Personal and Telephone Interviews

*AF refers to the Avon Foundation. GBCAS refers to the Global Breast Cancer Advocate Summit. LBCO refers to local breast cancer organizations.

All of the interviews were conducted in English. Sixteen interviews were conducted in person, and eight interviews were conducted over the phone, due to an inability to meet with the person. For personal interviews, I met the participants wherever they preferred to be interviewed. In most cases, the interviews were conducted in their organization's office. A couple of interviews were conducted outside in a public park setting at a RFTC event or an Avon Foundation event. For the telephone interviews, I talked to the participants while they were at work at their organization's office. I conducted the phone interviews from home using an earpiece recording device, once I had received informed consent to record via fax or mail from the participants.

I audio taped all of the interviews to ensure accuracy. The majority of the interviews lasted between forty-five minutes and one hour. Prior to each interview, I explained to participants the purpose of my research, that their participation was entirely voluntary and that they could halt or withdraw from the interview at any time, and that

their responses would remain confidential. To this end, pseudonyms have been given to all participants. All interviewees signed an informed consent form in which they agreed to the interview and separately agreed or refused to be tape-recorded (see Appendix). All of my participants agreed to have the interview tape-recorded.

The interview guides can be found in Appendix II. While the focus of the interview questions was in relation to the participants' perceptions, practices, and involvement with the global expansion of biomedical breast cancer advocacy, these questions varied to accommodate the affiliation of the different participants (e.g., SGKC, Avon Foundation, BHGI, LBCO). Moreover, the interview questions in my guide were not fixed but continued to evolve over time as I determined that it was necessary to explore some questions in more depth or add new questions altogether, this was the case because I conducted interviews over a two-year period, in 2007 and 2008.

I designed the interview questions to address how and why biomedical breast cancer advocacy organizations are expanding, how and why particular countries were chosen for expansion, which forms of advocacy (e.g., "racing for the cure," "breast cancer awareness month") have been incorporated into, and possibly adapted to, other political and cultural contexts, how the pink ribbon has been incorporated into, and possibly adapted to, other political and cultural contexts, and the role corporate sponsors/partners play in movement expansion.

I transcribed all of the interviews myself. They were transcribed verbatim. Then I entered all interview data into Atlas.ti (a software program for qualitative data analysis) and analyzed them. The purpose of the analysis was to develop an understanding of why and how biomedical breast cancer advocacy organizations have expanded globally, how

various organizations are involved, how the choice of countries to expand to was made, and how forms of advocacy, movement symbols, and corporate involvements have been adapted to, if at all, diverse political and cultural contexts.

I began the coding process by conducting line-by-line open coding of all of my interviews (Berg 2004). Next, I thematically organized the codes that emerged from the open coding process. The codes that I developed were drawn from my conceptual framework, my research questions, as well as inductively generated from the research process. Categorizing the data in this manner made it easier to organize the data, to identify major themes that emerged from the interviews, and to compare the views of different participants in light of my research questions (Maxwell 1998; Strauss 1998).

Qualitative Content Analysis

My research is also based on the analysis of an extensive collection of documents and statistics covering the years 1998 to 2008. These materials include SGKC, Avon Foundation, and BHGI primary documents related to the global expansion of biomedical breast cancer advocacy, such as annual reports, publications, conference agendas and reports, informational packets on how to train global advocates, materials used to educate the public about breast cancer and press releases from 1998, when the earliest documents addressing the global expansion of biomedical breast cancer advocacy began appearing, to 2008. Organizational documents were collected via organizational websites, visits to the organization's offices, personal communications in which informants offered to send me information, and GuideStar, Inc., an online database of nongovernmental organizations. Additionally, I collected primary documents from the pharmaceutical and corporate sponsors of SGKC, Avon Foundation and the BHGI that are involved with

these organizations outside of the US, Puerto Rican, Italian, and US government documents, NIH and WHO reports, scholarly publications, and Globocan statistics related to the global burden of breast cancer. Data about breast cancer as compared to other chronic and infectious diseases were also collected. Finally, newspaper articles and advertisements related to breast cancer advocacy, incidence, and/or organizations from *El Nueva Dia*, the most prominent daily newspaper in San Juan, PR, and from *The Metro*, a free daily newspaper in Rome, Italy were collected during the time that I was in each location (September/October 2007 and 2008).

According to Berg (2004, 269), qualitative content analysis is “a passport to listening to the words of the text and understanding better the perspective(s) of the producer of these words.” These materials were particularly valuable in expanding my understanding of the global expansion of biomedical breast cancer advocacy, the manner in which various organizations are involved, the partnerships between various advocacy organizations with medical professionals, other organizations, and corporations, the forms of advocacy that are being promoted globally, the burden of breast cancer on a global scale compared to other chronic and infectious diseases, and the presentation of transnational biomedical breast cancer advocacy organizations in local newspapers. I also used these materials to help clarify, probe, or confirm claims made by participants in the interviews.

Participant Observation

Participant observation is also an important methodological element of this project. This method was particularly useful for my research in terms of observing visual symbols and experiencing how the events actually unfolded and took place in different political and

cultural contexts. I was able to produce data through participant observation that did not emerge in interviews and content analysis. In particular, I was able to experience how the events vary in different political and cultural contexts. Further, I was able to observe which corporate sponsors/partners were present at events, what other organizations were present, the demographics of those who participated, and the various roles of the participants, including organizers, sponsors, and local participants, in the events.

I conducted participant observation at three Race for the Cure events in Lansing, MI between 2006 and 2009 in order to improve my ability to recognize similarities and differences between RFTC events in the US and other countries. I also attended the first RFTC event in Bologna, Italy in October 2007 and returned the following year for the same event, allowing me to notice any changes in the event from one year to the next. In addition to the actual RFTC events, I was able to conduct participant observation at volunteer planning meetings, at the *Villagio della Prevenzione*, as well as at the volunteer dinner the night before the race. While attending these events, I was able to observe the presence and activities of corporate sponsors/partners, medical professionals, SGKC affiliates, and other organizations. I also noted the demographics of the participants, the number of participants, the emotional tenor of the event, the mood of the participants, and the cultural, geographic and political context in which the event took place.

I conducted participant observation in Puerto Rico in October of 2007 and 2008 as well. I was unable to attend Race for the Cure events in Puerto Rico, due to an overlapping schedule between Italy and Puerto Rico events, and thus had to rely on documentary analysis and interviews with participants in the event for information. In San Juan, PR, I visited both the SGKC affiliate office and the Avon Foundation office on

numerous occasions, observing the workings of the organizations. I also attended an Avon-sponsored event, *Marcha Por Una Causa* in Yauco, PR. At this event, I was able to observe the presence and activities of corporate sponsors/partners, medical professionals, Avon representatives, as well as other organizations. I also noted the demographics of those who participated, and the various roles of the participants, including organizers, sponsors, and local participants, in the events. Finally, I was able to get a feel for the event, the emotional tenor of the event, the mood of the participants, and the cultural, geographic and political context in which the event took place.

CHAPTER SUMMARY

In this chapter I have presented my research design for the case study of the global expansion of biomedical breast cancer advocacy. I discussed the feminist research methodology that informs my approach to research. The rationale of the organizations and specific locations that I focused on in my research were then addressed. Following this discussion, I addressed issues related to gaining access to research participants in each research site. Finally, my rationale for utilizing qualitative methods for answering my research questions as well as descriptions of my data collection and analysis process were provided. In the chapters that follow, I discuss the findings of my research.

CHAPTER 4

ELITE ORGANIZATIONS AND GLOBAL EXPANSION

According to Reitan (2007, 16), “while there is growing evidence that activism is in fact ‘going global,’ there have been remarkably few studies to date that empirically investigate how and why this process is occurring” {e.g., Olesen 2005; della Porta 2005}. In her research on social movements that have mobilized against neoliberal policies, Reitan (2007) found that localized movements often shift to globalized action via a similar sequence of action. Movements expanded primarily due to a realization “of the need to ‘go global’ fueled by frustration in *not getting desired results* at the local or national level” (my emphasis, Reitan 2007, 19). Once local movement members developed this realization, movement organizers would reach across national boundaries to forge ties with potential allies. According to Reitan (2005), this process often involved frame alignment efforts, in which movement participants seeking global expansion extend the framing of their movement to a related issue in order to connect to potential allies working on similar issues. While Reitan (2005) found that this sequence of action applies to grassroots movements, I found that alternative explanations are required to account for the global expansion of elite advocacy organizations.

In this chapter I present my findings regarding the reasons for Susan G. Komen for the Cure’s and the Avon Foundation’s global expansion as well as the trajectory of each organization’s global expansion. In this chapter, I draw primarily on interview and documentary data. I found that in stark contrast to grassroots, anti-neoliberal globalization movements’ expansion, which is motivated by a lack of desired results at the local or national level, leaders of SGKC decided to “go global” precisely because

they *had achieved their desired results* in the US. The Avon Foundation, on the other hand, globally expanded due to the interests of the Avon Company in expanding its brand recognition in emerging markets, as Company sales slowed in the US market. SGKC and the Avon Foundation, despite organizational differences, both “went global” to expand their brand to new markets. For both organizations, global expansion was the logical extension of a general pattern of growth and expansion. In the case of SGKC, the leaders of the organization wanted to expand their successful brand of advocacy and their reputation as pioneers in breast cancer advocacy. The Avon Company, on the other hand, expanded the Avon Foundation to locations where the company already operated in order to expand and solidify the market for its beauty products and enhance the Company’s reputation as the “Company for Women.” Both organizations globally expanded based on a corporate model of market expansion.

In what follows, I first present an overview of the organizational and financial resources of SGKC and the Avon Foundation. I discuss the organizations separately in this chapter, as they developed independently of each other. I then argue that based on its organizational and financial successes in the US, SGKC expanded globally to extend its brand of advocacy and reputation as pioneers in breast cancer advocacy based on a corporate model of continual growth. Under the leadership of the Avon Company, the Avon Foundation globally expanded to extend the brand recognition of its cosmetic products and Avon’s reputation as “The Company for Women.”

ORGANIZATIONAL AND FINANCIAL RESOURCES

Susan G. Komen for the Cure

In slightly over twenty-five years since being founded by Nancy Brinker in 1982, Susan G. Komen for the Cure has grown into the largest breast cancer organization in the world and the largest non-governmental funder of breast cancer research (King 2006). Despite SGKC's claim of being "a global grassroots movement" and Nancy Brinker as demonstrating "the power of one" and acting as "proof of how personal activism can drive global social change," SGKC has elite origins and continues to be an elite-run advocacy organization that utilizes a corporate model to guide its organizational and financial endeavors (SGKC 2008).

Nancy Brinker's husband, Norman Brinker, owner of Brinker International, one of the world's largest casual dining companies, enabled the development of SGKC by providing access to capital and influence (*New York Times*, 1992).¹³ Norman Brinker, acting as Chair of the Board of Directors of SGKC during its early years, provided the initial funds needed to get SGKC off the ground and applied his business expertise to building the Foundation (Fetterman 2007). Well after SGKC had taken off and become the leading breast cancer advocacy organization, Norman and Nancy Brinker divorced. Nevertheless, Norman Brinker remains on the Board of Directors of SGKC, continuing to offer business advice and access to wealthy supporters and potential partners in the business world (SGKC 2009).

¹³ Brinker International is a restaurant group that includes Chili's Grill & Bar and Romano's Macaroni Grill, among others. Norman Brinker established the Jack-In-The-Box chain of restaurants in 1957. He started Steak and Ale in 1965. He became the president of the Pillsbury Restaurant Group in 1982, overseeing Steak and Ale, Burger King, and Bennigan's, to name a few (SGKC 2009).

After creating the organization with the financial support and input of her husband, Nancy Brinker launched the *Race for the Cure*, which has developed into “the most successful fundraising and education event for charity ever created” (SGKC 2009). Additionally, based on her connections in the business world, she “pioneered cause-related marketing, which has enabled millions more people—from top executives to everyday consumers—to join the fight against breast cancer” (SGKC 2009).¹⁴ To date, SGKC is the “world’s largest source of nonprofit funds” dedicated to biomedical breast cancer research (SGKC 2009). Based on her connections, Nancy Brinker was able to implement her vision of an advocacy organization that enlists “every segment of society to participate in the elimination of the disease,” in a way that less well-connected advocacy organizations would be hard-pressed to do (SGKC 2009).

In addition to her business background and her husband’s corporate connections, Nancy Brinker, and SGKC by proxy, has enjoyed a favorable relationship with the US government, especially during George W. Bush’s tenure in the White House.¹⁵ Nancy Brinker was a member of the National Cancer Panel under Presidents Reagan and H.W. Bush, served as US Ambassador to the Republic of Hungary from 2001 through 2003 under President George W. Bush, and was appointed Chief of Protocol of the United States, with the rank of Ambassador and Assistant Under-Secretary of State in 2007, which lasted until the end of Bush’s term (SGKC 2007). These government positions directly impacted the global expansion of SGKC, allowing Nancy Brinker to initiate

¹⁴ Prior to founding SGKC, Nancy Brinker had a successful career in business and marketing, working with such companies as ManPower, Inc., United Rentals, Inc., US Oncology, Inc, Netmarket, Inc., and Meditrust Corporation. She also started a health and wellness products business, which she later sold (JournalStar 1999).

¹⁵ Nancy and Norman Brinker contributed to George W. Bush’s first presidential campaign and Norman Brinker has a long history of financially backing Republican presidential candidates (Government 2009).

collaborative programs between SGKC and the US State Department to expand SGKC internationally as an act of governmental diplomacy.

Nancy Brinker also has had a long-term friendship with Laura Bush, who has dedicated herself to the breast cancer cause due to her mother's experience with the disease. As First Lady, Laura Bush used her position to further SGKC's global expansion, acting as Honorary Co-Chair of SGKC's Global Advocate Summit in Budapest, Hungary in 2007. Additionally, she has visited international SGKC affiliates, such as *Komen Italia*, commending them on the work that they are doing to eradicate breast cancer (SGKC 2006). She has also supported and participated in the US partnerships in the Middle East and Central and South America to raise breast cancer awareness. Encouraging other Presidents' and Prime Ministers' wives to take up the breast cancer cause, Laura Bush has spoken on behalf of SGKC in many countries (Figure 4.1). In addition to the involvement of former First Lady Laura Bush, US Ambassadors in countries where SGKC is active often attend events on behalf of the United States. Having US governmental representatives promoting SGKC on an international level, presents the organization to international audiences as simultaneously an advocacy organization and a governmental diplomatic initiative.

Figure 4.1. Laura Bush speaking to *Komen Italia* advocates on behalf of the US government and SGKC



Source: Press Release, Office of the First Lady, February 6, 2006

In addition to Nancy Brinker's governmental connections, the organization is headed by an elite board of directors and run by a professional staff in Dallas, TX, with two prominent business and marketing figures, Susan Braun (1996-2006) and Hala Modellmog (2006-present) acting as President and CEO of the organization after Nancy Brinker.^{16, 17} The board of directors governs the organization's efforts to support breast cancer research and community education, screening and treatment programs. It is a nine-member board whose members have extensive business and non-profit experience (Table 4.1) (SGKC 2009). The board consists of a number of breast cancer survivors, all with extensive business and/or voluntary non-profit experience as well (Table 4.1).

¹⁶ During her tenure as President and CEO of SGKC, Susan Braun simultaneously served on leadership committees for the National Action Plan on Breast Cancer, the American Society of Clinical Oncology (ASCO), the Cancer Leadership Council, and the World Society of Mastology. Prior to joining SGKC, she worked within the Oncology/Immunology Division of the Bristol-Myers Squibb Company. She also worked as an executive with the healthcare consulting firm, Pracon Inc. Her graduate educational background is in international marketing (ZoomInfo 2008)

¹⁷ Prior to joining, SGKC, Hala Modellmog was a Fortune 500 executive, serving as the founder and CEO of Catalytic Ventures, a company she founded to consult and invest in the food service industry. She was president of Church's Chicken. Prior to that, she held management and marketing positions at Church's Chicken, Arby's Franchise and BellSouth (Reuters 2008).

Table 4.1. SGKC's Board of Directors (2009)

Name/Position	Breast Cancer Survivor	Occupational History (Position/Sector)
Alexine Clement Jackson/Chairperson	Yes	YWCA of USA (National Board Chair/Non-Profit); Intercultural Cancer Council (Board Member/Non-Profit); Black Women's Agenda (Board Member/Non-Profit)
Nancy Brinker/Board Member and Past President and CEO	Yes	ManPower Inc. (Director/Employment Services); United Rentals (Director/Rental Equipment); US Oncology Inc.(Director/Healthcare Services); NetMarket Inc. (Director/Internet Product Provider; Meditrust Corporation (Director/Healthcare Real Estate Investment Trust); US Government (Ambassador to Hungary/Government); US Government (US Chief of Protocol/Government)
Norman Brinker/Board Member and Chairman Emeritus	No	Brinker International (Chairman Emeritus/Restaurant); Jack-in-the-Box (Founder/Restaurant); Steak and Ale (Founder/Restaurant); Pillsbury Restaurant Group (President/Restaurant)
Linda Custard/Board Member	No	Junior League of Dallas (President/Non-Profit); United Way of Dallas (Vice Chair/Non-Profit); Dallas Women's Club (President/Social Club); Southern Methodist University (Trustee/University); Dallas Center for the Performing Arts Foundation (Director/Non-Profit)
Aimee DiCicco/Board Member	Yes	FedEx Kinko's (Vice President of Sales/Service)
Brenda Lauderback/Board Member	Yes	Nine West Group (President of Wholesale and Retail/Clothing); Irwin Financial Corp. (Corporate Director of the Board/Financial); Big Lots Corp.(Corporate Director of the Board/Furniture) Select Comfort (Corporate Director of the Board/Bedding); Denny's (Corporate Director of the Board/Food)
Connie O'Neill/Board Member	No	Susan G. Komen for the Cure (Past Treasurer/Non-Profit); Children's Medical Center Foundation (Board Member/Non-Profit); Children's Health Services of Texas (Chair of Audit Committee/Government); Highland Park Education Foundation (Past President/Non-Profit); St. Paul Medical Center Foundation (Board Member/Non-Profit);
Robert Taylor/Board Member	No	Taylor Lohmeyer Law Firm (President/Legal Services); Dallas/Ft. Worth Duke University Alumni Admissions Committee (Chairman/Education); Highland Park United Methodist Church Board of Trustees (Past Chairman/Religious)
Dorothy Paterson/Affiliate Representative and International Race Ambassador	Yes	Oil business (Geologist); MD Anderson Cancer Research Center (Volunteer/Medical Research); Girl Scouts of American (Volunteer/Non-Profit)

Source: SGKC "Board of Directors" (2009)

In addition to the board of directors, the organization has a seven-person scientific advisory committee, which consists of M.D.s and Ph.D.s from prominent universities and cancer research centers (Table 4.2) (SGKC 2009). The Scientific Advisory Board guides the organization in scientific matters, making recommendations regarding the funding of medical research and the development of educational messages (SGKC 2009).

Table 4.2. SGKC's Scientific Advisory Board Members (2009)

Name	Position	Affiliation
Eric Winer, M.D.	Chief Scientific Advisor for SGKC; Director of the Breast Oncology Center; Senior Investigator in Breast Cancer Research	Dana-Farber Cancer Institute; Harvard Medical School
Melissa Bondy, Ph.D.	Professor of Epidemiology-specializing in the study of genetics and risk factors which cause cancer	University of Texas M.D. Anderson Cancer Center
Powel Brown, Ph.D.	Professor of Medicine; Associate Director of Cancer Prevention and Director of Cancer Prevention and Populations Study Program	Baylor College of Medicine; Dan L. Duncan Cancer Center; Breast Care Center Baylor-Methodist
H. Kim Lyerly, M.D.	Professor of Research; Director of the Duke Comprehensive Cancer Center; Principal Investigator of the Duke Specialized Program in Research Excellence	Duke University
Amelie Ramirez, M.D.	Chairman of Komen's National Hispanic/Latino Advisory Council; Professor of Epidemiology and Biostatistics; Founding Director of the Institute for Health Promotion Research	University of Texas Health Science Center at San Antonio; formerly affiliated with the National Cancer Advisory Board
George Sledge, M.D.	Professor of Oncology, Medicine, and Pathology; Co-director of Breast Cancer Program	Indiana University Melvin and Bren Simon Cancer Center; Indiana University School of Medicine
Sara Sukumar, Ph.D.	Professor of Oncology and Pathology; Co-director of the Breast Cancer Research Program	Sidney Kimmel Cancer Center at Johns Hopkins University School of Medicine

Source: SGKC "Scientific Advisory Board" (2009)

Specialist advisory councils organized around issues faced by African American women, Hispanic and Latina women, Asian American and Pacific Islander women, young women, and lesbian, gay, bisexual and transgender persons are also part of the organization. These advisory councils are made up of public health specialists and

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educators, M.D.s, RNs, and Ph.D.s specializing in particular demographics of women and breast cancer (SGKC 2009). Finally, local and international affiliates are constituted by survivors and activists in more than 120 cities and communities across the globe, which according to Brinker, she developed based on “the Chili’s Restaurant business model, used by her husband, Norman Brinker,” exemplifying the organization’s corporate business model for organizational expansion (Fetterman 2007).

Aided by Norman Brinker’s successful business model and corporate connections, SGKC has been an incredibly financially successful organization. This success is largely attributable to partnerships with over 170 corporations (SGKC 2008). Partnering corporations directly sponsor events and engage in cause-related marketing campaigns (King 2006).¹⁸ In an interview with *The Dallas Morning News*, discussing the organization’s 25 years of work fundraising for breast cancer research, Brinker stated, “I can’t tell you how many people said it wouldn’t work, *marketing a women’s disease*” (my emphasis, Fetterman 2007). This statement demonstrates the business model applied to breast cancer advocacy by the organization. Despite any skepticism, SGKC has successfully marketed breast cancer in the US, acquiring an unprecedented and to date an unmatched number of corporate partners that are marketing a disease-related cause. In Table 4.3, SGKC’s corporate sponsors are listed according to SGKC’s categorization of the partnerships.

¹⁸ More than one hundred Komen Race for the Cure events, consisting of over one million participants, were held in the US and internationally in 2008 {SGKC, 2009 #414}

Table 4.3. SGKC's Categorization of Corporate Sponsors and Partners

Komen Million Dollar Council*	Acushnet-Titleist, Cobra and FootJoy Worldwide, American Airlines, Bank of America, Better Homes and Gardens, Carlisle Collection Ltd, Coldwater Creek, Ford Division, General Mills' Pink Together, Hallmark Gold Crown Stores, Holland America Lines, KitchenAid, Lean Cuisine, Lowe's Companies Inc, Mars Snackfood US LLC, New Balance Athletic Shoe Inc., Pier 1 Imports, Rally for the Cure, REMAX International, The Bowling Foundation, The Mohawk Group, Wacoal America, Yoplait USA
Corporate Partners	3M, ACH Food Companies Inc., Acushnet, American Airlines, Atlas Garden Glove, Bank of America, Belk, Belkin, Best Buy and Virgin Mobile, Better Homes and Garden, BMW of North America, Brinker International, Carlisle Collection Ltd, Carnival Cruise Lines, Coldwater Creek, Don King Productions, Dr. Pepper Snapple Group, Energizer, Ford Division, Fox Home Entertainment, Fresh Express, FUZE Beverage, General Mills' Pink Together, Grand Traverse Pie Company, Hallmark Gold Crown Stores, Holland America Line, HSN, Kentucky Oaks Ladies First, KitchenAid, Ladies Professional Golf Association (LPGA), LEAN CUISINE, LIFE Event-The Val Skinner Foundation, LifeWorks Technology Group, Lowe's Companies Inc., LPGA Golf Clinics, Major League Baseball, Mars Snackfood LLC, Massage Envy, McNeil Nutritionals LLC-Viactiv, Microsoft, MMG Corporation, Mobile Giving, Mott's, NAPA AutoCare, New Balance Athletic Shoe Inc., North American Licensing, On Deck for the Cure, On the Border-Fiesta for the Cure, Oreck, Pandora Jewelry, Paramount Coffee, Payless ShoeSource, Pier 1 Imports, PiNKiTUDE, Pottinger Nichols Media Group LLC, Princess Cruises, Quilted Northern Ultra, Rally for the Cure, REMAX International, Simon Malls, Specialized Bicycle Components, The Bowling Foundation, The Mohawk Group, The Republic of Tea, Tubbs Romp to Stomp Out Breast Cancer Series, Wacoal America, Wyeth-Chapstick Brand Lip Moisturizer, Yoplait USA, Zale Corporation, Zeta Tau Alpha Fraternity
Race for the Cure National Sponsors	Yoplait USA, American Airlines, Bank of America, Coldwater Creek, Ford Division, FUZE Beverage, Mott's, New Balance Athletic Shoe Inc., REMAX International, Zeta Tau Alpha Fraternity

Source: <http://ww5.komen.org/milliondollarcouncil.aspx>; <http://ww5.komen.org/corporatepartners.aspx>; <http://ww5.komen.org/raceforthecuresponsors.aspx>

*The Komen Million Dollar Council Elite is a special group of sponsors and partners who have committed to invest a financial contribution of \$1 million annually in the fight to end breast cancer. Each of these organizations has found new and innovative ways to raise awareness about breast cancer and encourage people from all walks of life to get involved in finding the cures. We thank them for their generous support (SGKC 2009).

These partners raise significant funds for SGKC by engaging in cause-related marketing campaigns in which they sell pink products, donating a certain percentage of the sales to SGKC for breast cancer research. For example, from every sale of a \$350 pink mixer, KitchenAid donates \$50 to SGKC (Figure 4.2).

Figure 4.2. KitchenAid's Cause-Related Marketing Mixer*



Source: <http://www.kitchenaid.com/flash.cmd?/product/KSM150SPK/>

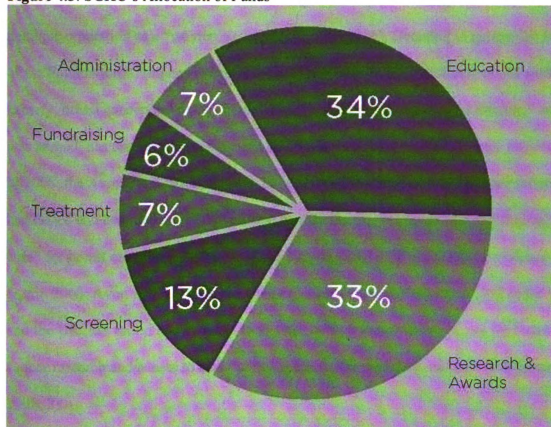
*The text in the advertisement reads, Cook for the Cure presented by KitchenAid. Susan G. Komen for the Cure. During 2008, KitchenAid is proud to donate a minimum of \$100,000 to Susan G. Komen for the Cure in conjunction with its pink product collection. Consumers must register each pink product purchased at CookfortheCure.com to generate a donation.

Through fundraising events and cause-related marketing campaigns, SGKC has become a financially lucrative organization. According to SGKC's 2004-2005 Annual Report,

In fiscal year 1995, the Komen Foundation invested \$10.1 million in the fight against breast cancer. Ten years later, in fiscal year 2005, the Foundation invested 135.8 million. This growth has allowed us to further our mission by advancing research, education, and screening and treatment worldwide. And while our growth over the past ten years has been significant, we are committed to ensuring this momentum continues, pushing us forward, searching for answers, putting our promise in action (my emphasis, SGKC 2006)

SGKC's financial resources continue to grow each year. The majority of funds are allocated for breast cancer research and education programs, followed by screening and treatment (see Figure 4.3).

Figure 4.3. SGKC's Allocation of Funds



Source: Susan G. Komen for the Cure 2008 Annual Report (SGKC 2008)

Based on a corporate business model, ever since its inception SGKC has grown, increasing its number of affiliates, corporate partnerships, and *Race for the Cure* events. Currently, the organization is well-known throughout the US, with at least one affiliate in every state, and multiple affiliates in a number of states. Based on the logic of expansion, and the organization's tremendous organizational and financial success in the US, having captured the US breast cancer advocacy market, it is not surprising that SGKC began looking beyond the US for future expansion opportunities in the late 1990s.

Avon Foundation

The Avon Company established the Avon Foundation in 1955. With the slogan "The Company for Women," Avon executives decided that having an affiliated Foundation

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addressing issues affecting women would support the tagline and help the Company build a unique reputation as a “women’s company” (Avon 2005). Deciding to narrow the focus of the Foundation, Company executives chose two women’s issues that it would work on, namely, breast cancer and domestic violence. To date, the “breast cancer crusade,” as it was named, has received more attention and funds than the domestic violence project. As of 2008, the Avon Foundation, through its breast cancer and domestic violence programs, had raised and awarded over \$660 million worldwide for “access to care and finding a cure” for breast cancer and “awareness and support programs” for domestic violence (Avon 2008; Avon 2005). The Avon Breast Cancer Crusade, founded in 1992 in the US and the UK, has raised and awarded over \$585 million in over 50 countries for breast cancer research and access to care “with a focus on the medically underserved” (Avon 2008, 2).

The Foundation is currently headed by Chairperson Robert Corti and Honorary Chairperson and celebrity spokesperson, Reese Witherspoon (Avon 2008, 3). Robert Corti oversees a ten-person board in charge of directing the Avon Foundation, both its breast cancer and domestic violence initiatives (Table 4.4). As shown in Table 4.4, the board members all have business backgrounds, many with a history in marketing and global strategy and overseas development. Most board members have worked for the Avon Company for many years and have moved up through a variety of positions within the company. In contrast to SGKC’s board of directors, none of the Avon Foundation’s board members have had breast cancer.

Table 4.4. Avon Foundation's Board of Directors (2009)

Name/Position	Occupational History (Position/Sector)
Robert Corti/Chairman	Activision Blizzard (Director/Video Games); Avon Products Inc.(Executive Vice President and CFO/Beauty); Bacardi Limited (Board of Directors/Alcohol); ING Direct (Board of Directors/Insurance)
Brian Connolly/Vice President	Avon Products Inc. (Global Sales Strategy/Beauty)
Nancy Glaser/Vice President	Avon Products Inc. (Global Communications; Global Advertising and Public Relations/Beauty); Carl Byoir & Associates (Member of Executive Committee/International Public Relations); American Museum of Natural History (Public Relations/Arts); Metropolitan Hospital Center (Communications/Medical)
Carol Kurzig/Vice President	Avon Products Inc. (Former Executive Director/Beauty)
Pauline Brown/Vice President	Avon Products Inc. (Global Business Development/Beauty); Estée Lauder (Corporate Strategy and New Business Development/Beauty); Bain & Company (Global Business Consultant/Consulting); Smith McCabe Ltd.(Director of European Business Development)
Andrea Slater/Vice President	Avon Products Inc. (Overseas Development; Marketing/Beauty)

Source: Avon Foundation Overview (2009); BusinessWeek (2009); WomensBiz (2005)

The Avon Breast Cancer Crusade also has a nine-member Scientific Advisory Board, which consists of two breast cancer survivors with non-profit experience and five professionals representing prominent universities, medical centers, the National Institute of Environmental Health Studies, and an international medical consulting firm (Table 4.5) (Avon 2008, 3).

Table 4.5. Avon Foundation's Breast Cancer Crusade Scientific Advisory Board (2009)

Name	Position	Affiliation
Renee Bernett	Survivor Advocate; Lay Reviewer for Department of Defense Breast Cancer Research Program	Department of Defense Breast Cancer Research Program
Matthew Ellis, MB, Ph.D., FRCP	Associate Professor	Washington University School of Medicine
Julius Few, M.D.	Clinical Associate	University of Chicago
Carrie Hunter, M.D., Ph.D.	President and CEO	Oncology Consulting International
Elizabeth Morris, M.D.	Associate Radiologist and Director	Breast MRI Memorial Sloan-Kettering Cancer Center
Christine Norton	Survivor Advocate; Co-Foundation of MBCC	Minnesota Breast Cancer Coalition (MBCC)
Kenneth Olden, Ph.D., Sc.D., L.H.D.	Director, Emeritus	National Institute of Environmental Health Sciences
Amelie Ramirez, Dr.P.H., M.P.H.	Director	Institute for Health Promotion Research, University of Texas Health Science Center at San Antonio
Marc Hurlbert, Ph.D.	Executive Secretary	Scientific Advisory Board

Source: Avon Foundation Impact Report: 2007-2008

<http://www.avoncompany.com/women/avonfoundation/impactreport.pdf>

Avon has become the second largest non-governmental funder of breast cancer research and care programs, following Susan G. Komen's \$750 million investment from 1985-2005, and leading the Breast Cancer Research Foundation, founded by Evelyn Lauder, and Revlon, which have invested \$117 million and \$60 million, respectively, since 1992 (King 2006, xxiv). Numerous Avon Crusade programs raise funds and awareness for the breast cancer cause, such as the US *Avon Walk for Breast Cancer* series, the global *Walk Around the World for Breast Cancer* and the sale of Breast Cancer Crusade pink ribbon products worldwide. The funds raised are allocated by the foundation to leading cancer centers as well as community-based non-profit health programs in five areas: "awareness and education; screening and diagnosis; access to

treatment; support services; and scientific research, all with a focus on the medically underserved” (Avon 2008, 5).

Like SGKC, the Avon Foundation has gained recognition as a large non-governmental funder of breast cancer research and education. Because of its organizational and financial success, leaders of the Foundation state that their organization is uniquely able to create “a *powerful international network of research, medical, social service, and community-based organizations* focused on defeating breast cancer” (my emphasis, Avon, 2008, 9), which would serve the interest of Avon Company by expanding their image as the “Company for Women” in countries where they already sell their beauty products.

REASONS FOR GLOBAL EXPANSION

According to King (2006, 81), “having successfully captured US public interest in breast cancer, nonprofit organizations, pharmaceutical companies, and other corporations have recently begun to pursue breast cancer-related activities overseas.” The global expansion of SGKC and the Avon Foundation supports King’s claim. SGKC is touted by its leaders as the organization that launched, and continues to lead, the “global breast cancer movement.” SGKC advocates support this statement based on the fact that their organization is the largest non-governmental funder of breast cancer research. Similarly, the Avon Company, via its Foundation, describes itself as the “leading corporate supporter in the battle against breast cancer,” stating that Avon “runs the most extensive ‘global’ breast cancer program, with more than fifty countries participating in its endeavors in 2004” (King 2006, 82). Therefore, while SGKC raises more money for breast cancer research than any other breast cancer organization, Avon Foundation’s

Breast Cancer Crusade has a presence in more countries than any other breast cancer organization. Both SGKC and the Avon Foundation pride themselves in being pioneers in breast cancer advocacy: SGKC by developing an extensive fundraising program via cause-related marketing and the Avon Foundation by being the first company to “start with the movement of awareness and doing something to increase the awareness of breast cancer and raising money for a cause” (Gabriella Lopez, Personal Interview, Caguas, Puerto Rico, September 14, 2007).¹⁹

Susan G. Komen for the Cure

Although the organization’s leadership refers to SGKC as a “grassroots breast cancer movement,” as I demonstrated, the organization is actually an elite advocacy organization utilizing corporate strategies for organizational expansion (i.e., affiliate expansion modeling Chili’s expansion) and fundraising (i.e., marketing breast cancer-related products). Just as corporations respond to a successful brand or product by seeking and expanding to new markets in a process of continual growth (King 2006; Peterson 2008), SGKC is globally expanding because of its success in capturing the US breast cancer advocacy market.

Similar to how business owners reinvent their companies to reinvigorate their brand and differentiate it from other similar brands, Susan Braun, the President and CEO of SGKC during the organization’s 25th anniversary, oversaw the rebranding of SGKC. In celebration of the 25th anniversary of the organization, the Board of Directors rebranded the organization, changing its name from The Susan G. Komen Foundation to Susan G.

¹⁹ Pseudonyms are used for all interviewees.

Komen for the Cure and introducing a new logo, distinct from other pink ribbons, which had become ubiquitous in the US over the past 25 years (Figure 4.4).

Figure 4.4. New SGKC Name and Logo



Source: Susan G. Komen for the Cure, www.komen.org

In discussing the brand name change, the Chair of Atlanta's SGKC affiliate stated,

As the only organization fighting to cure breast cancer at every stage, the vision of Susan G. Komen for the Cure is to save lives by empowering people, ensuring quality care for all and energizing science to find the cures. The new brand encompasses the vision with a unique logo – a “moving ribbon” symbolizing the energy and forward momentum in the race to find a cure (my emphasis, SGKC 2007).

Differentiating themselves from other breast cancer advocacy organizations by stating that they are fighting to cure breast cancer “at every stage” and stating that the new “unique” logo represents “energy and forward momentum,” SGKC leaders demonstrate their desire to reinvigorate their brand and distinguish SGKC from similar organizations in moving forward. SGKC leaders do not present the organization as working with all of the related breast cancer advocacy organizations in a joint effort to eradicate the disease. Rather, the rebranding effort sets them apart in terms of their mission, presenting SGKC as the superior breast cancer advocacy organization.

Global expansion provided an avenue for SGKC to differentiate itself from similar advocacy organizations as well as reinvigorate the organization by doing something new, allowing SGKC to redefine itself as the “leader of the *global* breast cancer movement.” Through this global expansion, SGKC leaders were able to redefine their organization to US audiences, emphasizing the global reach of the organization, while expanding their brand of breast cancer advocacy to new audiences in other countries. In Puerto Rico, one of the locations where SGKC expanded via the establishment of an international affiliate, a few small grassroots breast cancer support and advocacy organizations already existed, but SGKC did not partner with them upon the organization’s development on the island, maintaining a separate identity.²⁰

Through its global expansion, the recognition of the SGKC brand remained important to organizational leadership. As Carmen Arollo, a *Komen Puerto Rico* organizer stated,

Breast cancer is known for the pink ribbon, so they [SGKC] have a different one, now we have this new one, the running one. So it’s like, *that’s our branding. That’s what we want to do, like everybody who sees that recognizes Susan G. Komen*. They recognize us as the *trusted brand of breast cancer advocacy*, but the pink ribbon is just for breast cancer in general (my emphasis, Personal Interview, San Juan, Puerto Rico, September 12, 2007).

As this statement exemplifies, SGKC is expanding globally as a unique brand of breast cancer advocacy. SGKC advocates seek to set the organization apart from other advocacy organizations by establishing it as “the trusted brand of breast cancer advocacy,” just as companies compete with regard to their products. Moreover, according to Sara Friedman, who heads SGKC’s international program initiatives, SGKC is very selective about

²⁰ The trajectory of SGKC’s global expansion, including the organization’s international locations and forms of global expansion will be discussed in detail in the next section.

which organizations it trains in its model of advocacy through the *Course for the Cure*, a program designed to train international advocates. As she stated,

Because we have to be very, you know, very selective in determining who we would want to partner with *because as a nonprofit, the only thing that we really have is our brand*. That is what we have to protect more than anything else, so that is something that is always, you know, quite important to us (Telephone Interview, November 16, 2008).

As this statement demonstrates, while SGKC expanded to differentiate itself from other breast cancer advocacy organizations, reinvigorate its brand image, and expand its mode of advocacy to new locations, the organizational leadership acted selectively to maintain the integrity of the brand. This may explain why the organization has not aggressively expanded internationally, but instead has acted on opportunities to expand in partnership with the US government, the Fred Hutchinson Cancer Research Center and in partnership with trusted medical professionals, discussed in detail in Chapter 6. As shown in Table 4.6, SGKC expanded via international affiliates from 2000 to 2003. In 2006, the organization began collaborating with the US government to create breast cancer advocacy initiatives, first in the Middle East, then in Central and South America and finally in other countries based on its collaboration with the Fred Hutchinson Cancer Research Center.

Table 4.6. SGKC's International Expansion Trajectory

International Affiliate Locations (established 2000-2003)
Germany
Italy
Puerto Rico
US-Middle East Partnership for Breast Cancer Awareness and Research Locations (established 2006-2007)
Jordan
Saudi Arabia
United Arab Emirates
Partnership for Breast Cancer Awareness and Research in the Americas Locations (established in 2007)
Brazil
Costa Rica
Mexico
Panama
Global Initiative for Breast Cancer Awareness Locations (established 2007-2009)
Ghana
India*
Romania
Ukraine

Source: Telephone Interview with Sara Friedman, SGKC Advocate with International Programs, October 29, 2008

*The initiative in India has not begun yet, but is scheduled to start in 2009 or 2010.

In sum, after 25 years of working in the US, where messages of breast cancer awareness are now ubiquitous, leaders of SGKC rebranded the organization to reinvigorate the organization and differentiate themselves from other breast cancer advocacy organizations. Priding themselves on being at the forefront of breast cancer advocacy and having exhausted expansion efforts within the US, leaders of SGKC began

of advocacy, rather than aggressively expanding to many countries, SGKC strategically partnered with trusted individuals in their expansion efforts (see Chapter 6).

Avon Foundation

In her analysis of breast cancer philanthropy, King (2006, 84) argues that global corporate philanthropy and community relations programs “are often cursory efforts that are more effective in building a coherent and readily identifiable ‘global’ brand image than they are in tackling the specific issues they purport to address.” Elaborating, King (2006, 84) argues,

In other words, as corporations seek to produce and sell goods in an ever-expanding number of locations, philanthropy and community relations are increasingly deployed not merely to further some social good, but as techniques for market penetration and retention, both in the domestic market and abroad.

The Avon Foundation, as discussed by King (2006) as well, has been deployed globally by the Avon Company in order to expand Avon’s brand recognition and to promote brand loyalty by demonstrating Avon’s commitment to women.

The Avon Company prides itself in being “The Company for Women” and, more recently, “the girl-powered beauty brand” (Avon 2008). According to the Company’s most recent Impact Report (Avon 2008), “Avon, whose name appears on more beauty products than any other brand in the world, has an unmatched commitment to breast cancer charities,” donating proceeds from pink ribbon products for research, education, and treatment for breast cancer sufferers. While Avon is the largest distributor of beauty products globally, the Company’s success varies geographically. In particular sales in the US have slowed over the past ten years, likely because the door-to-door sale of beauty products, pioneered by the Avon Company to help women make their own money at a time when many women did not have careers, is no longer appealing to women who

time when many women did not have careers, is no longer appealing to women who pursue careers or other types of part-time work. At the same time that Avon sales have slowed in the US, according to King (2006, 86),

[p]rofits garnered elsewhere have continued to grow steadily and commentators point to Avon's success in the Latin American and Asian markets, in particular, as the reason for their survival. Avon obtains two-thirds of its revenues from overseas transactions, and markets in Asia, Eastern Europe, and Latin America commonly post double-digit increases in sales and profits.

As this statement suggests, to survive as a company, Avon has shifted its focus away from the declining US market and toward the thriving markets in Latin American, Eastern European, and Asian countries and potentially emerging markets elsewhere (see Table 4.7). By expanding the Foundation along with the Company, Avon increases exposure to their brand while demonstrating Avon's commitment to women through their breast cancer advocacy projects in order to give the company an edge in these markets.

Table 4.7. Avon Foundation's International Expansion Locations*

Year Established	Location
1992	United Kingdom, Argentina
1993	Canada, Mexico, Puerto Rico
1994	Malaysia, Philippines, Spain, Venezuela
1995	Brazil, Indonesia, Turkey
1996	Australia, New Zealand
1997	Chile, Italy
1998	Hungary, Ireland, Poland, Slovakia, Thailand
1999	Ecuador, Portugal, Taiwan
2001	Bulgaria, Guatemala, Ukraine, South Africa
2002	China, El Salvador, Japan, Lithuania
2003	Czech Republic, Germany, Honduras, Slovenia
2005	Bolivia, Dominican Republic**, Estonia, France, Greece, India**, Latvia**, Peru**, Romania**, Russia**
2006	Oman
2007	Bosnia, Colombia, Finland, United Arab Emirates, Macedonia, Serbia**
2008	Kazakhstan**

Source: King (2006), Table 1; Avon Foundation *Walk Around the World for Breast Cancer* countries, http://walk.avonfoundation.org/site/PageServer?pagename=WorldWalk_Main.

*I am not sure how the Avon Foundation decided on the order in which to expand the Foundation, except that it seems to be correlated with how established the Company was in each country. For example, the

In Puerto Rico, for example, the expansion of the Avon Foundation and the Avon Breast Cancer Crusade events are directly related to the reputation of the Avon Company. As Gabriella Lopez, the Avon representative in charge of the Breast Cancer Crusade in Puerto Rico, stated

Each year the Avon Company does a tracking study in all the categories [e.g., fragrances, cosmetics] and they also include the breast cancer campaign. Phone calls are made here in Puerto Rico and they are made in different countries. This [the chart she was showing me] is for Puerto Rico only. They have a sample of people they call and they ask these questions and they came out with the results and I was very impressed that the increase of our efforts in raising awareness about Avon and breast cancer. In 2003 it stayed flat, 2005 raised to 49%, 2006 to 68%, and they compared to other companies and Avon's was the most recognized breast cancer company campaign. They asked "do you know what efforts Avon is making?" They ask if you have seen Avon's campaign. Then the people answer yes or no, so that's the percents. We are very proud of this (Personal Interview, Caguas, Puerto Rico, September 14, 2007).

As the results of Avon's survey in Puerto Rico demonstrate, Avon Foundation's Breast Cancer Crusade events raise awareness, not only about breast cancer, but about the Avon Company. By expanding their message of breast cancer awareness, the Avon Foundation promotes the Avon Company as the brand that cares about women, reinforcing the company's tagline. Currently in Puerto Rico, an increasing number of corporations are using cause-related marketing to demonstrate the company's commitment to breast cancer. According to Gabriella Lopez, as of September 2007, Pfizer, Johnson & Johnson, Proctor & Gamble, Elizabeth Arden, Estée Lauder, and Avon all engaged in some type of sponsorship of breast cancer events or cause-related marketing campaign to demonstrate their commitment to the breast cancer cause and promote their company as "woman-friendly." In fact, according to Gabriella,

We are not competing with the other companies because it's the same message of awareness that we are going to deliver and we want the message to be expressed. So we are very proud that each year many more companies are doing something for breast cancer. So it's not a competition. We find that it's great if in each year we have more and more companies doing something for breast cancer (Personal Interview, Caguas, Puerto Rico, September 14, 2007).

Despite this statement, the Avon Company conducts this survey each year to determine Avon's brand recognition via its foundation's breast cancer advocacy projects in comparison to other companies' brand recognition. The survey in Puerto Rico, for example, included questions about all of the companies engaging in some type of breast cancer project on the island. The Avon survey, therefore, did not assess an overall increase in breast cancer awareness in Puerto Rico, but awareness about the Avon brand through its foundation in comparison to other companies.

In sum, with slowing sales in the US, the Avon Company refocused its attention on lucrative international markets and potential emerging markets. By extending Avon Foundation's breast cancer advocacy projects to international locations where Avon already operated, the Company solidified its reputation as the "Company for Women." This reputation is increasingly difficult to maintain with the proliferation of breast cancer cause-related marketing projects in the US, and in other countries as well.

CONCLUSION

Given SGKC's and the Avon Foundation's elite and corporate origins it could be argued that they should not be discussed as social movement or advocacy organizations at all. King's (2006) research focused on the Avon Foundation, referring to it as "corporate philanthropy." Despite Avon Company's control over Avon Foundation's expansion, the foundation promotes a specific type of advocacy (e.g., biomedical, cause-related marketing projects), which, along with SGKC, it has successfully promoted in the US and

is now expanding to over 50 countries. Similarly, even though SGKC has elite origins and access to prominent medical, governmental and corporate partners in addition to conducting its affairs utilizing a corporate model of continual growth and marketing concepts for fundraising strategies, it is important that we not ignore this organization as a type of social movement organization because it is promoting a particular brand of advocacy that has caught on in the US and is now being introduced in a number of countries.

Despite the elite and corporate nature of these organizations, SGKC and Avon Foundation are presented by their members as “grassroots movements” consisting of “activists” and “advocates,” thereby masking their organizational clout. This is significant because given their organizational and financial resources, these organizations have the potential to be much more successful/influential in promoting their advocacy agendas than actual grassroots movements, which typically lack anything resembling the resources of these organizations.

CHAPTER 5

THE SOCIAL CONSTRUCTION OF A GLOBAL BREAST CANCER CRISIS

According to Brown (1995), in exploring how illnesses are socially constructed we are actually investigating how social forces shape our understanding of and actions toward health, illness, and healing. Social constructions of diseases are significant in that they are “powerful channels for the expression, legitimization, and expansion of certain groups’ social power” (Lantz 1998, 909). Specifically, Foucault (1973) argued that the social construction of diseases serves to establish and solidify the authority of professionals, particularly medical professionals, over the individual. The social construction of a disease as an epidemic, therefore, is a powerful means of defining a social problem, demanding resources for its alleviation, and reifying the authority of “experts,” both experienced advocates and medical professionals, as those with the ability to rectify the problem.

As discussed in Chapter 2, health social movements have participated in processes of socially constructing various diseases. The process of meaning-making in which advocates engage, referred to in the social movement literature as framing, involves the creation of a shared understanding of an issue, that requires action on the part of the advocates and legitimizes the existence of their organization(s) (Benford 2000). Based on her research on biomedical breast cancer advocacy in the US in the 1990s, Kolker (2005, 825) argues that breast cancer advocates created a sense of urgency around breast cancer by socially constructing it as “an epidemic.” By doing so, breast cancer advocates legitimized the need for their organizations to attain financial resources, public support, governmental attention, and medical researchers’ attention. Additionally, advocates

framed breast cancer as a problem of gender equity, arguing that because it is a disease that almost exclusively affects women, it had been under-funded by the government and overlooked by medical researchers. Finally, advocates framed breast cancer as a threat to families, in that, by affecting women during their thirties, forties and fifties, husbands often lost their wives and children their mothers, thereby creating social disorder (Kolker 2005).

My findings demonstrate that SGKC and the Avon Foundation, in the promotion of their brand of biomedical breast cancer advocacy, continue to socially construct the problem of breast cancer, now on a global scale. According to Benford and Snow (2000, 624), social movement organizations engage in frame alignment processes, which are deliberative, strategic, and goal-oriented. Globally expanding biomedical breast cancer advocacy organizations are engaging in processes of “frame diffusion” by actively transmitting their framing of breast cancer to other political and cultural contexts (Benford and Snow 2000, 627). By engaging in processes of “strategic fitting,” these organizations are tailoring their frames, not to fit a specific host culture, as Benford and Snow (2000, 627) discuss, but rather to apply more generally across cultures, as a global issue, requiring a global movement and a global solution.

To strategically fit their frames to a global community, SGKC and the Avon Foundation have extended their framing of breast cancer as a US epidemic to framing the disease as a global epidemic, with the potential to affect women everywhere. No longer framed as an issue of gender equity, biomedical breast cancer advocates are constructing the disease as an issue of global health inequality. Biomedical breast cancer advocates argue that women in the US have attained a high level of breast cancer awareness,

leading to early detection, and thereby lowering the US breast cancer mortality rate. At the same time other countries, particularly developing countries, are still struggling with issues of social stigma, myths, and misinformation about breast cancer. Thus, these organizations argue that women in other countries do not have an equal opportunity to survive breast cancer and by expanding their organizations to these locations, they are increasing global health equality. Finally, breast cancer is still framed by biomedical breast cancer advocates as a threat to families. US biomedical breast cancer advocates often draw on their experience as mothers, sisters, wives and daughters to connect US women's experiences with breast cancer with women's experiences with the disease globally. These organizations, therefore, explain their global expansion as an effort to combat the global epidemic of breast cancer, global health inequality and the threat posed by breast cancer to families by spreading their advocacy model, emphasizing awareness and early detection, a campaign that has proven successful in the US.

SGKC and the Avon Foundation began to reframe their efforts in confronting breast cancer by shifting from a national to an international scale in the mid to late 1990s after SGKC had expanded throughout all of the US and the Avon Company was experiencing stagnation in the US market, while observing increasing success in international markets. To justify their global expansion, leaders from both organizations constructed breast cancer as a pressing global health crisis in need of a global biomedical breast cancer movement, which SGKC and Avon Foundation leaders claimed to be equipped to lead based on their success in the US. In this chapter, I demonstrate SGKC and Avon Foundation leaders' framing of a global breast cancer crisis while simultaneously challenging the claim that breast cancer is a global health crisis in need of

a global *biomedical* breast cancer movement. I do this by examining how biomedical breast cancer advocates have actively constructed breast cancer as a global epidemic and crisis in light of actual global breast cancer incidence and mortality rates. Additionally, I argue that advocates from both organizations frame the causes of the global breast cancer problem as a lack of awareness of and education about breast cancer leading to low levels of early detection, thereby positioning their biomedical advocacy model as the appropriate solution to the problem.

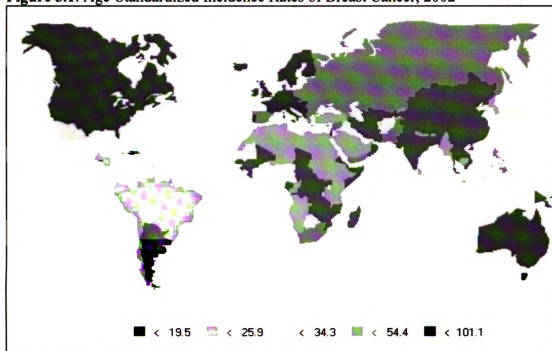
BREAST CANCER AS A GLOBAL EPIDEMIC

Beginning in the 1990s and increasing in the 2000s, SGKC and the Avon Foundation abandoned their exclusive focus on breast cancer in the US, and shifted their attention to the global burden of breast cancer. As discussed in Chapter 1 and depicted in Figure 5.1, the global burden of breast cancer is quite uneven, with the majority of cases still appearing in the US, Canada, Western European countries, Australia, New Zealand, and Argentina. Incidence rates remain relatively low in Central America, Eastern Europe, Asia, Africa, and parts of South America (see Figure 5.1).

While global breast cancer incidence rates vary widely by geographic region, representatives of SGKC and the Avon Foundation often emphasize the general trend of increasing incidence rates, providing a justification for the need for their organizations to expand globally as well as motivational framing to recruit new allies and participants based on the severity of the problem. In explaining the need for their *Walk Around the World for Breast Cancer* events, Avon representatives often repeat the following statement, “Breast cancer remains the most commonly diagnosed cancer among women worldwide. According to the World Health Organization, breast cancer is responsible for

502,000 deaths per year worldwide” (Avon Foundation 2007). Similarly, SGKC leaders argue that “with more than one million women worldwide receiving a breast cancer diagnosis each year, the organization believes it is critical to increase advocacy for and education about this life-threatening disease” (SGKC 2008).

Figure 5.1. Age-Standardized Incidence Rates of Breast Cancer, 2002*



Source: IARC, Globocan 2002

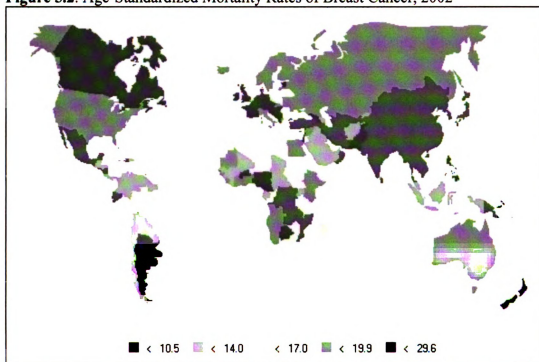
*Age-standardized rates (ASR world standard) per 100,000 of the population

Sometimes, rather than emphasizing the global incidence rates, which remain lower in many countries than in the US, SGKC and the Avon Foundation instead emphasize mortality rates from breast cancer in conjunction with incidence rates or by themselves. Similar to breast cancer incidence rates, mortality rates also vary significantly worldwide (see Figure 5.2). In explaining the need for breast cancer advocacy on a global scale, an Avon Foundation representative stated that “although progress has been made, breast cancer continues to be a leading cause of death for women, accounting for 1.6 percent of all female deaths worldwide” (Avon Foundation

2005). The chairman and director of the Breast Health Global Initiative, founded by SGKC and the Fred Hutchinson Cancer Research Center, stated

Breast cancer is a problem of global proportion and the magnitude of this problem cannot be overestimated. In the United States, one in five women diagnosed with breast cancer will die from the disease and the mortality rate is more dire in developing countries (SGKC 2007).

Figure 5.2. Age-Standardized Mortality Rates of Breast Cancer, 2002*



Source: IARC Globocan 2002

*Age-standardized rates (ASR world standard) per 100,000 of the population

While the breast cancer mortality rates in developing countries are high relative to their lower incidence rates, the mortality rate due to breast cancer, when compared to other diseases affecting women in many developing countries, is not particularly high. In her argument about why the global expansion of SGKC is crucial, Nancy Brinker stated that “an estimated 25 million women will be diagnosed with breast cancer and 10 million could die in the next 25 years without the cure” (SGKC 2007). All of these arguments

made by biomedical breast cancer advocates emphasize the severity of the global burden of breast cancer in order to justify their expansion and motivate potential participants and allies to collaborate in their efforts.

In addition to framing the global burden of breast cancer in terms of its severity, biomedical breast cancer organizations also emphasize the urgency of the issue in order to explain their expansion and motivate potential participants and allies. Whether addressing breast cancer incidence rates, mortality rates, or both, SGKC and the Avon Foundation consistently frame breast cancer as a global crisis in need of immediate attention. This is a common form of rhetoric used with cancer in general, as argued by Sontag (1989). Such dreaded diseases, require a “fight,” “crusade” or “war” (Sontag 1989, 57). For example, Nancy Brinker, in promoting the *Ignite the Promise* Global Advocate Summit, stated “*alarming* global cancer statistics underscore the *urgency* of Komen’s mission to end breast cancer forever, and to *attack* breast cancer on domestic as well as international fronts” (my emphasis, SGKC 2007). In the same speech, she later insisted that “while we have made many strides, the breast cancer *crisis* facing our world is *enormous*” (my emphasis, SGKC 2007). When referring to global breast cancer rates, instead of actually stating the statistics, in some cases SGKC and Avon Foundation representatives will make a blanket statement about the global burden of breast cancer, such as “*staggering* incidence and mortality rates throughout the world” (my emphasis, SGKC 2008). Biomedical breast cancer advocates’ consistent use of crisis rhetoric frames breast cancer as a pressing global health issue in need of immediate attention.

To emphasize the severity and urgency of global breast cancer rates, biomedical breast cancer advocates often refrain from discussing breast cancer in the context of other

diseases affecting women globally, the reality of which might undermine their arguments regarding the severity and urgency of breast cancer internationally. In cases where they want to contextualize breast cancer among the global burdens of other diseases, they often draw on general cancer statistics, rather than solely breast cancer statistics to emphasize the dire need for global breast cancer advocacy. As Nancy Brinker stated in her announcement of the Global Advocate Summit in Budapest, “cancer already claims twice as many lives as AIDS worldwide. At least seven million people die of cancer each year and close to 11 million new cases are diagnosed. That’s more than AIDS, tuberculosis, and malaria put together” (SGKC 2007). Given that she is announcing a summit addressing only breast cancer, it is likely that unless listening closely, audiences may assume that these statistics refer only to breast cancer. Relying on general cancer statistics in contexts where audiences are expecting to hear about breast cancer makes the statistics sound even more alarming than simply relying on global breast cancer statistics alone.

By framing breast cancer as a severe and urgent global women’s health issue, biomedical breast cancer organizations are socially constructing the disease as a global epidemic in need of immediate attention. Given that the majority of breast cancer cases still exist in the US, Canada, Western European countries, Australia, New Zealand and Argentina, a single global approach to breast cancer may not be needed. Furthermore, constructing breast cancer as a global epidemic or crisis is misleading, given the uneven distribution of breast cancer globally. Rather, strategic efforts in particular countries may be needed where breast cancer incidence rates are in fact quite high. As discussed in Chapter 4, SGKC expanded to countries based on partnerships with the US government,

medical professionals, and medical centers, rather than based on the need for breast cancer advocacy in certain countries whereas the Avon Company directed the expansion of the Avon Foundation based on the desire to solidify their international markets. Both organizations expanded to countries where the incidence rates of breast cancer are not high. Instead of always emphasizing the global incidence of breast cancer, both organizations also stressed the global mortality rate from breast cancer. While it is true that some countries have incidence rates lower than the US, but higher mortality rates, it is a leap to assume that this is due primarily to the lack of awareness, which is the solution that both organizations advocate. As argued in the World Health Organization's most recent report on the world's health, the main factor negatively influencing health globally is the lack of primary healthcare (WHO 2008). Finally, to argue that breast cancer is a greater global health problem than AIDS, tuberculosis or any other disease, these organizations rely on general cancer statistics. In reality, while cancer is becoming increasingly prevalent in many countries this can at least partially be attributed to increased life expectancy, as cancer still is largely a disease of advanced age. It is also arguably linked to processes of industrialization. Industrialized countries, like the US, have the highest rates of cancer, including breast cancer, and as countries industrialize and populations are exposed to an increasing number of chemicals, the cancer rate may increase as well. While there is an increase in cancer globally, this does not diminish the fact that for many countries cancer is not the predominant health priority.

BREAST CANCER AND GLOBAL HEALTH INEQUALITY

In addition to framing their global efforts in terms of the severity and urgency of the global burden of breast cancer, biomedical breast cancer advocacy organizations also

present their expansion as a necessary means of addressing global health inequality, specifically with regard to breast cancer. In the US, breast cancer advocates often emphasized the issue of gender equity, arguing that because it is a disease predominantly affecting women, breast cancer is under-funded and researched (Kolker 2005). On a global scale, rather than framing the issue in terms of gender equity, biomedical breast cancer advocates frame the disease as an issue of global inequality in which the US has been able to reduce its breast cancer mortality rate, largely due to the work of biomedical breast cancer organizations in promoting awareness, education, and early detection. Biomedical breast cancer advocates argue that developing countries deserve their attention as well as the attention of their respective governments, medical professionals and other organizations committed to helping women. Nancy Brinker demonstrates this sentiment by stating,

For nearly 25 years, the Komen Foundation has mastered scientific and community research funding, putting dollars into ideas that no one else has funded, yielding discoveries that have significantly changed how we detect, diagnose, treat and manage this disease. And, while we have made great progress, a desperate situation continues to exist in our world and millions of people have no access to those discoveries. So, we are challenging ourselves and others to put the full weight of our resources behind efforts to attack the disparities problem in new ways (SGKC 2006).

In her statement, Nancy Brinker emphasizes that SGKC has been incredibly successful in the US with regard to raising a significant amount of money, which the organization then funnels into breast cancer research. She argues that given the success of the organization in the US, it is now up to US biomedical breast cancer advocates to challenge global breast health disparities.

As stated at the conclusion of the previous section, the global burden of breast cancer is very uneven, still predominantly affecting women in the most industrialized

countries. Therefore, to effectively address global health concerns, women's health priorities and country-specific disease statistics would need to be taken into account and, in many cases, breast cancer may not be a health priority, nor a significant health concern in comparison to other diseases. Additionally, while the statement by Nancy Brinker implies that the global expansion of the organization is targeted at increasing access to medical advances, both SGKC and the Avon Foundation focus their international advocacy efforts on raising awareness about breast cancer, as I discuss in the following sections.

Social Stigma, Myths, and Misinformation in Developing Countries

Advocates from SGKC and the Avon Foundation credit biomedical "awareness"

advocacy with the lowering of breast cancer mortality in the US. They argue that in countering myths and social stigma previously surrounding the disease, by raising awareness about breast cancer and educating women about the importance of early detection, biomedical breast cancer advocates reduced breast cancer mortality in the US by increasing early detection.²¹ SGKC and the Avon Foundation often stress the social stigma, myths, and misinformation still surrounding breast cancer in other countries, particularly in developing countries, which they argue are preventing early detection of breast cancer, leading to higher mortality rates from breast cancer in the 3rd world.

Biomedical breast cancer advocates argue that as in the US prior to biomedical breast cancer advocacy, breast cancer is a fear-inducing and socially stigmatizing disease

²¹ Between 1975 and 1990, the breast cancer mortality rate for all races combined increased by 0.4 percent annually in the US. Between 1990 and 2002, the rate decreased by 2.3 percent annually. The percentage of decline was larger among women under 50. The mortality rate for white women decreased more than the rate for women in other racial and ethnic groups. Medical experts attribute the decline in mortality rate to both improvements in breast cancer treatment and early detection. Nevertheless, there is debate among experts regarding the role of each in the decline in mortality rate (American Cancer Society 2006).

in developing countries, often leading to late-stage diagnosis and high mortality rates from the disease. In 2005, when the Avon Foundation celebrated its 50th Anniversary with events in nearly 40 countries, Avon Foundation President at the time, Kathleen Walas, in discussing the need for global breast cancer advocacy, stated that “In many nations breast cancer still carries a powerful stigma. Although progress has been made, breast cancer continues to be a leading cause of death for women” (Avon Foundation 2005). Similarly, leaders of SGKC and the BHGI presented the *Ignite the Promise* Global Advocate Summit in Budapest, Hungary in 2007 as an opportunity for international delegates to share “strategies on how to increase awareness about breast cancer, early detection and treatment options in their communities, with the goal of reducing stigma surrounding this often taboo disease” (SGKC 2007). One of the SGKC international delegates from India stated that “It is crucial to educate the community. We must bust some of the myths about this disease—such as cancer is contagious or god is punishing you—so that women can express themselves and their health needs” (SGKC 2007). The Avon Foundation and SGKC argue that despite their current efforts, there is still much work to be done in countering the powerful stigma surrounding breast cancer globally.

In addition to the challenge to early detection and treatment posed by the social stigma surrounding breast cancer in developing countries, biomedical breast cancer advocates also emphasize the myths, misinformation and lack of information about breast cancer plaguing many developing countries. In a National Public Radio interview, Gabrielle Union, a *Celebrity Ambassador of Hope* for SGKC, reported on her visit to Ghana for SGKC (2008), stating that,

The biggest thing is just reaching out to survivors and dispelling myths, you know, as much as I hate rumors and gossip in the United States, they don’t kill

me, but in Ghana you know where people think if you put change in your bra that you can get breast cancer that way. There are so many different crazy myths about how you can acquire the disease and treatments, that if you go to the hospital here you're going to die, they're going to cut off your boobs and you're going to die anyway. So just getting the word out, showing people that there are survivors, this doesn't have to be a death sentence and pointing people in the direction of treatment.

Biomedical breast cancer advocates argue that it is women not knowing about early detection that leads to mortality from breast cancer in developing countries, rather than lack of access to healthcare, lack of medical expertise in breast cancer, or lack of adequate detection and treatment technologies. In collaboration with the Tanzania Breast Cancer Foundation, SGKC held the first Race for the Cure event in Tanzania in 2008. At the event, SGKC and Tanzania Breast Cancer Foundation advocates recounted the story of a Tanzanian woman named Zubeda who died of breast cancer, stating that,

Zubeda discovered a breast lump in 2003 and visited a traditional healer for help. When that approach did not work, she reluctantly sought medical attention. By the time she agreed to undergo a mastectomy in 2006, the cancer had spread. By the last months of 2007, her arm was so swollen and painful she could not move it or touch it. The only painkillers she had were weak and ineffective as the cancer invaded her liver, lungs and bones. Before Zubeda died in March 2008, she agreed to be photographed. The pictures show a woman who died - needlessly and in great pain - *because she did not have the right information at her fingertips. By not knowing about early detection and the curability and survivability of breast cancer in its earliest stages, Zubeda lost her life* (my emphasis, SGKC 2008).

This story demonstrates biomedical breast cancer advocates' view that it is the lack of information about early detection that leads to needless death and suffering for women in developing countries. In 2006, Avon China held the first *Avon Walk Around the World for Breast Cancer* event in a poor rural area in Southern China.

According to a joint survey conducted by Avon China and the Conghua Women's Association, prior to this event nearly 70 percent of women interviewed had no knowledge about breast cancer prevention, and over 80 percent had never

received a breast examination nor had they ever performed a self-examination (Avon Foundation 2007).

SGKC and the Avon Foundation stress the social stigma, myths, misinformation and lack of information surrounding breast cancer in developing countries as the reason for the need for their global expansion. SGKC and the Avon Foundation frame the global burden of breast cancer as affecting women in all countries, often glossing over significant incidence and mortality rate differences. In contrast, with regard to countries' abilities to address breast cancer, these organizations emphasize global inequalities. For example, Carol Kurzig, the Executive Director of the Avon Foundation, stated that "breast cancer does not discriminate between nations or ethnicities, but both the understanding and support of the issue of breast cancer varies greatly [from] country to country" (Avon Foundation 2007).

Although SGKC and the Avon Foundation have expanded to both developed and developing countries, as mentioned previously, they often emphasize their expansion in developing countries. Hala Modellmog, President of SGKC, stated "Susan G. Komen for the Cure already has changed the way we talk about and treat breast cancer in the United States, and we're bringing what we've learned to developing countries in Asia, Africa, Latin America, the Middle East and Eastern Europe" (SGKC 2008). Susan G. Komen for the Cure and the Breast Health Global Initiative, of which SGKC is a co-founder, often stress that while breast cancer has been a health problem predominantly in developed countries, that is currently changing and their organizations are one step ahead of the shift by addressing breast cancer in developing countries. As Nancy Brinker put it,

More than 25 million cases of breast cancer are expected to be diagnosed over the next 25 years, with more than 70 percent expected in developing countries, where

cultural and economic issues create barriers to care. To address these issues, Komen for the Cure formally expanded its international work by launching a global breast cancer initiative in 2007. Earlier this year, Komen launched the Global Promise Fund, with attention focused on partnerships in the Middle East, Latin America, Eastern Europe and Africa. *By doing this, Komen for the Cure will address breast cancer in developing countries before the crisis worsens* (my emphasis, SGKC 2008).

In this statement, Nancy Brinker makes a case for organizational expansion to developing countries, despite the current lack of high breast cancer incidence rates. Other advocates working with SGKC echoed this sentiment. As Francisco Bacci, a *Komen Italia* advocate and Global Breast Advocacy Summit delegate, stated,

There is a lot of work to do in developing countries where cancer is still today not a major priority. But it will, according to the epidemiological studies, in 20 years become a major health problem also in these countries. And where the face of breast cancer is completely different, meaning 70 percent of cases are locally advanced, or metastatic, very difficult to treat, very expensive with very limited resources available *and no action going on, no interest about doing something by anyone. Just Komen, Komen is already starting to focus on this. Because Komen is starting to focus on this, this is already by itself, from my point of view, a very important thing and something that should be strongly encouraged* (my emphasis, Personal Interview, October 16, 2007).

Biomedical breast cancer advocates, therefore, present themselves as filling a significant gap in global breast cancer advocacy, in pursuit of global health equality with regard to increasing women's awareness of and knowledge about breast cancer and the importance of early detection. Reiterating this point, Mansoor Wan Abdullah, General Manager for Avon Malaysia, Thailand, Vietnam and Indonesia stated in his opening speech at the Avon Malaysia *Walk Around the World for Breast Cancer* event in 2007,

let us all work together for a better tomorrow today where women across the globe are adequately equipped to face this pandemic, subsequently becoming more self-sufficient, independent and able to benefit from medical research and success (Avon Foundation 2007).

Both SGKC advocates and Avon Foundation representatives present the problem in developing countries as women's lack of awareness of and education about breast cancer, thereby hindering early detection. By arguing that this is the problem, rather than lack of adequate healthcare services and treatment or even questioning why breast cancer rates are increasing in developing countries to begin with, they are able to present their organizations, which focus on awareness, education, and early detection, as the solution.

BREAST CANCER AS A THREAT TO FAMILIES

Finally, in framing breast cancer as a global issue, biomedical breast cancer advocates emphasize the nearly universal role of women as crucial family members, particularly as mothers, but also as daughters, sisters, and wives. In framing breast cancer as a threat to families on a global scale, biomedical breast cancer advocates are amplifying a frame that proved culturally resonant in the US (Kolker 2005). Motherhood is often assumed to be an experience that unites all women regardless of political, economic, cultural or geographic differences. By presenting breast cancer as a threat not only to women, but also to families, biomedical breast cancer advocates trust that this frame will resonate in diverse cultural and political contexts. In her speech in the United Arab Emirates announcing the US-Middle East Partnership for Breast Cancer Awareness and Research, Nancy Brinker, emphasizing the universal experience of breast cancer, despite cultural and political differences, argued that,

Breast cancer is not an *American* disease. It is not an *Arab* disease. It is a disease that can strike *any* woman, *any* family. And when it does - as it did my sister, and then me - we all have the same fears, feel the same pain, cry the same tears and pray for the same thing - to survive - for ourselves and our families (SGKC 2007).

In these opening remarks, Nancy Brinker puts her personal experience with breast cancer into a universal context, in which all women, despite any differences they may have,

experience breast cancer as a threat to their personal well-being as well as a threat to their families.

At international events, SGKC and Avon Foundation representatives often discuss women in terms of their familial roles. In addition to appealing to women, presenting women in terms of their familial roles frames breast cancer as a broader threat, in that it is not only an issue for the isolated women who have breast cancer or may be diagnosed with breast cancer, but also for all the people in their families who rely on them. The US Ambassador to the Bahamas, in discussing the Bahamas Breast Cancer Initiative, a partnership between the US Embassy in the Bahamas, SGKC, and the Cancer Society of the Bahamas, stated that,

Since launching the Bahamas Breast Cancer Initiative, we have seen an overwhelming amount of support in our effort to improve the odds for so many Bahamian women through early detection, proper education and excellent care. The turnout for this morning's walk makes me even more confident we will be able to *save the lives of so many young Bahamian mothers, sisters, wives and daughters who are at risk for contracting breast cancer* (my emphasis, SGKC 2008).

In addition to addressing women in terms of their familial roles, biomedical breast cancer advocates also present breast cancer as a direct threat to families, as SGKC's Vice President of the International Division, Annetta Hewko, demonstrates in this statement at a ceremony announcing Panama's involvement in the Partnership for Breast Cancer Awareness and Research of the Americas. "Breast cancer is a disease that knows no boundaries-it can strike any woman, any family, anywhere" (SGKC 2008). When a woman is diagnosed with breast cancer, in other words, she not only suffers, her family suffers.

Breast cancer, therefore, becomes a broad global social issue, not relegated to “women’s issues.” Kathleen Walas, past-President of the Avon Foundation, in discussing the trajectory of the Avon Foundation at the celebration of the organization’s 50th Anniversary, stated “We want to honor our first 50 years of the Avon Foundation by setting the stage for an even stronger next half century. This celebration is in honor of the women, men and families who have battled breast cancer across the globe and a commitment to eradicating this disease in the future” (Avon Foundation 2005). Breast cancer, therefore, becomes a health issue that is fought, not only by women, but also by men and families internationally.

CONCLUSION: BIOMEDICAL BREAST CANCER ADVOCACY AS THE SOLUTION

As argued by Brown (1995), in exploring how illnesses are socially constructed we are actually investigating how social forces shape our understanding of and actions toward health, illness, and healing. In this case, elite and corporate advocacy organizations are taking a leading role in defining how breast cancer should be addressed globally. By shaping the understanding of breast cancer as a pressing global health issue and defining the problem as one of lack of awareness of and education about breast cancer, biomedical breast cancer advocacy organizations are promoting awareness-raising and education campaigns as the necessary actions to reducing global breast cancer rates, to the noteworthy exclusion of broader healthcare reform.

In their discussion of the social construction of diseases, Lantz and Booth (1998, 909) argued that social constructions of diseases are significant in that they are means for the “legitimization and expansion of certain groups’ social power.” Given the extensive organizational and financial resources of SGKC and the Avon Foundation discussed in

the previous chapter, they both had the ability to expand globally, however, by reframing breast cancer as a global health crisis, problem of global health inequality, and threat to families, the organizations legitimized their expansion. By continually expanding its organization, SGKC has been able to attract an ever-increasing amount of money, allowing the Board of Directors and the Scientific Advisory Council to allocate the funds according to their biomedical breast cancer agenda. The Avon Company is able to solidify its international markets by socially constructing breast cancer as a global issue, which its Foundation is well-equipped to address through awareness and education.

Finally, as argued by Foucault (1973), the social construction of diseases serves to establish and solidify the authority of professionals, particularly medical professionals, over the individual. The social construction of a disease as an epidemic, therefore, is a powerful means of defining a social problem, demanding resources for its alleviation, and reifying the authority of “experts,” both experienced advocates and medical professionals, as those with the ability to rectify the problem. By constructing breast cancer as a global health crisis, SGKC and the Avon Foundation have legitimated their global expansion and reified their authority as “experts” with regard to their history of breast cancer advocacy in the US.

CHAPTER 6

THE CONSTRUCTION OF TRANSNATIONAL MIXED ACTOR COALITIONS

As discussed in Chapter 2, transnational social movement (TSM) scholars have identified a variety of forms of transnational advocacy organizational structures, ranging from loosely connected informational networks, strictly NGO- and social movement-based coalitions, and mixed actor coalitions. Although NGOs and social movements are the primary actors within transnational mixed actor coalitions (MACs), (parts of) states and intergovernmental organizations, as well as other non-state actors such as research institutions and corporations could also be included as their members (Khagram et al. 2002, 9). According to Khagram and his colleagues (2002, 11), the non-governmental sector, of which TSMs and NGOs are a significant part, represent a third sector of society “distinct from, but interacting with, government and business, in which the characteristic form of relation is neither authority or hierarchy, nor the market, but rather the informal and horizontal network.”

The findings that I present in this chapter indicate that biomedical breast cancer advocacy organizations have formed MACs, in which they are the central organizations, but government agencies, medical professionals, medical research centers, corporations, and local NGOS are also included. While Khagram and his colleagues (2002, 11), like many other social movement scholars, argue that the non-governmental sector, and specifically, social movements, represent a distinct sector of society, I found that in their effort to globally expand, biomedical breast cancer advocacy organizations are intricately tied to governmental, medical, and corporate sectors in ways that blur the boundaries

between their identities. This is significant because it suggests that the non-governmental or social movement sector of society may need to be reassessed with regard to its increasing overlap with other powerful sectors of society.

In this chapter, I discuss Susan G. Komen for the Cure's and the Avon Foundation's construction of transnational mixed actor coalitions separately, as they developed independently of each other. In each section, I highlight the collaboration between these biomedical breast cancer advocacy organizations and relevant governmental, corporate, and/or medical sectors as well as other NGOs, demonstrating the ways in which these alliances have blurred the boundaries between the various social sectors.

SUSAN G. KOMEN FOR THE CURE: DEVELOPING A TRANSNATIONAL MAC

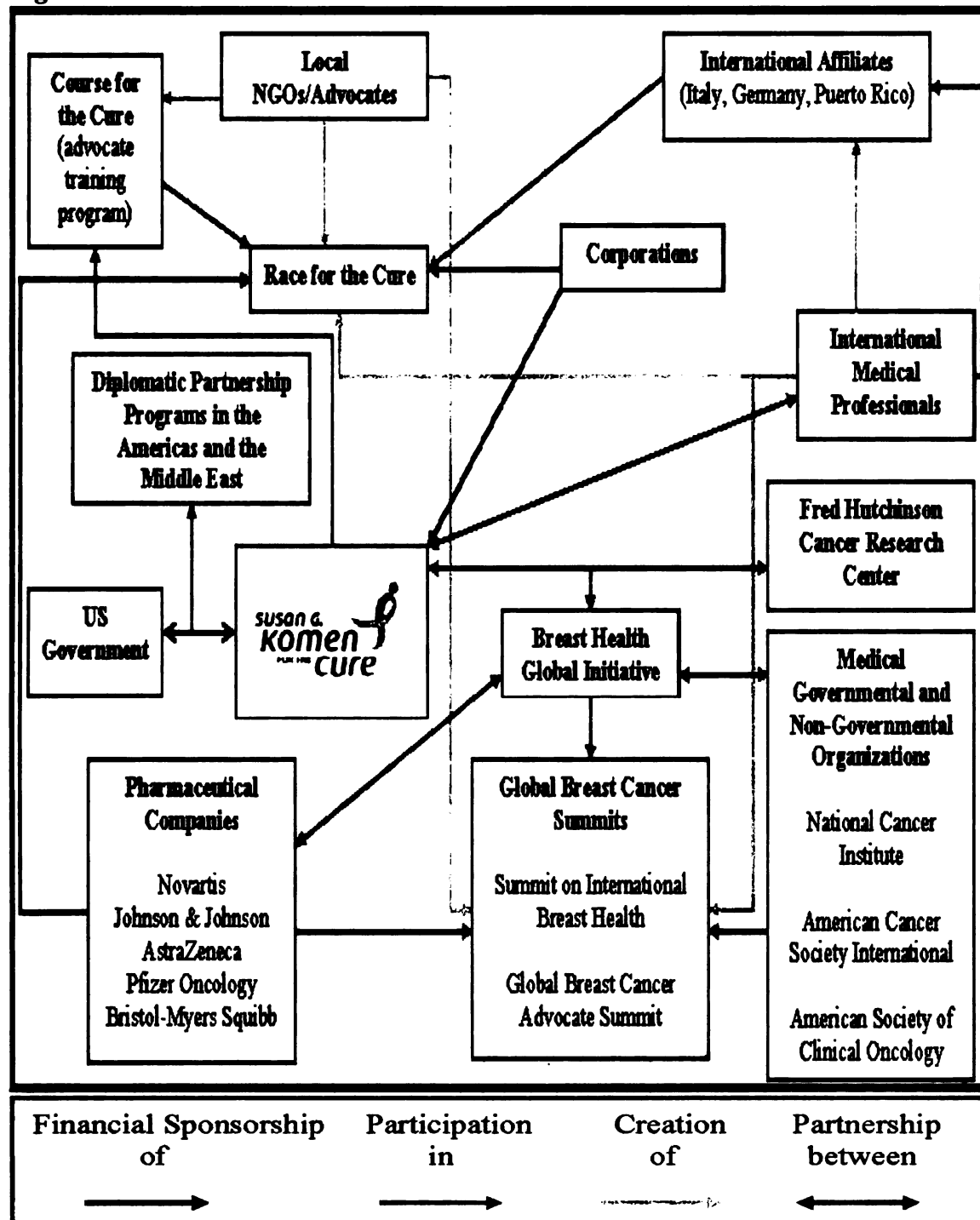
Based on my research, I constructed Figure 6.1 as a visual representation of the SGKC transnational mixed actor coalition. To expand globally, SGKC collaborated with medical professionals, the US government, medical research centers, medical governmental and non-governmental organizations, corporations, and pharmaceutical companies. The different arrows in Figure 6.1 represent the various relationships between SGKC and its partners. Pharmaceutical companies and corporations directly acted as financial sponsors to the organization, via cause-marketing campaigns, and as sponsors and participants at events (i.e., *Race for the Cure* and global breast cancer summits).

In pursuing a global breast cancer advocacy agenda, SGKC partnered with the US government, the Fred Hutchinson Cancer Research Center (FHCRC), and international medical professionals. The partnership between SGKC and the US government led to the creation of two hybrid breast cancer awareness and research programs, in Central and

South America and in the Middle East. The Breast Health Global Initiative (BHGI), a hybridization of medical, advocacy, and corporate identities, was created out of the partnership between SGKC and the FHCRC. This collaborative initiative in turn led to the creation of international medical and advocacy breast cancer summits. Finally, SGKC partnered with prominent international medical professionals, who facilitated the creation of international SGKC affiliates that developed as hybrid medical/advocacy organizations in a way that US affiliates typically did not.

SGKC also created the *Course for the Cure* advocacy training program, in which local breast cancer advocates participate to learn SGKC advocacy strategies, including how to host *Race for the Cure* (RFTC) events. In addition to participating in RFTC events, local advocates also participated in the Global Breast Cancer Advocate Summit. Finally, international medical professionals actively participate in running international affiliates, RFTC events, and the Summit on International Breast Health. The integral role played by medical professionals, corporations, and pharmaceutical companies in international RFTC events has introduced a hybrid form of advocacy, which, while becoming commonplace in the US, is quite new in many countries.

Figure 6.1. SGKC's Transnational Mixed Actor Coalition



These collaborations have enabled SGKC to create international RFTC events, affiliates, advocacy training programs, and conferences. Through this transnational MAC, SGKC is expanding its brand of biomedical breast cancer advocacy via hybrid initiatives

and events. These hybridizations diverge from past understandings of relationships between advocacy organizations, governments, corporate sponsors, and the medical community in which each maintained a clearly separate identity, but in which governments, corporations, and/or the medical community provided financial or informational resources to advocacy organizations (McCarthy 1977). Increasingly, scholars are recognizing the complex interrelationship between advocacy organizations and corporations and the need to examine how advocacy organizations, corporations, and other sectors of society are intertwined with one another (see, e.g., Yaziji 2009).

In the US, SGKC developed a brand of biomedical breast cancer advocacy, facilitated by the founder's corporate connections, that embraced a hybridization of corporate/advocate initiatives and events, primarily through cause-related marketing campaigns (McCormick 2006; King 2006). To expand globally SGKC developed a transnational MAC that expands this hybrid model of advocacy by increasing SGKC's partnerships with medical professionals, medical research centers, the US government, multinational corporations, and companies in the countries into and within which they are expanding.

Partnering with Medical Professionals

In 1998, SGKC began considering global expansion. Susan Braun, President and CEO at the time, began attending international breast health conferences looking for international partners, particularly medical professionals specializing in breast cancer, who were interested in developing a partnership to form international affiliates of the organization. At one such meeting in Rome, Italy, Braun and a prominent Italian breast surgeon began

discussing the development of the first international affiliate. As recalled by Francisco

Bacci, the founder of *Komen Italia*,

Actually I was very fortunate to run into Komen, just our roads crossed one on top of the other back in 1998 when they started to look for international expansion. The president and CEO of Komen came to Rome for a meeting that I was organizing that brought together presidents or general secretaries of twenty-five different national breast societies to present their work. And I work very much myself with international collaboration particularly in the United States, so it came out that many of the medical groups that they were [financially] supporting in the United States were groups which I had worked with, so kind of a special feeling developed and that was really a very, very big luck in my life because working with Komen has allowed me to improve a lot of the work that I am doing in Italy and here in Rome.[Working with Komen has] just given me tools to impact breast healthcare in Italy on a larger scale than I could have done on my own. So I'm very, very grateful for this opportunity (Personal Interview, Rome, Italy, October 16, 2007).

The positive interaction between Francisco Bacci and the President of SGKC at this conference led to a partnership between SGKC and this Italian breast surgeon, who recruited other breast surgeons and oncologists to bring the SGKC advocacy model to Italy and form the first SGKC international affiliate, *Komen Italia*. The founding of *Komen Italia* demonstrates how from their inception international affiliates were hybrid medical/advocacy organizations. In the US, breast cancer advocacy organizations, including SGKC affiliates, are predominantly initiated by breast cancer patients, relatives of people who have had breast cancer, and/or people who perceive themselves as high-risk for the disease, as was the case with the Lansing, MI SGKC affiliate. International affiliates, on the other hand, were formed with medical professionals at the outset.

The partnership between SGKC and the Italian medical professionals led to a mutually beneficial relationship: the leaders of SGKC found trusted partners with whom it could globally expand the Komen brand of advocacy; the University Hospital within

which the founding breast surgeons and oncologists worked were able to construct a breast cancer center within the hospital using funds raised through SGKC advocacy techniques. The use of SGKC advocacy strategies proved beneficial to the founding doctors. Specifically, *Komen Italia* successfully campaigned to get a breast cancer stamp, similar to the breast cancer stamp in the US, issued by the national postal service (Figure 6.2). With the initial funds from the sale of the breast cancer stamp, the Catholic University Hospital, in which the *Komen Italia* office is housed and the breast surgeons who founded *Komen Italia* work, a center dedicated specifically to breast cancer was constructed with the latest breast cancer screening and treatment equipment. The founders of *Komen Italia* now work together in this new Center. Francisco Bacci recalled the story of how this happened,

This [Center] was something that our university had planned to construct but it was really only when we were able to raise additional funds to support the university in doing this, and this was made possible through a breast cancer stamp, similar to the one that was created in the United States. This was just a perfect example of how we've looked at something that was very successful [in the US] and strived to introduce it with the necessary adaptations in Italy. And so [the construction of the breast cancer center] was really something very far in the distance, nobody had a clue of how it could happen, but when you have a good model, you have some additional chances to make changes happen. Eventually we were able to convince the Italian postal system that this was a nice thing to do. It was the first time in history that there was a stamp that would collect money. We asked the president of Italy to make, not a law, but to dictate how this money eventually collected should be used and *at our urging, he included a percentage of this money to help the university to build this new center and so this has happened, so this place where we are sitting now today is due to in this case to a joint effort between our university and Komen.* We joined forces together to convince the Italian postal system to make this stamp, and the stamp generated money and *part of this money was supposed to be spent for this center and so it was.* And also the rest of the money that was collected was used to support young researchers, young scientists, to develop some research programs in top cancer centers in Italy and in the United States (my emphasis, Personal Interview, Rome, Italy, October 16, 2007).

Figure 6.2. US Breast Cancer Research Stamp and Italian Breast Cancer Stamp



Source: US Postal Service, <http://www.usps.com/communications/community/semipostals.htm>; Komen Italia, <http://www.komen.it/iniziativa.htm>

The implementation of the breast cancer stamp and the funding of the breast cancer center demonstrate how, through its global expansion, SGKC has become intricately tied to medical professionals, who benefit from the relationship. *Komen Italia* often serves the interests of breast cancer patients by improving the resources of medical professionals.

The organization has a strong medical identity (see Chapter 7), which has merged with its advocacy identity in that young doctors receiving training in breast surgery are now introduced to SGKC during their medical training and often work on advocacy projects with the organization. As Margarita Solice, a 26-year-old medical resident at the Catholic University where *Komen Italia* is located, stated

I am very biased about Komen because I am like their daughter. I came to my breast surgery rotation not knowing what to specialize in and now I am specializing in breast surgery for sure. The advocacy they do is so wonderful and makes you feel that you are not just being a doctor, but are doing extra good things. So I love being a part of it and as a doctor, I can help with their events, like doing screenings and exams, in ways that other volunteers cannot (Personal Interview, Bologna, Italy, October 27, 2008).

Margarita's comments exemplify the way in which medical and advocacy identities are blurred by the collaboration between SGKC and breast health professionals in the establishment of international affiliates.

The Puerto Rican affiliate was similarly established through a partnership between breast health medical professionals and SGKC, at the urging of a breast cancer survivor from the US who had relocated to Puerto Rico. As explained by Carmen Arollo, a *Komen Puerto Rico* advocate, the ex-president and founder of *Komen Puerto Rico* was a breast cancer survivor who knew about Komen from the time she lived in the States, "so when she came down here she just got a group of doctors who helped her get all the information for the application [to become an affiliate] and that's how it all started" (Personal Interview, San Juan, PR, September 12, 2007).²² Again, breast cancer surgeons and oncologists were familiar with the SGKC advocacy model and were amenable to bringing the organization to Puerto Rico to raise funds that could be allocated for medical research and new equipment. The board of directors of *Komen Puerto Rico*, like that of *Komen Italia*, consists of a combination of breast cancer survivors, surgeons and oncologists who direct the focus of the organization (e.g., awareness, education, fundraising, research) and have control over the allocation of the affiliate's funds.²³

Similar to the Puerto Rican case, a group of US expatriates, who had worked with SGKC in the US, founded the German affiliate, *Komen Deutschland*. While I did not visit this affiliate, Sara Friedman informed me that

²² The founder and first president of *Komen Puerto Rico* was the daughter of a well-known man in the medical insurance industry. He was the founder of a Puerto Rican insurance company. She was also in the insurance business. The Senate of Puerto Rico granted her a special award for bringing SGKC to Puerto Rico, advancing breast cancer awareness and education (Rios Santiago 2006).

²³ The allocation of funds will be discussed in Chapter 8.

with the German affiliate, that began with a group of US expats who were there and throughout time the affiliate has become much more, obviously, much more German, with German staff members and it is really a German organization. It's really become their own, rather than started by a group of American expats and continued to be that way (Telephone Interview, November 16, 2008).

While the German affiliate is now run by native Germans, like the other international affiliates, the board of directors consists of a mixture of breast cancer survivors and medical professionals specializing in breast cancer, who like medical professionals working with SGKC in Puerto Rico and Italy, are likely benefiting from their involvement with SGKC via increased funds for medical technology and research.

The development of SGKC international affiliates, therefore, entailed significant collaboration between US directors of SGKC and breast cancer surgeons and oncologists in the affiliate locations, who took the lead in the formation of international affiliates. Breast surgeons and oncologists continue to play a prominent role in the organization, serving on their directorial boards and participating in events (see Chapter 7). Medical professionals became trusted partners for SGKC, allowing the organization to create affiliates internationally, expanding the SGKC brand of biomedical breast cancer advocacy, increasing opportunities for fundraising, and solidifying the organization's reputation as a pioneer in breast cancer advocacy by being one of the first organizations to expand globally. At the same time, medical professionals benefited from the partnership by drawing more financial resources to their medical practices, in the process also increasing the public's attention to breast cancer.

The partnership between SGKC and international medical professionals is a hybridization of medical and advocacy organizational identities. Medical professionals are playing a prominent role in an advocacy organization and participating in advocacy

events, utilizing their medical expertise.²⁴ In the case of *Komen Italia*, the affiliate office is physically located within a hospital, strongly associating the organization with the medical profession. Young Italian breast cancer surgeons and oncologists learn about SGKC during their medical training and may participate in advocacy events for the organization. SGKC activities, such as RFTC, are hybridizations of both advocacy and medical activities, in that in addition to the race, which raises awareness about breast cancer and funds for medical research, medical professionals maintain a strong presence at the events, providing breast health education, clinical exams and mammograms (see Chapter 7).

Partnering with the US Government

After establishing these three international affiliates, SGKC moved away from the model of international affiliates and began collaborating with the US government to create initiatives in which SGKC would teach advocates in other countries about their brand of biomedical breast cancer advocacy. Unlike many other transnational advocacy networks and coalitions that situate themselves in opposition to neoliberal globalization, often critical of the US government's furthering of neoliberal policies, SGKC's biomedical breast cancer advocacy model provides an opportunity for partnership with the US government in the interest of diplomacy. The US government potentially benefits from these diplomatic efforts by building positive relations with political regions where they are otherwise in conflict and/or have political and economic interests such as in the Middle East. As stated by Laura Bush (2006), in her comments regarding the partnership to an audience of advocates from SGKC, executives from MD Anderson Cancer Center

²⁴ I discuss the role of medical professionals in advocacy activities in detail in Chapter 7.

and Johns Hopkins Medical Center, and breast cancer specialists and advocates from Saudi Arabia and the United Arab Emirates,

This is the first major women's health campaign in the Middle East, and the United States is proud to be a part of it. The pain of losing a loved one to breast cancer—and the joy of seeing a loved one triumph over it—are universal. By confronting the challenge of breast cancer together, this partnership—which represents the very best kind of public diplomacy—*will also help build lasting friendships between our countries*. Most important, this partnership will help women throughout the Middle East find hope in a life free from breast cancer (my emphasis).

Laura Bush's comments demonstrate the attempt by the US government, in partnering with SGKC, to improve its relationship with countries in the Middle East through breast cancer advocacy, which had proven in the US to be a non-partisan "feel good" cause that everyone can support (King 2006). In addition to benefits to the US government in terms of their international reputation, SGKC financially benefits from this relationship since the partnership allows SGKC to expand its organization to many new countries because the US State Department finances the majority of the expansion. As Sara Friedman, a SGKC advocate with their international programs, explained,

With our international affiliates, we fund them from our headquarters. But with the partnerships, and by these I'm referring to the US-Middle East Partnership that we have for breast cancer research and awareness and the partnership of the Americas, both of those, since they are managed by the US State Department and Komen's really an advocacy partner and MD Anderson is the lead medical partner, they are largely financed by the State Department, *which is very nice for us*. We can have a strong presence in more locations without such a large financial expenditure (my emphasis, Telephone Interview, November 16, 2008).

The US government and SGKC have jointly established partnerships with the Middle East and with Central and South America for breast cancer awareness and research. According to Laura Bush, who has been actively involved in the diplomatic events announcing these partnerships in Washington DC and establishing the partnerships

in Middle Eastern, Central and South American countries, “breast cancer does not respect national boundaries, which is why people from every country must share their knowledge, resources and experiences to protect women from this disease” (SGKC 2007).

US-Middle East Partnership for Breast Cancer Awareness and Research

An outgrowth of the US Department of State’s Office of Public Diplomacy and Public Affairs and the Middle East Partnership Initiative in collaboration with SGKC, the US-Middle East Partnership for Breast Cancer Awareness and Research is touted as being “the first major women’s health campaign in that part of the world” (SGKC 2007).²⁵ The US Department of State’s Office of Public Diplomacy and Public Affairs and SGKC, in collaboration with the MD Anderson Cancer Research Center and Johns Hopkins Medical Center, developed the US-Middle East Partnership for Breast Cancer Awareness and Research with the purported goal of making breast cancer a “global priority,” raising awareness about breast cancer in the Middle East, and empowering women (SGKC 2007). As Nancy Brinker stated in her speech announcing the partnership in the United Arab Emirates,

We have a very important role in this historic partnership. Over the past 25 years, the Komen Foundation has been proud to work with women from every race, ethnic group and religion—including Arab-American women in the United States and Muslim women in Bosnia, Turkey, Egypt, the Palestinian territories, and Pakistan (SGKC 2007).

²⁵ The US Department of State’s Middle East Partnership Initiative (MEPI) was founded in 2002, with bipartisan support from Congress. “It has brought the resources, experience, and the determination of the United States to bear in an effort to bolster the reform movement in the Middle East. MEPI has set in motion more than 350 programs in 15 countries of the Middle East and in the Palestinian territories. In four years, MEPI has underwritten a number of projects in the areas of education, economic growth, and women’s empowerment and political participation. Its partners include local and international non-governmental organizations, businesses, universities, international institutions, and, in some cases, the governments of the regions themselves” (SGKC 2007).

In October 2006, SGKC Founder Nancy Brinker, and US Under-Secretary of State for Public Diplomacy and Public Affairs, Karen Hughes, launched the US-Middle East Partnership for Breast Cancer Awareness and Research (Figure 6.3). The Partnership, initiated in the United Arab Emirates, was lauded by former First Lady Laura Bush, who first announced the partnership in Washington DC in June 2006, as

helping local UAE organizations to address [breast cancer mortality rates] by uniting them with SGKC, which is the world's largest and most progressive grassroots network of breast cancer survivors and activists, along with the first class medical expertise of Johns Hopkins Medical International (SGKC 2006).

The implementation of the partnership was facilitated by the pre-existing collaboration between Sheika Fatima, a medical breast specialist in the UAE, and Johns Hopkins International. Through this collaboration, the UAE is “developing an Oncology Center of Excellence that will include a women’s breast cancer center” (Bush 2006).

Figure 6.3. Announcement of the US-Middle East Partnership for Breast Cancer Awareness and Research



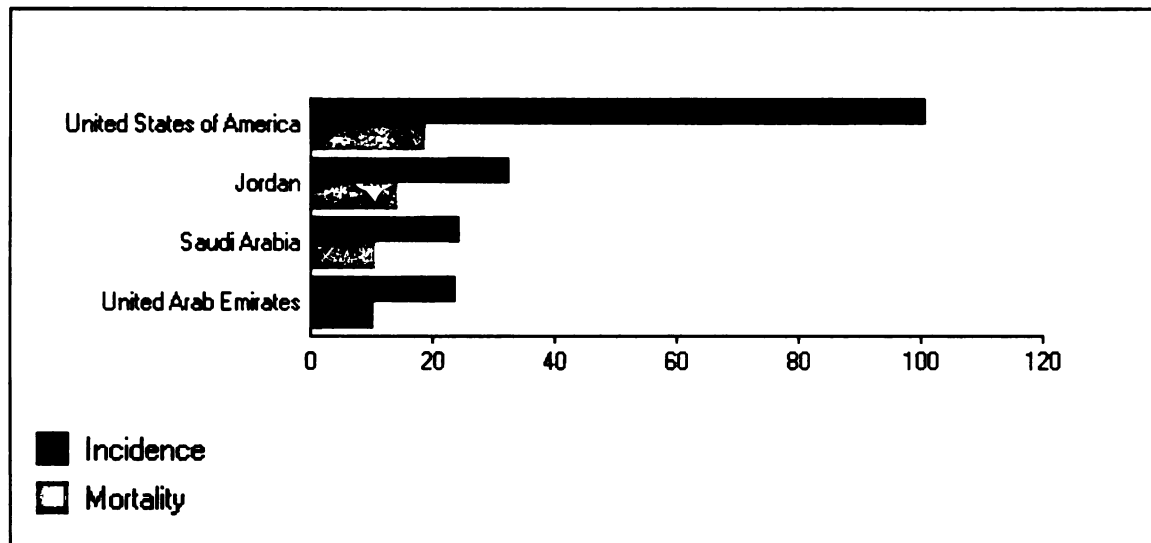
Source: Press Release, Office of the First Lady, June 12, 2006. Available at http://www.whitehouse.gov/news/releases/2006/06/images/20060612_p061206sc-0043-515h.html

In developing this partnership, SGKC emphasized that while breast cancer incidence in the Middle East is considerably lower than in the US, the mortality to

incidence ratio for breast cancer is higher than in the US and Europe. This means that while a relatively small proportion of women in the Middle East will be diagnosed with breast cancer in their lifetime, of the ones who do get breast cancer a relatively high number will die from the disease (see Figure 6.4 for incidence and mortality rates for the Middle East expansion countries as compared to the US). As stated by Nancy Brinker, “The death rate is truly alarming. We know we can reduce that rate significantly through education and early detection” (SGKC 2007). The partnership does not involve creating SGKC affiliates in the Middle East. Rather, the emphasis is on SGKC-led education and training programs so that local organizations can learn from the SGKC advocacy model and develop their own local awareness programs.

In March 2007, not too long after its implementation in the UAE, the US State Department and SGKC expanded the partnership to Jordan. This partnership includes the MD Anderson Cancer Center and the King Hussein Cancer Foundation and Cancer Center. Just as in the UAE, the Jordan initiative did not formally establish SGKC affiliates in the country. Rather, according to Hala Modellmog, current SGKC President, “through this partnership, breast cancer activists and health professionals in Jordan will have access to experts from SGKC and MD Anderson as they work to develop programs geared toward their communities” (SGKC 2007).

Figure 6.4. Age-Standardized Breast Cancer Rates for countries participating in the US-Middle East Partnership for Breast Cancer Awareness and Research, World Standard (per 100,000)*



Source: IARC, Globocan 2002

*An age-standardized rate (ASR) is a summary measure of a rate that a population would have if it had a standard age structure. The most frequently used standard population is the World standard population. The calculated incidence and mortality rates presented here are the World age standardized rates, which are expressed as a rate per 100,000. The age-standardization technique is useful in making cross-country comparisons (IARC Globocan 2002).

The most recent expansion of the partnership to Saudi Arabia in October 2007 was facilitated by the pre-existing collaboration between the King Fahad Medical City, Saudi Arabia Cancer Society, and the University of Texas MD Anderson Cancer Center (Bush 2006). Dr. Suad Bin Amer, a Saudi Arabian breast surgeon, started the Breast Cancer Research Unit at the King Faisal Specialist Hospital. “Like Nancy Brinker, Dr. Suad was inspired by a patient she loved—her mother” (Bush 2006). This effort brought together distinguished medical professionals and breast cancer awareness advocates from Saudi Arabia and the US to “work collectively in the areas of awareness, research, community outreach, and women’s empowerment” (SGKC 2007).

This partnership blurred the boundaries between the US government and SGKC, as an advocacy organization. The expansion of SGKC’s brand of biomedical breast

cancer advocacy through a partnership with the US government, merged governmental diplomacy and non-profit advocacy. Furthermore, with Nancy Brinker shifting from her position running SGKC to a US Ambassador and Laura Bush simultaneously speaking as the First Lady of the United States and a breast cancer advocate working with SGKC, the governmental/non-profit identities became increasingly blurry. In addition to the partnership between the US State Department and SGKC, this initiative also involved prominent US medical centers, continuing to blur medical professional and advocate identities.

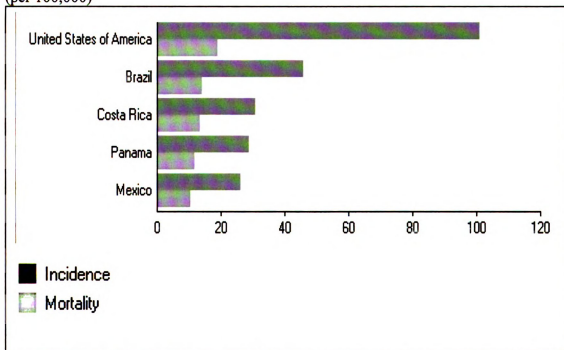
Partnership for Breast Cancer Awareness and Research of the Americas

In addition to expanding the partnership to other Middle Eastern countries, SGKC and the US State Department, in collaboration with the MD Anderson Cancer Research Center, have also created a parallel partnership between the US and countries in Central and South America. In late 2007, Laura Bush and Hala Modellmog initiated the Partnership for Breast Cancer Awareness and Research in the Americas. Brazil, Costa Rica, Mexico and Panama currently constitute the participating countries. According to Hala Modellmog, this initiative “unites experts from the United States of America, Brazil, Costa Rica, Mexico, and Panama to affect a measurable decrease in breast cancer incidence and mortality in the Americas” (SGKC 2008).

Breast cancer incidence rates are fairly low in Mexico, Costa Rica and Panama and are higher in Brazil, but still considerably lower than in the US (Figure 6.5). Rather than addressing the particular reasons for expanding to these countries, Nancy Brinker insisted that because “breast cancer is the leading cause of cancer-related death for women worldwide..., it is crucial that women begin to take ownership of their health”

(SGKC 2007). The only case where Nancy Brinker addressed the specific incidence or mortality rates in one of the Central or South American expansion countries was at the launch of the Partnership in Brazil. There she stated that “Breast cancer...is the leading cause of death for women in South America, and is the leading cause of death from cancer among Brazilian women” (SGKC 2007). According to the World Health Organization (2008), however, cardiovascular disease is the leading cause of death for women in South America, and incidence rates of cervical and uterine cancer are more pressing health issues for women than is breast cancer. Nevertheless, partnering with the US State

Figure 6.5. Age-Standardized Breast Cancer Rates for participating countries in the Partnership for Breast Cancer Awareness and Research in the Americas, World Standard (per 100,000)



Source: IARC, Globocan 2002

Department allowed SGKC to pursue expansion into new countries to further extend the reach of their brand of advocacy and enhance their organizational reputation as the largest and most prominent breast cancer advocacy organization in the world.

The US-Middle East Partnership for Breast Cancer Awareness Research and the Partnership for Breast Cancer Awareness and Research of the Americas exemplify the blurring of boundaries between government and advocacy identities. The role of Nancy Brinker in the US government and Laura Bush in SGKC demonstrates this blurring between governmental and advocacy identities. The Partnerships themselves are simultaneously forms of advocacy and diplomacy. MD Anderson Cancer Research Center and Johns Hopkins also played significant roles in brokering the expansion, given the pre-existing relationships between medical professionals in the US and a number of the expansion countries, thereby making these initiatives hybridizations of medical, governmental, and advocacy identities.

Partnering with the Fred Hutchinson Cancer Research Center

In addition to partnering with the US government in their global expansion efforts, SGKC and the Fred Hutchinson Cancer Research Center (FHCRC) jointly founded the Breast Health Global Initiative (BHGI) in 2002. The mission of the BHGI is to “develop, implement and study evidence-based, economically feasible, and culturally appropriate guidelines for international breast health and cancer control for underdeveloped nations to improve breast health outcomes” (BHGI 2008). Although the initiative was founded by SGKC and FHCRC, it consists of partnerships between US governmental and non-governmental health organizations, international health organizations, pharmaceutical and medical equipment companies, and advocacy organizations (Table 6.1). According to Sally Wellington who works with the BHGI, the various organizations involved do not merely provide financial resources for the initiative. Rather many of the organizations, as indicated in Table 6.1, are on the BHGI steering committee (Telephone Interview,

September 5, 2008). When asked about the role of corporations in the initiative, which are all pharmaceutical and medical equipment companies, Sally Wellington responded that,

Well, they're on our steering committee and they provide financial resources but they also provide their intellectual resources and we involve them in our steering committee because we want their direction if we're going down the right path (Telephone Interview, September 5, 2008).

This statement exemplifies how the BHGI embraces a hybrid organizational structure, in which all of the members of the steering committee, including pharmaceutical and medical equipment companies, direct the organization. This is similar to representation on the Board of Directors of SGKC and the Avon Foundation, but those boards consist mainly of members with corporate backgrounds unrelated to the medical field, whereas the BHGI steering committee has more representation from pharmaceutical and medical equipment companies.

The BHGI has initiated a number of global breast health summits, the most recent of which was in Budapest, Hungary in September 2007. These summits, which target medical professionals rather than lay advocates, but included advocacy representatives from a number of countries, each had different focus areas: health care disparities in 2002, resource stratification in 2005, and breast health guideline implementation in 2007 (BHGI 2008).²⁶ In 2007, in conjunction with the Global Summit on International Breast Health, SGKC hosted *Ignite the Promise* Global

²⁶ The 2002 summit was held in Seattle, Washington. Panels of medical professionals from 17 countries were brought together to discuss the creation of international guidelines to address early detection, diagnosis and treatment of breast cancer in countries with limited health care resources. The 2005 summit was held in Bethesda, Maryland. This summit consisted of 67 participants from 33 developed and developing countries, including health care professionals, epidemiologists, advocates, sociologists, economists, and representatives from health ministries and health organizations. This conference was dedicated to reassessing the recommendations made at the first summit. The guidelines developed at the summit addressed: (1) early detection and access to care, (2) diagnosis and pathology, (3) breast cancer

Table 6.1. Founders, Partners, and Sponsors of the BHGI

Founding Organizations
Susan G. Komen for the Cure*
University of Washington Fred Hutchinson Cancer Research Center*
Global Summit Host Organization
American Society of Clinical Oncology*
Sustaining Scientific Organization Partner
National Cancer Institute, Office of International Affairs*
Sustaining Corporate Sponsor
Pfizer Oncology*
Scientific Organization Partners
American Cancer Society*
Livestrong Lance Armstrong Foundation*
Corporate Partners
AstraZeneca*
Bristol-Myers Squibb Company*
Ethicon Endo-Surgery, Inc., a Johnson & Johnson Company*
Novartis
GE Healthcare*
Roche
Collaborating Organizations
Pan American Health Organization*
Office on Women's Health, National Cancer Institute
Office of Research on Women's Health, National Institute of Health
Oncology Nursing Society*
American Society for Breast Disease*
Centers for Disease Control and Prevention*
Participating Organizations
World Health Organization*
Breast Surgery International*
International Union Against Cancer
International Network for Cancer Treatment and Research
International Atomic Energy Agency of the United Nations*
International Society of Nurses in Cancer Care
International Society of Breast Pathology
Middle East Cancer Consortium
World Society for Breast Health

Source: Report from the Breast Health Global Initiative (2008)

treatment and allocation of resources, and (4) health care systems and public policy. The 2005 recommendations were stratified into 4 resource levels, which each consisted of recommendations in the four areas, based on resource levels. The stratified resource levels consist of basic, limited, enhanced, and maximum based on a country's health care infrastructure and access to breast health detection, diagnosis and treatment equipment. The most recent summit was held in Budapest, Hungary. One hundred participants from 40 countries attended the summit to discuss the implementation of the resource-stratified guidelines (BHGI 2009).

*These are also on the BHGI Steering Committee along with representatives from University of Texas MD Anderson Cancer Research Center, Evanston Northwestern Healthcare, the European School of Oncology-Italy, Latin American and Caribbean Society for Medical Oncology (SLACOM)-Argentina, and Breast Surgery International-Austria.

Breast Cancer Advocate Summit, the first international breast cancer advocacy summit bringing together advocates from over twenty-five countries (BHGI 2008). First Lady Laura Bush and Dr. Klara Dobrev, wife of the Hungarian Prime Minister, served as Honorary Co-Chairs of the event. While this summit focused on advocacy, many of the advocates involved were also medical professionals specializing in breast cancer.

Although SGKC and the FHCRC founded the BHGI, they actually work in separate, but complementary, ways in international activities. Based on their three international breast health summits, FHCRC, through the BHGI, is creating “Learning Laboratories,” starting in Ghana, where they have established strong ties to a group of breast cancer doctors in order to implement their breast health guidelines on the ground. At the same time, SGKC is creating breast cancer advocacy initiatives, via their *Course for the Cure* training program, in these countries (Ghana, Romania, and Ukraine).

The BHGI, therefore, is a hybrid initiative, founded by an advocacy organization and a medical research center. It is run by an even more diverse board, consisting of representatives of medical research centers, advocacy organizations, US governmental and non-governmental health organizations, international health organizations, and pharmaceutical and medical technology corporations.

Course for the Cure: Training International Breast Cancer Advocates

As mentioned in Chapter 4, SGKC moved away from establishing international affiliates, and instead has created global initiatives, implementing its *Course for the Cure* advocacy training program in partnership with the US Government in Middle Eastern and Central

and South American countries and in collaboration with the BHGI in Ghana, Romania, the Ukraine, and soon in India. These initiatives involve the implementation of SGKC's *Course for the Cure* training program, which integrates key principles of SGKC's advocacy model, which the organization boasts has successfully built "the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find and deliver the cure for breast cancer" (SGKC 2008). In implementing this training program, SGKC partners with various groups including NGOs, governments, and healthcare centers in each country. The *Course for the Cure* consists of five training modules that "capture the methodology and best practices that led the organization to becoming the world's largest and most successful breast cancer advocacy group" (SGKC 2007). The modules include community breast cancer assessment techniques, volunteer and organization development, awareness and education, fundraising, and advocacy (SGKC 2007).

SGKC collaborates with experts from the Institute of International Education (IIE) to train global advocates.²⁷ The IIE jointly developed the *Course for the Cure* to train advocates in the selected countries in the SGKC breast cancer advocacy model. IIE is also responsible for providing program management, hiring and managing the field staff and monitoring the results. According to Sara Friedman, a SGKC advocate working on international initiatives,

²⁷ The Institute for International Education is an independent non-profit dedicated to international education and training. One of IIE's missions is building leadership skills and enhancing the capacity of individuals and organizations to address local and global challenges. A number of financial sponsors fund IIE's programs, including US private sector organizations (e.g., American Airlines, Kraft Foods International), US governmental agencies (e.g., Department of Energy, Department of State, Department of Defense), foreign government agencies (e.g., Italian government, Chilean Ministry of Education), overseas private sector organizations/international organizations (e.g., International Monetary Fund, The World Bank), and individuals and special funds (e.g., Ratner Trust Fund) (2009).

We're working very closely with IIE, their San Francisco Office. And they are the organization that actually manages *Course for the Cure* for Komen because they're such a leader in international education. And they work directly in our selected countries. We have a program manager and a master trainer in each country. And these people are in charge of utilizing *Course for the Cure* in training people (Telephone Interview, November 16, 2008).

In describing the purpose of the *Course for the Cure*, Sara Friedman stated,

We've been working in conjunction with the State Department and BHGI to bring what we are calling *Course for the Cure* to a select group of countries, as a pilot program and this is a program in which we train individuals in the selected countries who are working with specific partners that have been chosen. We're working with them to teach them about volunteerism and advocacy, fundraising, all the components that they need in order to do their advocacy work on the ground and to, you know, implement breast health and breast cancer programs locally (Telephone Interview, November 16, 2008).

This model of global expansion allows SGKC to expand its brand of advocacy to an increasing number of countries, through collaboration with the US government and the BHGI as well as on the ground collaboration with local NGOs, healthcare centers, breast cancer survivors and "others who are in a position to spread awareness to the general population" (SGKC 2009). SGKC is never, therefore, expanding solely as an advocacy organization. Rather it has expanded internationally through hybrid initiatives that have blurred the boundaries between governmental, medical, and non-governmental sectors.

Partnering with Corporations and Pharmaceutical Companies

Finally, corporations, and specifically, but not exclusively, pharmaceutical and medical technology and equipment companies have participated in SGKC's international expansion efforts. As with SGKC affiliates in the US, international affiliates actively recruit corporate sponsors for their events, primarily the RFTC, which is the largest event for all affiliates. According to Carmen Arollo, a *Komen Puerto Rico* advocate working on soliciting corporate partnerships, *Komen Puerto Rico* sustains itself through fundraising

events, personal donations and corporate donations (Personal Interview, San Juan, Puerto Rico, September 12, 2007). These partnerships benefit SGKC, as I discussed in Chapter 4, by financially supporting the organization's events and contributing funds to the organization via cause-related marketing campaigns. Carmen Arollo explained that she started recruiting corporate partners by asking companies that were already working with SGKC in the US. She contacted Yoplait, a consistent partner of SGKC in the US. At the time, Yoplait was not distributed in Puerto Rico, but in 2006 they expanded their distribution to Puerto Rico and sponsored the RFTC in 2007. At the urging of *Komen Puerto Rico*, Yoplait agreed to initiate the *Save Lids, Save Lives* cause-related marketing campaign, which has existed in the US for years, to benefit the Puerto Rican affiliate (Carmen Arollo, Personal Interview, San Juan, Puerto Rico, September 12, 2007). *Komen Puerto Rico*, therefore, acted as an impetus for Yoplait's expansion to a new market. The *Save Lids, Save Lives* campaign has also benefited the image of the yogurt brand in the US and has the potential to draw attention to the brand in Puerto Rico, as one of the first few breast cancer cause-related marketing campaigns. As in the US, these corporate/advocate partnerships blur the boundaries between corporate and advocacy identities, creating a hybrid corporate/advocate identity for the advocacy organization and for the corporation. By visibly sponsoring SGKC and engaging in cause-related marketing campaigns, corporations present themselves to consumers as more than businesses simply interested in profit, but as advocates supporting a cause. Similarly, SGKC is a hybrid advocate/corporate organization, not simply operating as a non-governmental organization, but, as discussed in Chapter 4, engaging in marketing

practices modeled after corporate strategies and including corporations as significant partners in the organization and in events.

Figure 6.6. Johnson & Johnson Presence at SGKC's *Race for the Cure*, Bologna, Italy



Source: Personal Photo taken on September 28, 2008, 2nd Annual *Race for the Cure*, Bologna, Italy

In addition to contributing financially to international affiliates and to specific events, corporations, pharmaceutical companies, and medical technology and equipment companies also maintain a physical presence at international RFTC events. For example, Johnson & Johnson Medical, developer of MAMMOTOME Biopsy System, a minimally invasive device that helps doctors diagnose breast cancer at its earliest stages, is an active participant in *Komen Italia* RFTC events (Johnson & Johnson 2009) (Figure 6.6). At the RFTC events, corporate sponsors, like Johnson & Johnson Medical, have a booth in which representatives from the company give out literature regarding the company and their commitment to the breast cancer cause. In the case of pharmaceutical, medical technology and equipment sponsors, literature is often provided regarding the breast cancer treatments or equipment that they develop to serve breast cancer patients or to facilitate the early detection of breast cancer. Often sponsors, such as Johnson & Johnson representatives in Italy, wear shirts distinct from the Race day shirts to stand apart and

announce their presence at the event. Johnson & Johnson gave out blue J & J balloons to all of the children who stopped at the booth, which stood apart from the light pink Neutrogena balloons, which were only distributed to breast cancer survivors; Neutrogena was the official sponsor of the survivors.

Non-medical companies also sponsor and participate in events. These sponsors have booths at the events and often sell cause-related marketing products at the events or distribute samples of their products with their logo on it. For example, New Balance, a sponsor of RFTC in Italy, used its booth to demonstrate the company's commitment to breast cancer by selling pink ribbon running shoes (Figure 6.7). A portion of the proceeds from the sale of the shoes benefit SGKC.

The partnership between SGKC and corporations therefore is not merely financial. Corporations participate in the events. The literature provided by the corporations at events often merges a corporate (profit-oriented) identity with an advocate (support-oriented) identity. In closing ceremonies at RFTC events, corporations are recognized by SGKC as significant partners and committed advocates of "the cause," making corporations, more than "sponsors," integral members of an advocacy organization.

Figure 6.7. New Balance's Booth (left) and Advertisement for Pink Ribbon Running Shoes (right)



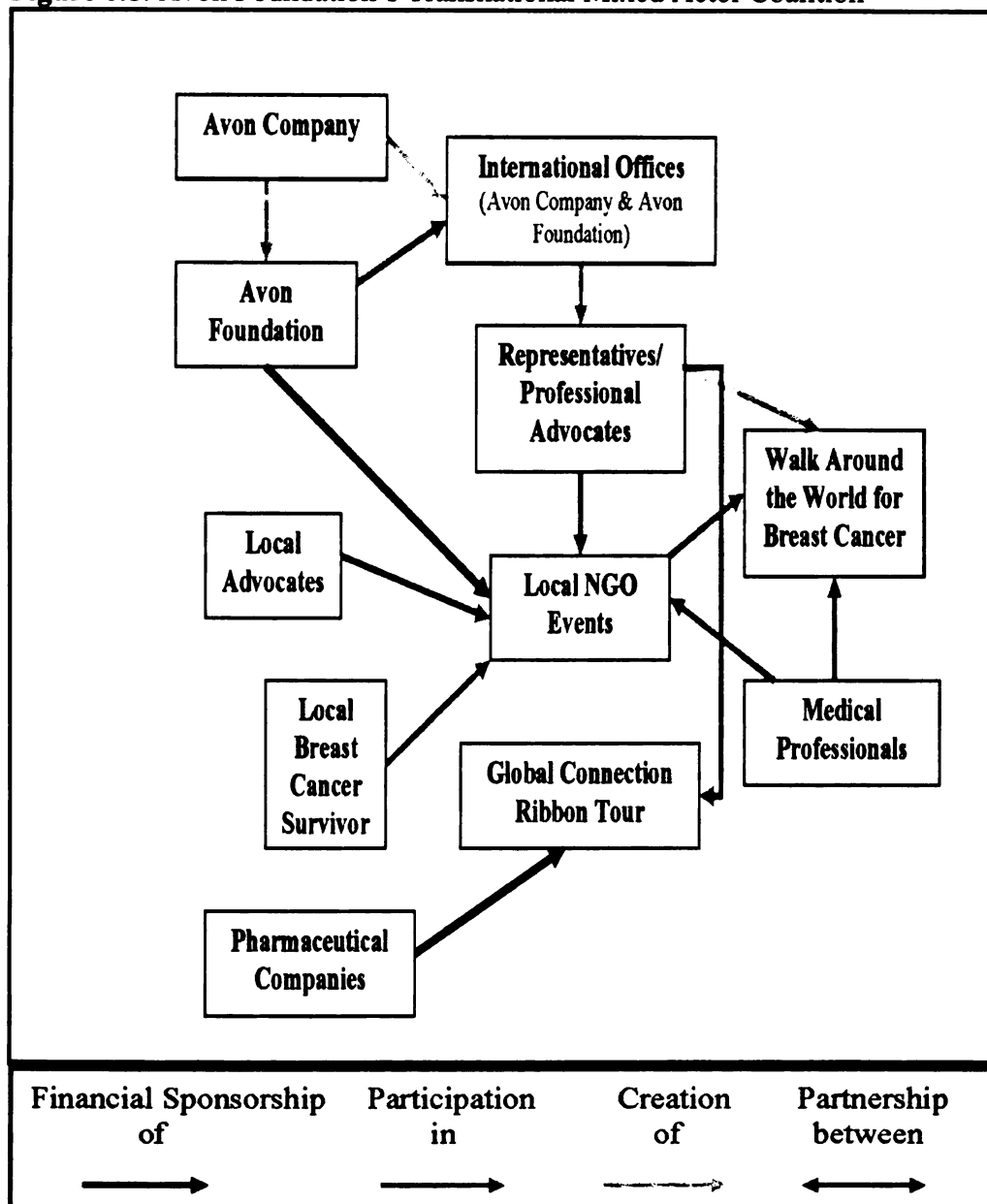
Source: Personal Photos taken on September 28, 2008, 2nd Annual Race for the Cure, Bologna, Italy

As I have demonstrated, SGKC has expanded internationally as the central organization in an extensive transnational mixed actor coalition consisting of partnerships with the US government, medical research centers, medical professionals, and corporations. These partnerships have blurred the boundaries between the non-governmental/social movement sector and governmental, medical, and corporate sectors of society. Because the US government, medical professionals, medical research centers, and corporations did not simply provide financial or informational resources to SGKC, but instead served on boards with SGKC leaders, created joint initiatives, and participated in events, these partnerships have led to a hybrid form of advocacy in which previously separate sectors of society are joining forces.

AVON FOUNDATION: DEVELOPING A TRANSNATIONAL MAC

While the SGKC transnational MAC is defined primarily by collaboration among SGKC, the US government, medical professionals, cancer research centers, and corporations, the transnational MAC created by the Avon Foundation is defined by the hybridization of Avon corporate and advocate identities, as well as collaboration with Novartis Pharmaceuticals and NGOs. Based on my research, I constructed Figure 6.8 as a visual representation of the Avon Foundation's transnational MAC. As discussed in Chapter 4, the Avon Company, a multinational cosmetics corporation, developed the Avon Foundation, which established the Breast Cancer Crusade in 1992. The international expansion of Avon's biomedical breast cancer advocacy occurred through Avon's international corporate offices, in locations where the Company already operated, as discussed in Chapter 4. These international offices house the Company and the Foundation, creating a hybrid corporate/advocate organizational identity.

Figure 6.8. Avon Foundation's Transnational Mixed Actor Coalition



Through the international offices, certain Avon representatives who were previously working with fragrances or cosmetics are assigned to the Breast Cancer Crusade. Once charged with the Breast Cancer Crusade, these representatives are responsible for the promotion and sales of breast cancer-related products, finding local women's health NGOs to partner with for the *Walk Around the World for Breast Cancer*

events, recruiting other Avon representatives to attend and participate in the events, and selecting Avon representatives who are breast cancer survivors to participate in the *Global Connection Ribbon Tour*. Avon representatives in charge of the Breast Cancer Crusade select a local NGO with which to partner. Through this partnership, Avon Foundation sponsors an NGO event, and Avon representatives participate in the event and sell cause-related marketing products at the event. These local hybrid NGO/Avon Foundation events constitute Avon's WAWBC events. Additionally, from 2005 to 2008, Avon Foundation partnered with Novartis Pharmaceuticals, jointly creating the *Global Connection Ribbon Tour*. The Tour, which is part of the WAWBC events, consists of the passing of a breast cancer ribbon from survivor to survivor around the world. Medical professionals also participate in local NGO/Avon WAWBC events by providing breast cancer screening as well as other health-related services in some cases.

Avon Foundation events have expanded globally, therefore, based on the locations of Avon Company offices, with an increasing number of countries participating in Avon Foundation breast cancer events throughout the 1990s and 2000s. Avon Foundation's international breast cancer advocacy is a hybridization of corporate/advocate identities. The expansion of Avon Foundation breast cancer advocacy benefits the company through its cause-related marketing campaign. By collaborating with Novartis Pharmaceuticals, Avon Foundation was able to create the *Global Connection Ribbon Tour*, spreading awareness about breast cancer and international solidarity among breast cancer survivors, while simultaneously advertising Avon Company as the "Company for Women" and Novartis Pharmaceuticals as a company that cares about women. As stated previously regarding SGKC, these hybridizations and

collaborations diverge from past understandings of relationships between advocacy and corporate social sectors. Instead of maintaining separate identities, the Avon Foundation and the Avon Company, along with Novartis Pharmaceuticals represent a hybridization of corporate/advocate identities, in which advocate and corporate identities are blurred.

Corporate Origins of International Advocates

Unlike SGKC, in which US advocates are mostly women who currently have or have had breast cancer, or who have been personally affected by breast cancer, and international advocates who are mainly medical professionals and women who currently have or have had breast cancer, the Avon Foundation advocates are company employees who have been assigned to the breast cancer crusade as part of their job. For example, in Puerto Rico, when asked how she became involved with the *Avon Breast Cancer Crusade* and the *Walk around the World for Breast Cancer* (WAWBC) events, Gabriella Lopez, an Avon representative answered, “I was in charge of fragrances last year, and this year I am in charge of breast cancer” (Personal Interview, Caguas, Puerto Rico, September 14, 2007). The additional training involved to run the *Avon Breast Cancer Crusade* did not consist of health advocacy information. Rather it entailed information about the new pink products Avon was selling at the time to fundraise for breast cancer awareness and research. Moreover, the representative in charge of the Breast Cancer Crusade was placed in charge of finding local organization(s) with which Avon could partner for WAWBC events. Finally, Avon representatives responsible for the Breast Cancer Crusade were charged with developing advertising campaigns, and selecting an Avon representative, who was a breast cancer survivor, to participate in the *Global Connection Ribbon Tour*.

The Avon staff of professional advocates promotes Avon as the “Company for Women” in collaboration with local NGOs in expansion countries. The Breast Cancer Crusade professional advocates choose a local breast cancer organization to partner with for the WAWBC event. In many countries a breast cancer-specific NGO does not exist, given that breast cancer is not a prominent health concern in all of the countries to which Avon has expanded. In countries where a breast cancer-specific NGO does not exist, Avon’s professional advocates choose a general women’s health or cancer organization to partner with for the WAWBC event. Avon acts as the main sponsor of the local event. Avon representatives are encouraged to attend the event, where they sell pink breast cancer products, wear Avon shirts, which are distinct from other participants’ shirts, and donate the funds raised to local organizations dedicated to improving women’s access to breast cancer screening.

Therefore, the Avon Company, through the Avon Foundation, creates “professional advocates” who are charged with organizing breast cancer advocacy events in the company’s international locations. These professional advocates are not trained as advocates and often have no personal connection to the issue of breast cancer, but are nevertheless, presented by the company as “breast cancer advocates” at NGO events in countries where the company has expanded. This demonstrates the hybridization of corporate/advocate identities within the Avon Company, which runs the Avon Foundation. The corporation actually “creates” advocates, who both promote breast cancer awareness, by distributing breast cancer information along with pink Avon products and running, walking and marching in breast cancer events, and advertise the

Avon Company by promoting the company to breast cancer advocates at local NGO events as the “Company for Women.”

Participation of Medical Professionals

As at SGKC events, medical professionals often play a role at Avon-sponsored WAWBC events. In contrast to SGKC, medical professionals do not participate directly in the Avon Foundation. Rather, medical professionals from local medical associations, hospitals, or cancer centers are asked to attend WAWBC events to provide free mammograms, information on breast self-exams and clinical exams, and in some cases additional general health information and screening. In Puerto Rico, for example, the Avon Foundation sponsored and participated in *Marcha Por Una Causa, Cancer de Seno* (Walk for a Cause: Breast Cancer), a *Sociedad Americana del Cancer* (American Cancer Society, Puerto Rican Branch) event. Doctors from the Puerto Rican Medical Association attended the event, providing breast and pelvic exams, taking participants’ blood pressure, glucose level and weight and giving general health advice (Figure 6.9).

Figure 6.9. Event participant being weighed by a medical staff volunteer



Source: Personal Photo taken at *Marcha Por Una Causa*, Yauco, Puerto Rico, October 6, 2008

Medical professionals, therefore, participate in Avon-sponsored events, but do not collaborate with Avon Foundation in the same way that they do with SGKC. By participating in advocacy events, however, medical and advocacy identities are often blurred, as medical professionals are there to provide medical screening, while also participating in the events and often speaking as breast cancer advocates at opening and closing ceremonies.

Partnering with Novartis: Global Connection Ribbon Tour

From 2005 to 2008, Avon Foundation's *Walk Around the World for Breast Cancer* events consisted of the *Global Connection Ribbon Tour* (GCRT). According to the Avon Foundation (2006),

WAWBC participating countries are linked by a *Global Connection Ribbon Tour*, which serves as a unique grassroots, woman-to-woman connection. In the *Global Connection Ribbon Tour*, a selected breast cancer survivor from each event travels to another country to attend the next WAWBC event as an honored guest. This visiting breast cancer survivor passes to a local breast cancer survivor a unique "Connection Ribbon" as a symbol of shared hope and survivorship—an oversized pink ribbon imprinted with "Thank You" in multiple languages.

In Figure 6.10, a visiting breast cancer survivor from Peru is passing the Global Connection Ribbon to a local breast cancer survivor in Ecuador during the GCRT in October 2007 (Avon 2007).

In addition to traveling to another country to pass along the ribbon, in October of each year most of the women participating in the GCRT are brought to New York City for the Avon Foundation's Global Breast Cancer Survivors' Day luncheon and the Avon Walk for Breast Cancer-New York, the largest Avon walk event. At the Avon Walk in New York City the international survivors are stationed in a special "cheering section" and are recognized in the closing ceremony (Avon 2006).

Figure 6.10. *Avon Ecuador's Global Connection Ribbon Tour Event*



Source: Avon Foundation, Walk Around the World for Breast Cancer, Countries, Ecuador, http://walk.avonfoundation.org/site/PageServer?pagename=Samer_Ecuad

Each year, Novartis Oncology sponsors the *Global Connection Ribbon Tour*. At the ribbon passing event in every country, a representative of Novartis Oncology is present and speaks at the closing ceremony. At the 50th Anniversary celebration of Avon Foundation in New York, before recognizing the international survivors brought to New York through the partnership between the Avon Foundation and Novartis Oncology, Dr. Diane Young, Head of Global Clinical Development for Novartis Oncology, stated that

Novartis is delighted to be a partner with Avon in its crusade against breast cancer. This initiative will increase awareness of breast cancer, help provide women with better access to the latest medical information on breast cancer and celebrate survival (Avon 2005).

Through this partnership, Novartis has been able to gain exposure in over 40 countries. Novartis “develops and markets patent-protected prescription drugs” for various medical conditions, including breast cancer. Specifically, they developed *Femara*, which is used

for the treatment of postmenopausal women with hormone receptor positive breast cancer (Novartis 2009).

The partnership between the Avon Foundation and Novartis pharmaceuticals is a hybridization of corporate/advocate identities. Novartis pharmaceuticals is not simply sponsoring the event, rather Novartis representatives are present at and participate in the events. Through the partnership, a particular advocacy event, the *Global Connection Ribbon Tour*, was created to celebrate survivors and connect breast cancer survivors from different countries. In doing so, the Avon Company, through the Avon Foundation, as well as Novartis Pharmaceuticals gain exposure among breast cancer advocates and promote themselves as more than just companies; they are advocates as well.

Partnering with Local NGOs

Unlike SGKC international affiliates, which do not partner with local organizations in presenting *Race for the Cure* events, the Avon Foundation partners with local NGOs, sharing in local events and donating 100 percent of funds raised from their cause-related marketing campaigns to the partnering organizations. Given that the Avon Foundation has expanded globally based on the locations of the Avon Company's international offices, and not on whether or not countries are particularly afflicted by or actively advocating against breast cancer, as mentioned earlier in the chapter, in some cases NGOs specific to breast cancer do not exist. Because of this, the Avon Foundation representatives in charge of the WAWBC events may choose to partner with a general cancer society or women's health organization. As shown in Table 6.2, the Avon Foundation partners with a variety of NGOs ranging from international affiliates of the

American Cancer Society, as is the case in Puerto Rico, to transnational breast cancer organizations, as is the case in Italy, to local cancer and breast cancer groups.

Through these partnerships, the partnering NGOs receive funding for their events and often a lengthy fundraising commitment from the Avon Foundation. In Puerto Rico, for example, the Avon Foundation donates all of the proceeds from sales of breast cancer-related products to the *Sociedad Americana del Cancer* (SAC). These funds are not a general donation to the SAC, but rather they are allocated to breast cancer-specific projects. In Puerto Rico, the SAC has a mammogram program, in which uninsured women can get a voucher, take it to their doctor, and receive a mammogram free of charge. Through these partnerships between the Avon Foundation and NGOs, the Avon Company gains positive exposure in its support for the breast cancer cause, leading to a solidification of the Company's reputation as the "Company for Women" in their increasingly profitable international markets.

Table 6.2. A Selection of Avon Foundation's Partnering NGOs*

Country	NGOs
Multiple Countries	American Cancer Society
Argentina	Liga Argentina de Lucha Contra el Cancer (Argentinean League Against Cancer)
Australia	YWCA Encore Program; Australian New Zealand Breast Cancer Trials Group
Bosnia	International Women's Club Sarajevo
Canada	Healing Arts Environments; Canadian Breast Cancer Research Alliance
Chile	Arturo Lopez Perez Foundation
China	China Cancer Foundation; China Women's Development Foundation; Conghua Women's Association
Czech Republic	Alliance of Czech Breast Cancer Associations

Table 6.2 (Continued)

Dominican Republic	Northern Cancer Patronage; Dominican Cancer League
Ecuador	SOLCA (Cancer NGO)
El Salvador	Liga Nacional Contra el Cancer (National League Against Cancer)
Estonia	Estonia Cancer Union
France	Odyssea
Germany	Bavarian Cancer Society; Berlin Breast Cancer Project
Greece	Hellenic Anti-Cancer Association
Guatemala	Liga Nacional Contra el Cancer
India	Cancer Patients Aid Association
Italy	Italian League Against Cancer, Europa Donna (pan-European organization)
Latvia	Tree of Life
Macedonia	Borka
Malaysia	Breast Cancer Welfare Association
Mexico	Grupo RETO; Casa de la Amistad and Caras de Esperanza (House of Friendship and Faces of Hope)
Oman	National Association for Cancer Awareness
Poland	Post Mastectomy Women's Club "Amazons"; Warsaw Breast Cancer Survivor Society
Romania	Renastra Foundation (Breast Cancer NGO)
Spain	Asociacion Espanola Contra el Cancer (Spanish Association Against Cancer)
UK	Breakthrough Breast Cancer; Crazy Hats Breast Cancer Apparel

Source: http://walk.avonfoundation.org/site/PageServer?pagename=WorldWalk_Main

*For some countries, Avon Foundation just lists "local NGOs" and for others, the organization did not specify NGO partners. This table consists of all of the partnering NGOs that I was able to identify via the Avon Foundation website as of May 2009.

CHAPTER SUMMARY

In this chapter I have argued that SGKC and the Avon Foundation have expanded globally separately, but similarly, in creating transnational mixed actor coalitions. The SGKC mixed actor coalition is more extensive than the Avon Foundation's MAC, in that

it encompasses extensive partnerships among SGKC, the US government, medical professionals, medical centers, and corporations. The Avon Foundation, on the other hand, was created through a corporation, giving it a unique corporate/advocate identity from its inception. Through these mixed actor coalitions, SGKC and the Avon Foundation have expanded biomedical breast cancer advocacy globally. Rather than expanding based on the need for breast cancer advocacy in particular countries, SGKC expanded based on relationships with trusted medical professional partners and the US government's goals in creating the breast cancer initiatives. Avon Foundation, on the other hand, expanded according to the locations of Avon Company offices, but also not with regard to particular breast cancer advocacy needs in particular countries. The MACs exemplify a blurring of the boundaries between advocate, corporate, governmental, and medical identities, which will be further explored in Chapters 7 and 8.

CHAPTER 7

THE GLOBAL EXPANSION OF PROCESSES OF BIOMEDICALIZATION VIA BIOMEDICAL BREAST CANCER EVENTS, CAMPAIGNS, AND PROGRAMS

In this chapter I draw on my findings regarding how forms of biomedical breast cancer advocacy have been incorporated into, and adapted to, other political and cultural contexts to argue that the diffusion of biomedical breast cancer advocacy events, campaigns and programs are furthering processes of biomedicalization globally. With only minor cultural and political adaptations, SGKC and Avon Foundation events, campaigns and programs in other countries are strikingly similar to their advocacy activities in the US. By raising awareness about early detection and disseminating medical information, biomedical breast cancer organizations are promoting surveillance medicine and creating new at-risk identities among women across the globe. Biomedical breast cancer advocacy organizations are playing a significant role in establishing a biomedical understanding of breast cancer outside of the US by engaging in awareness-raising activities and disseminating medical information about breast cancer. The focus of SGKC and Avon Foundation events, campaigns, and programs is twofold: raising awareness and raising funds. This chapter addresses the former, and Chapter 8 addresses the latter.

In this chapter, I first discuss the discourse of awareness, early detection, and individual responsibility promoted by biomedical breast cancer advocacy organizations through their global events, campaigns, and programs. Then I present the various ways in which globally expanding biomedical breast cancer organizations are disseminating medical information about breast cancer. Next, I discuss the promotion of surveillance medicine by these organizations. Finally, I explore the creation of new at-risk identities.

RAISING AWARENESS: THE IMPORTANCE OF EARLY DETECTION

The similarities among biomedical breast cancer advocacy events in the US, Puerto Rico, and Italy far exceed the differences. While the Avon Foundation has held different types of events throughout the world ranging from ubiquitous walks and runs, relatively commonplace press conferences, concerts, fashion shows, balloon releases, and unique mountain climbs and motorcycle tours, all of the events focus on raising awareness and raising funds. Similarly, SGKC's *Race for the Cure* and similar events may be slightly altered in terms of cultural content (e.g., an Italian band performed before the Race in Bologna, Italy; *Salsa for the Cure* event in Puerto Rico); nevertheless the focus on raising awareness about breast cancer remains consistent. In this section, I discuss the global proliferation of "raising awareness" through biomedical breast cancer advocacy events, campaigns, and programs, arguing that through these activities, SGKC and the Avon Foundation are introducing and promoting a biomedical discourse regarding breast cancer, specifically with regard to the discourse of early detection and individual responsibility for monitoring one's bodily health.

The notion of "awareness," closely associated with breast cancer in the US, is now being introduced and promoted in a number of countries by biomedical breast cancer advocacy organizations. Awareness is promoted in ever-proliferating forms of events, campaigns and programs. "The word about breast cancer even made it to the top of Kilimanjaro as *Avon South Africa* staff headed to the top of the mountain clothed in *Kiss Goodbye to Breast Cancer* shirts, spreading awareness with each step they climbed" (Avon Foundation 2007). In Puerto Rico, SGKC has created an awareness campaign based on using pink, the signature color of breast cancer awareness, to engage in any type

of “awareness-raising” activity. According to Carina Candall, a *Komen Puerto Rico* advocate,

We have an event that we set up last year and it’s not on any specific date, any day you pick, any day during the month of October, and either you do a walk, you can light a building in the color pink, you can just light candles, you can wear pink, something, anything, to create awareness. So we promote that in different municipalities all around the island (Personal Interview, San Juan, Puerto Rico, September 12, 2007).

In Romania, in 2006, Avon held “The Pink March” as part of their breast cancer educational campaign. According to *Avon Romania*, this campaign was

aimed at reaching women in common locations such as subway stations, movie theaters and hair salons. Subway and movie theater chairs were painted pink, and messages of the importance of early diagnosis and treatment appeared on television shows and in magazines (Avon Foundation 2007).

Since the Avon Foundation and SGKC began expanding globally, the number of these types of awareness-raising events increases each year.

In her discussion of breast cancer philanthropy, as she refers to biomedical breast cancer advocacy, Samantha King (2006, 95) presents the following quandary regarding “awareness,”

What exactly does “awareness” mean in the context of breast cancer, and what is it that consumers are being asked to gain “awareness” of? When Avon campaigns do venture into specifics, awareness usually means preaching the benefits of early detection through mammograms. Although this approach might prompt women to discover if they already have breast cancer, this selective brand of awareness asks women to take personal responsibility for fending off the disease, while ignoring more difficult questions related to what might be done to stop it at its source, or for that matter, to treat it once those underserved women whom Avon claims to assist receive a positive diagnosis.

Through their global expansion, SGKC and the Avon Foundation continue to promote this same message of awareness, early detection and individual responsibility for one’s

health. As stated by Hala Modellmog, president and CEO of SGKC, regarding a breast cancer initiative in the Bahamas,

Research has shown that too many Bahamian women are dying of breast cancer because of lack of awareness and lack of access to early detection and treatment. Fortunately, organizations like Susan G. Komen for the Cure, the Cancer Society of the Bahamas and the Bahamas Breast Cancer Initiative have pledged to work together to raise awareness and tackle these issues, so that together we can help save lives here in the Bahamas (SGKC 2008).

Even though raising awareness is often mentioned along with lack of access to detection and treatment due to lack of healthcare coverage, the relative absence of hospitals or medical centers equipped to handle breast cancer detection and treatment effectively, or a combination of the two, SGKC and the Avon Foundation focus their efforts on raising awareness and stressing the importance of early detection, emphasizing the need for women to be responsible for their breast health. For example, Annetta Hewko, SGKC's vice president of international programs, stated that the goal in establishing the breast cancer awareness and research initiative in the Americas was "to educate and empower women in the Americas to take charge of their breast health" (SGKC 2008). By being aware of their breast cancer risk, performing self-exams, and routinely being screened by a physician in order to detect any cancer at its earliest stage, Hewko implies, women will have the ability to "take charge" of their breast health, without consideration of access to healthcare services. Similarly, when asked about the main goal of *Komen Italia*, Rosa Valentino, an advocate with the organization, responded,

to promote the prevention, I mean early detection, because I think that from personal experience my mom she was lucky because she was 44 and she went to the doctor for a normal check and he discovered she had a lump and it was a very aggressive cancer and so...but I mean my mom she has a degree, she studied hard, I mean she lives in, we live in Venice so it's not a little village but she personally at 44 she didn't have any mammography before so I mean that, it's something that we have to promote, the detection and the prevention is the thing we have to do and to promote in general I mean I think that is our principle goal.

Although Rosa Valentino notes the importance of early detection based on her mother's experience with breast cancer at the age of 44, it is not clear how much earlier her mother would have detected her breast cancer even if she had a greater level of awareness given that national healthcare coverage in Italy provides women with free mammographic screening biannually only between the ages of 50 and 69. It is not surprising, therefore, that her mother had not previously had a mammogram. Nevertheless, Valentino asserts that the main goal of *Komen Italia* is to increase awareness, with no mention of extending the age range for breast cancer screening covered by the national healthcare plan.²⁸

While many Italian women, at least many urban Italian women, had been exposed to breast cancer awareness messages prior to the arrival of SGKC and the Avon Foundation through other breast cancer advocacy organizations, such as *Europa Donna*, for many women in other countries, this form of "awareness advocacy" is being introduced for the first time by SGKC and the Avon Foundation. According to the Avon Foundation,

The inaugural 2005 WAWBC series launched in 35 countries and attracted over 87,000 participants, creating *the first awareness events of their kind in many regions*. The need for continued awareness of breast cancer is great (my emphasis, Avon Foundation 2006).

Similarly, the following excerpt from an Avon press release describes the passing of the Global Connection Ribbon from a breast cancer survivor from the UK to a survivor in Ireland,

²⁸ This is particularly significant because another breast cancer advocacy organization in Italy, *Europa Donna*, petitions at the national and international level to increase the age range for breast cancer screening covered by national health plans as well as making sure that there is a standard level of breast cancer detection and treatment throughout Italy, given that access to quality care is often limited to urban areas.

Visiting survivor from the United Kingdom, Ann McGee, passed on the Global Connection Ribbon to local survivor Bernie Weir. The passing of the Global Connection Ribbon marked *one of the first times that a woman in Ireland stood publicly to be recognized as a breast cancer survivor* (my emphasis, Avon Foundation 2006).

Members of these organizations argue that public events focusing on awareness are what is needed globally to reduce the rising rate of breast cancer. According to Charles Bradley, a founding member of the BHGI,

awareness is inappropriately low in low- and middle-income countries and it used to be that way here [in the US] that people wouldn't say the word "breast" or the word "cancer" in public and you would talk about a "woman's diseases." I mean being able to have races where people are running with pink hats on actually is very important for early detection (Telephone Interview, October 21, 2008).

The raising of awareness about breast cancer and the public advocacy events where breast cancer survivors are recognized, therefore, are actually important precursors to early detection according to Charles Bradley.

While ubiquitous in the US, these events are often reaching audiences of women who have not previously been exposed to messages about breast cancer or to this form of advocacy. While the form of awareness advocacy and the message of awareness, early detection and individual responsibility remain consistent, events are often adapted to cultural preferences, locations, and specific breast cancer risk information. For example,

On October 21, 2005, *Avon China* made history as the first enterprise to hold a social charity event at the Great Wall. *Avon China* partnered with the China Cancer Research Fund to launch the *Avon China* Walk Along the Great Wall for Breast Cancer at the first gate of the Great Wall in Jiayuguan City in Western China. More than 300 participants walked the Great Pink Wall and 2,000 homing pigeons were set free (Avon Foundation 2007).

By naming their WAWBC event, Walk Along the Great Wall for Breast Cancer, *Avon China* incorporated a culturally significant location into an unfamiliar type of event, making it uniquely Chinese. At *Marcha Por Una Causa: Cancer de Seno*, in Yauco,

Puerto Rico, the message of awareness, early detection, and individual responsibility was repeated every twenty minutes during the two-hour walk. A man inside a truck leading the walk through Yauco shouted the message, which boomed out of the loudspeakers on top of the truck (Figure 7.1).²⁹ The message repeated was

Marcha por una causa, cancer de seno, dos mil ocho,
La esperanza comienza conmigo
Es muy importante, el autoexamen y muy importante el deteccion temprano
Y recordamos que una de cada trece mujeres hoy en Puerto Rico encontrar cancer
de seno en qualquier ano de su vida. (Fieldnotes, Yauco, Puerto Rico, October 4,
2008).³⁰

By citing the breast cancer risk statistic for Puerto Rico, the message was tailored to the specific audience, while otherwise remaining consistent in terms of promoting awareness and the importance of self-exams and mammography for early detection.

Figure 7.1. *Marcha Por Una Causa: Cancer de Seno* event



Source: Personal Photo, Yauco, Puerto Rico, October 4, 2008

²⁹ Having a truck with loudspeakers leading a march is very common in Puerto Rican political rallies. This form of political rally was adapted for this breast cancer awareness walk.

³⁰ In English, the message is Walk for a Cause: Breast Cancer, 2008. Hope begins with me. It is very important, the self-exam and early detection. And remember that today one out of every thirteen women in Puerto Rico will get breast cancer at some point in her life.

In addition to their events, SGKC and the Avon Foundation seek media attention in order to reach an even larger audience with the message of breast cancer awareness. After their 2005 5K walk for breast cancer, *Avon France* noted that “the event was covered by more than 30 media outlets helping to spread awareness and the important message of early detection” (Avon Foundation 2007). Similarly, the Smile Walks, *Avon Japan*’s breast cancer events held in Tokyo and Kagoshima in 2005, received extensive media coverage, “further spreading the important message of early detection and helping to break the stigma of breast cancer in Japan” (Avon Foundation 2007).

By introducing their events, campaigns and programs to an increasing number of countries, SGKC and the Avon Foundation are expanding a particular brand of health advocacy, namely “awareness advocacy,” as well as promoting a message of breast cancer awareness, early detection, and individual responsibility for one’s health. These messages are intended to produce change, not in healthcare structures, but in individual’s health behaviors. While the events, campaigns, and programs are slightly altered for cultural or political context in some cases, the message remains consistent. Women are encouraged to “take charge” of their breast health, and these organizations are the ones telling them how to do so. To be a responsible woman, one must regularly conduct breast self-exams and seek clinical exams and mammograms when one reaches a certain age, and regularly from then on.

ADVOCACY ORGANIZATIONS AS DISSEMINATORS OF MEDICAL INFORMATION

In addition to being promoters of the message of awareness about early detection and individual responsibility, biomedical breast cancer advocacy organizations are also providers of medical information. As discussed by Clarke and her colleagues (2005, 450)

processes of biomedicalization have transformed information, knowledge production, and distribution of medical information. Information about health and illness “is proliferating in all kinds of media; especially newspapers, on the internet, in magazines, and through direct-to-consumer prescription drug advertising” (Clarke et al. 2005, 450). Furthermore, Clarke and her colleagues (2005, 450) argue that there are multiple sources creating and distributing health-related information and “non-expert” individuals are increasingly expected to navigate and make sense of various health-related messages. Finally, according to Clarke and her colleagues (2005, 450), while the proliferation of sources of information, knowledge production and distribution has implications for democratizing biomedicine, the interests of the pharmaceutical industry still predominate.

Although Clarke and her colleagues (2005) discuss this shift toward the proliferation of health-related information, they do not directly address health advocacy organizations. My findings indicate that globally expanding biomedical breast cancer advocacy organizations are significant sources of breast cancer-related health information. Given that direct-to-consumer pharmaceutical advertising is currently legal only in the US and New Zealand, most people are not exposed to medical information directly by pharmaceutical companies. Additionally, because biomedical breast cancer advocacy organizations are expanding to many countries where breast cancer is not a health priority, public breast cancer-related health messages were often very limited or non-existent prior to the arrival of these organizations (WHO 2008).

Both SGKC and the Avon Foundation disseminate medical information about breast cancer through their respective events, campaigns and programs. One of the main

ways that both organizations do this is through the distribution of educational materials.

According to Sara Friedman, a SGKC advocate with their international programs,

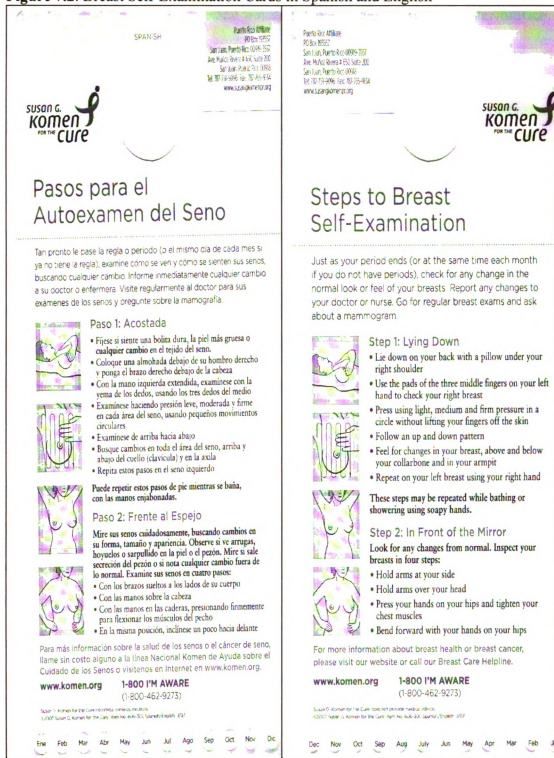
Even with people [from other countries] who aren't looking for collaboration or want to be an affiliate or hold a Race for the Cure, people will call in, you know, wanting educational materials or they're holding an event in some location and want materials translated into another language and you know it's just those sorts of inquiries we receive quite frequently and depending on where they are and what they're looking for sometimes we may have access to something and we can send it directly to them or, you know, we'll send them to komen.org where we have a lot of our educational materials that can be printed out, including our BSE [breast self exam] cards and just all of those types of you know, informative pieces and very basic information that we want people to be able to have (Telephone Interview, November 16, 2008).

All SGKC Affiliates have these educational materials at their offices and distribute them at *Race for the Cure* and other events. Additionally, as stated by Sara Friedman, organizations and individuals not affiliated with SGKC also have access to its educational materials. In addition to educational materials available on their website, SGKC also translates all of their materials for affiliate and *Course for the Cure* locations and allows other organizations to translate educational materials for distribution as well. As Sara Friedman indicated,

We do allow people to translate our materials into other languages. They simply have to just let us know what they'd like to do and we have them fill out a very basic form and we provide them with a version that they can make edits to and you know, work right in with, using our template and all that and we just simply ask that they provide us back with a translation whenever they're finished with it so we can share that information. Because I think one thing that Komen, we feel very strongly about, is the idea that we share what we know and that everyone does not have, you don't have to recreate the wheel. We want to save people time (Telephone Interview, November 16, 2008).

In Figure 7.2, SGKC's breast self-examination (BSE) cards are shown in Spanish and English. The information is exactly the same in Spanish and English.

Figure 7.2. Breast Self-Examination Cards in Spanish and English



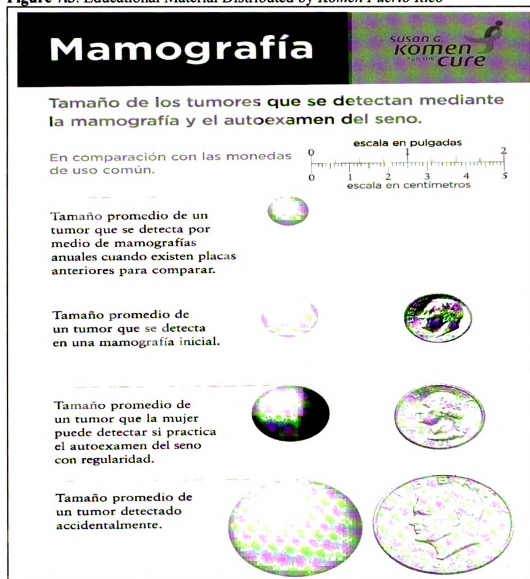
Source: Komen Puerto Rico, educational material, 2008

Figure 7.3 is an educational handout created by SGKC. This handout is available at the *Komen Puerto Rico* office and was distributed at Komen events in Puerto Rico. The handout provides information about the sizes of tumors that can be discovered by mammograms and breast self-exams, comparing the tumor sizes to common coins. The purpose of the handout is to demonstrate that yearly mammograms lead to the earliest detection of breast tumors, finding them at a very small size because previous mammographic images are used for comparison. The next larger size represents the typical size of a tumor that can be found through an initial mammogram. The second to largest size tumor is the size that a woman performing regular self-exams would likely be able to detect on her own. Finally, the largest tumor, equivalent to the size of a half dollar coin, is what a woman who does not perform monthly self-exams or have regular mammograms may detect accidentally. This material emphasizes the importance of early detection through regular mammographic screening.

Similarly, the Avon Foundation has a Breast Health Resource Guide (Figure 7.4) that is included with all purchases of Breast Cancer Crusade products from their brochure. Although the resource guide shown is in English, the brochure is translated into a number of different languages and is distributed in all countries where Breast Cancer Crusade products are sold. The resource guide is an eight-page pamphlet that includes general breast health and breast cancer information, a glossary of relevant terms (e.g., biopsy, mastectomy), a list of organizational resources, information about the Avon Breast Cancer Crusade, and a form to make a tax-deductible donation to the Avon Foundation. The excerpt from the resource guide in Figure 7.4 shows the medical information that is distributed with the purchase of pink ribbon products from Avon. The

guide includes a list of symptoms of breast cancer that women should be aware of and look for, information about breast cancer risk, and finally information about early detection through mammograms, clinical exams and self-exams.

Figure 7.3. Educational Material Distributed by *Komen Puerto Rico*



Source: *Komen Puerto Rico*, educational materials, 2008

The Avon Foundation often cites the “fact,” based on anecdotal accounts, that its educational material is directly leading to early detection, particularly in countries where other informational resources about breast cancer are not readily available. For example,

at the WAWBC *Global Connection Ribbon Tour* events in Brazil in 2005, Maria, a young Brazilian breast cancer survivor, accepted the connection ribbon from a survivor from another country. According to the Avon Foundation, “At the age of 29, Maria found a lump in her breast after reading an Avon breast cancer awareness brochure” (Avon Foundation 2007). In this way, the Avon Foundation demonstrates that it is filling a gap in breast cancer knowledge through the distribution of its resource guide, thereby changing individual behavior and leading to breast cancer detection.

Beginning in 2009, in addition to the current resource guide, the Avon Foundation plans to distribute SGKC breast health information. According to Marta Munoz, a representative of *Avon Puerto Rico*, Avon will be including SGKC informational resources because,

They have very, very, very good instruments in education. And that’s going to be additional to the resource guide. We also serve the Caribbean. So we always do everything in Spanish and English. The same brochure [of products] we have also in English and Spanish and the same thing with the resource guide (Personal Interview, Caguas, Puerto Rico, September 13, 2007).

In addition to educational pamphlets, SGKC and Avon Foundation advocates engage in educational campaigns and programs in which biomedical breast cancer advocates lecture or give seminars related to breast health. For example, Margarita Solice, an advocate with *Komen Italia* and a breast surgeon, described a joint high school educational program co-sponsored by *Komen Italia* and the Ministry of Education. For the past five years medical professionals, like herself, working with SGKC visit high schools to “teach young people about breast cancer and basically just try to change the culture of silence around breast cancer, which is a big problem in Italy” (Personal Interview, Bologna, Italy, October 27, 2008).

Figure 7.4. Excerpt from Avon Foundation's Breast Health Resource Guide

Symptoms, abnormalities and changes

Early breast cancer usually does not cause pain. In fact, when breast cancer first develops, there may be no symptoms at all. If you have any concerns or find even a small change, call your doctor. Some symptoms that may indicate breast cancer include, but are not limited to:

- Nipple discharge or tenderness
- Lumps in breast/underarm area
- Visual change, including:
 - Size of the breast, including swelling
 - Inverted nipple (which looks as though it has caved in)
 - Pitting (the skin looks like the skin of an orange) or scaling of the breast skin

Your breast health

Early detection can help save lives. There is a 97% five-year survival rate when breast cancer is caught before it spreads to other parts of the body. Follow the recommended guidelines to aid in early detection of breast cancer. If there is a history of breast cancer in your family, consult your doctor and start earlier than noted below.

Who is at risk for breast cancer recurrence?

Patients at a higher risk of recurrence include those whose cancers had previously spread to the lymph nodes and whose tumor was larger in size. Estrogen receptor status, menopausal status and family history are also factors *

Approximately one-third of women with estrogen-receptor positive early breast cancer experience a recurrence, and over half of those recurrences occur more than five years after surgery **

Reducing the risk of recurrence

Guidelines from the American Society of Clinical Oncology (ASCO), a leading physician's association, recommend that post menopausal women diagnosed with early breast cancer, use an aromatase inhibitor as treatment after 2-5 years of tamoxifen therapy to reduce the risk of tumor recurrence ***

Whether surgery was recently completed or undertaken several years ago, women concerned about ongoing risk or relapse and options that may be available should talk to their doctor

* Saphner T. Annual Hazard Rates of Recurrence for Breast Cancer after Primary Therapy. J. Clin. Oncol. 1996; 14: 2738-2746.

** Introduction and methods sections reproduced from: Early Breast Cancer Trialists' Collaborative Group "Treatment of Early Breast Cancer. Volume 1. Worldwide Evidence 1985-1990." Oxford University CTSU. <http://www.ctsu.ox.ac.uk>. Accessed: August 21, 2004.

** Goss PE, Ingle JN, Martino S, et al. Updated Analysis of the NCIC CTG MA.17 randomized placebo (P) controlled trial of letrozole (L) after five years of tamoxifen in postmenopausal women with early stage breast cancer [abstract]. Proc Am Soc Clin Oncol. 2004;23:87 [Abstract 847].

*** Winer E. American Society of Clinical Oncology Technology Assessment on the Use of Aromatase Inhibitors As Adjuvant Therapy for Postmenopausal Women With Hormone Receptor-Positive Breast Cancer: Status Report 2004. J. Clin. Oncol. 2004; 23: 1-11

According to Margarita Solice,

Young people are very excited about the opportunity to have a doctor speaking with them, without the white coat (laughs) and just like jeans and everything, and just the youngest doctors are sent to these, so that the age gap is less and they are more able to tell you about everything, I mean when you go there, you actually do clinical examinations in the classes or the young women telling you, asking you about contraceptive pills and everything. But its very nice and I think we, you can change something in the culture and the awareness, and even the fear of speaking about disease and cancer and giving them the message that you don't really have to die of cancer and that cancer is not, every time a death sentence. And if you have understood this then you will not fear to do exams for early detection and that was what was, fear was the major barrier to early detection in the study that was done by *Komen Italia* in 2003 so if you fight the fear you will have the opportunity that these people will just do what they should do and not just put their head in the sand...and yeah, that is really, I mean I think it's a nice project and the ministry does too, because they are funding us (Personal Interview, Bologna, Italy, October 27, 2008).

Through this educational campaign, *Komen Italia* is reaching very young women with the message of awareness and early detection as well as teaching them about breast self-exams and clinical exams.

In 2007 *Avon Malaysia* held a charity hi-tea event, *Saving Lives Thru' Early Detection*, as part of the WAWBC events. The funds raised by the event are being used "to finance about 25-odd breast health educational workshops at the grassroots communities in Malaysia" (Avon 2007). According to *Avon Malaysia*,

These hands-on workshops will be conducted by Breast Cancer Welfare Association (BCWA) volunteers to train women in the local communities on the importance of saving lives through early detection of breast cancer and the techniques of breast-self examinations. Those trained in these workshops will then be empowered to share the knowledge and skills with the members of their respective communities, particularly in smaller towns and rural villages (Avon Foundation 2007).

Through these educational workshops, *Avon Malaysia* is able to reach a greater number of women throughout the country, rather than only the self-selected group of women who attend their events. Again, the educational component consists of raising awareness about

the importance of early detection and teaching women how to perform breast self-exams so that they are able to understand breast health issues and teach other women about what they have learned.

Through the *Global Initiative for Breast Cancer*, SGKC advocates are working in Brazil, Costa Rica, Jordan, Mexico, Panama, Romania, Saudi Arabia, Ukraine, and the United Arab Emirates to adapt Komen's advocacy model to these countries' political and cultural realities. As part of this initiative, SGKC advocates

work with government entities and non-governmental organizations (NGOs) to educate girls and women about breast health and breast cancer through community-based training workshops. The workshops will include grassroots health educators, NGO workers, nurses, students and local community leaders. As a result, a network of dedicated, trained advocates will be put in place, armed with the tools they need to improve breast cancer outcomes (SGKC 2008).

Through this initiative, biomedical breast cancer advocates are training new biomedical breast cancer advocates, who will be equipped with information regarding early detection, breast self-exams, clinical exams, and mammography in order to develop their own awareness campaigns in their respective countries.

In addition to specific campaigns and programs designed to disseminate breast cancer information, SGKC and Avon Foundation events often also consist of an educational component. *Race for the Cure* events, for example, always entail educational presentations either the day prior to or the day of the event. The educational component of the event is often referred to as the Prevention Village, which consists of a tent, or a number of tents, where lectures are given regarding breast self-exams, clinical exams, mammograms and the importance of early detection. For example, the *Villaggio della Prevenzione* (Prevention Village), held the day before the *Race for the Cure* in Bologna, Italy, consisted of a tent with folding chairs facing a large white screen for a PowerPoint

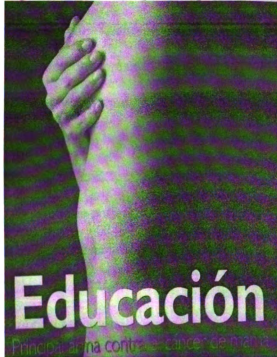
presentation. A young, female breast surgeon working with SGKC gave a presentation about breast cancer four times throughout the day, each time for an audience of about five to fifteen women. The doctor discussed the importance of early detection of breast cancer. She explained how to do breast self-exams, while pictures on the screen demonstrated what she was saying. Mammograms and clinical breast exams were also discussed with regard to the appropriate age to start having these exams and how often one should have them.

Avon events also frequently contain an educational component for the dissemination of medical information. In 2006, for example, in describing the WAWBC events in Thailand, *Avon Thailand* reported that “There were a number of activities at the event including, educational exhibition booths, like a booth demonstrating how breast cancer testing is performed” (Avon Foundation 2008). In Japan in 2006, a series of breast cancer lectures designed to raise awareness and disseminate information about breast cancer risk, self-exams, clinical exams, and mammograms “took place across the country throughout the month of October” (Avon Foundation 2007).

Finally, in addition to educational materials, lectures and workshops, biomedical breast cancer advocacy organizations also disseminate medical information through newspaper stories and television advertisements. In Italy, for example, SGKC urged *Metro*, a free daily newspaper distributed through the Italian public transit system, to run a brief “pink ribbon” article every day during October, Breast Cancer Awareness Month. The content of these articles varied from announcing and reporting on RFTC events, explaining how to do a breast self-exam, interviewing breast cancer survivors, and presenting the latest genetic, detection, and treatment breast cancer-related news. In

Puerto Rico, SGKC advertised RFTC events and encouraged the publication of breast cancer-related health information during the month of October in *El Nuevo Dia* and *El Vocero de Puerto Rico*, the two most widely-read daily newspapers in Puerto Rico. In Figure 7.5, the cover page of a special section dedicated to breast cancer in *El Vocero* is pictured. The text reads “*Educacion: Principal arma contra el cancer de mama*,” which translates to, “Education: the main weapon against breast cancer.” The special section consisted of articles about heredity and breast cancer, Puerto Rican breast cancer statistics, how to “prevent” breast cancer through monthly self-exams, annual clinical exams and mammograms.

Figure 7.5. Cover Page of a Special Section dedicated to Breast Cancer



Source: *El Vocero de Puerto Rico*, Monday, October 6, 2008

Globally expanding biomedical breast cancer advocacy organizations, therefore, are significant sources of breast cancer-related health information, disseminating medical information via their educational materials, lectures, workshops and media efforts. Given

that direct-to-consumer pharmaceutical advertising is illegal in all but a few countries, most people are not exposed to medical information directly from pharmaceutical companies. Additionally, because biomedical breast cancer advocacy organizations are expanding to many countries where breast cancer is not a health priority, public breast cancer-related health messages were often very limited or non-existent prior to the arrival of these organizations (WHO 2008). Given the dearth of breast cancer-related health information globally, biomedical breast cancer advocacy organizations' dissemination of medical information becomes even more significant.

SURVEILLANCE MEDICINE: EARLY DETECTION AS PREVENTION

According to Klawiter (2008, 87), prior to the 1970s in the US, “early detection” meant the “absence of delay in consulting a physician if ‘danger signals’ were observed by a symptomatic woman.” The doctor would refer the woman to an appropriate specialist for rapid diagnosis and, if necessary, treatment. During the 1970s, the previous regime of medicalization began its transformation into biomedicalization, altering discourse and practice around “early detection” (Klawiter 2008). The medical gaze, once reserved for symptomatic patients, refocused on asymptomatic populations and medical professionals reconfigured asymptomatic women “as permanent subjects of the disease regime” (Klawiter 2008, 87). While doctors utilized mammography, an x-ray technology that uses ionizing radiation to create images of the breast’s interior, to diagnose breast cancer in the early 1900s, it was not until the mid-1970s, that mammography began being used as a screening technology. Klawiter (2008, 95) describes this as a shift in the discourse and practice of early detection from “Do Not Delay” to “Go in Search.” It was in the 1980s in the US that breast self-examination, clinical breast exams, and screening mammograms

became the “new trilogy” of doctor-recommended breast cancer discourse and practice (Klawiter 2008, 95). This shift in early detection discourse and practice ushered in “surveillance medicine,” the “creation of *potentially* diseased persons through risk analyses of individuals, communities, and populations” (Clarke et al. 2005, 22).

The trilogy of self-examination, clinical breast exams and screening mammograms is now being promoted globally by biomedical breast cancer advocacy organizations. As discussed in the previous two sections, SGKC and the Avon Foundation in their global expansion endeavors are spreading awareness and providing medical information about the importance of breast self-exams, clinical exams and mammography. In addition to their awareness and educational messages, SGKC and the Avon Foundation also provide free breast cancer screening during their various events, programs and campaigns that are targeted to medically-underserved populations.

SGKC and the Avon Foundation’s international events almost always involve opportunities for women to receive free breast cancer-related screening. Breast cancer specialists working with SGKC or invited by the Avon Foundation attend the events to provide medical exams. Some events offer clinical exams, which involve a doctor taking a woman’s medical history and examining her breasts visually and physically. In addition to clinical exams, at many events mammograms and/or ultrasounds are also offered. This is usually possible through the use of a mobile mammography unit, as shown in Figure 7.6. These units are often donated by a pharmaceutical company, medical technology company, and/or a hospital in collaboration with SGKC or the Avon Foundation. As demonstrated by the text on side of the mobile mammography unit in Figure 7.6, the unit

at the *Race for the Cure* in Bologna, Italy was funded by *Komen Italia*, Gemmeli Hospital, and Johnson & Johnson Medical.

Emphasis is often placed on the fact that the provision of free screening at events is especially intended for underserved populations of women. For example, in 2007 *Avon China* launched a *Kiss Goodbye to Breast Cancer* program, "For Our Sisters' Health and Happiness," in 30 cities across China (Avon 2007). According to Avon Foundation's press release about the campaign,

In each city, 100 women, being jobless or with very low income, enjoyed a set of free services sponsored by Avon and the local medicine industry. The services included lectures taken by gynecologists, health consultation and examinations with the most up-to-date technologies on breast and cervix. Pamphlets on preventing breast and cervix were also spread in those cities (Avon 2007).

Similarly, in Italy, Margarita Solice, a breast surgeon working with *Komen Italia*, discussed medical screening at *Race for the Cure* events by stating,

We would like to target the kinds of people that cannot use the regular health system and also to women with the regular health system but are maybe too young to be in a screening program or that will not do it for cultural reasons so homeless people or we have these nomads that came from Russia, that now live in Italy. They have the national health system but they will not go there so we address the organizations that go to their village and maybe they will be able to take one or two or three women to us and just to reach people that normally are not reached by every other program and it seems to me that it is difficult to get these people involved, it's really difficult, that maybe they tell you ok we will come and then they don't show up. We usually also give the chance to other people just showing around they come and they will also be able to do this and in Rome since we have the opportunity to perform a lot of exams and everything we will also give people the opportunity just to phone because there are a lot of waiting lists in Italy so if they have a problem, they just phone to *Komen Italia* and we have a some, a number of exams for them if they need an appointment. But we would like to target the people that usually would not do a mammogram under normal conditions for economic or sociocultural problems.

Figure 7.6. Mobile Mammography Unit at *Race for the Cure* in Bologna, Italy



Source: Personal Photo, Race for the Cure, Bologna, Italy, October 28, 2008

As demonstrated by Margarita Solice's comments, medically underserved women, or women who fall outside of the national health program, are sought by *Komen Italia* to receive screening at their events.³¹ Despite recruiting these women for free screening, very few women, less than 40 women at each race that I attended in Bologna, utilized the free screening. Again, as Margarita Solice's statement suggests, given that free screening is available, women are held accountable for taking charge of their own breast health and should show up to take advantage of the opportunity.

In 2008 *Komen Puerto Rico*, in partnership with Doral Bank, commenced *Ruta Pink: El camino hacia detección temprano del cáncer de seno* (Pink Route: The Road to Early Breast Cancer Detection). According to Doral Bank, this community program, sponsored by *Komen Puerto Rico*, Doral Bank, *Supermercados Grande*, Ford,

³¹ Given the national healthcare coverage in Italy, if any woman who has a free screening, but lacks health insurance, finds out that she has breast cancer, she will be referred to a government hospital for treatment and her care will be covered by the government.

GlaxoSmithKline Oncology, Telemundo, and Senos de Puerto Rico, is “an effort to promote goodwill throughout the communities that we serve” {Doral Bank \, 2009 #162}.

Figure 7.7. Flyer for *Ruta Pink* in Puerto Rico



ruta pink
El camino hacia la detección temprana del cáncer de seno.

La Ruta Pink está llevando bienestar a nuestra comunidad.
Acompáñanos en este recorrido por toda la Isla donde recibirás:

- **Mamografías gratis** a mujeres mayores de 35 años sin plan médico
- Mamografías sin deducible para mujeres con plan privado o Reforma
- Referido médico para hacerte la prueba
- Charlas y materiales educativos

Visítanos en una de las 11 paradas entre junio y noviembre por las sucursales de Doral.

La detección temprana es la ruta a seguir.
Lo hacemos por tu salud. Lo hacemos por ti.

787.625.5830
www.rutapink.com

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gsk GlaxoSmithKline Oncology

Se selecciona

ford

FIDELITY

Source: Komen Puerto Rico, September 12, 2007

As described in Spanish in Figure 7.7, the program consists of a mobile mammography unit that stops in 12 communities around the island of Puerto Rico providing free mammograms to women 35 and older without health insurance, mammograms with no deductible for women with private health insurance or “Reforma”, mammography referrals so that women can schedule a mammogram at their convenience, and educational lectures and reading materials related to breast cancer.³² Since its inception in 2008, *Ruta Pink* has provided free mammograms for 1,698 women in Puerto Rico (Doral Bank 2009). In Italy if a woman is diagnosed with breast cancer based on the results of her free screening, she would be referred to a government hospital and any necessary treatment would be covered by the government. In Puerto Rico, however, this is not the case. If a woman finds out that she has breast cancer, but is uninsured, she will have to find a way to pay for any necessary treatment. In this regard, by providing free screening for underserved women in all the countries to which they expand regardless of the healthcare system, SGKC and the Avon Foundation are promoting surveillance medicine and women’s individual responsibility to submit to screening, while neglecting broader issues of healthcare coverage and access to medical treatment, which are crucial if early detection is to “save lives.”

Survivorship as the Reward for Personal Vigilance

In addition to providing free clinical exams and mammograms at many of their events and through various programs, SGKC and the Avon Foundation both uphold survivors as evidence that medical surveillance saves lives by leading to early detection. Survivors are

³² “Reforma” refers to the government-run healthcare program, *Reforma de Salud de Puerto Rico* (Puerto Rico Health Reform). This program provides medical and healthcare services to indigent and impoverished citizens of Puerto Rico through the contracting of private health insurance companies, as opposed to government-owned hospitals (Puerto Rican Department of Health 2005).

living proof of the effectiveness of routine medical surveillance. Survivors, therefore, are praised for their personal vigilance and submission to medical surveillance that led to the detection (implicitly early detection) of their cancer. At the SGKC *Race for the Cure* events in Bologna, Italy in 2007 and 2008, for example, survivors were singled out from other participants, which is typical of all RFTC events. According to Cecelia Dilleta, a *Komen Italia* RFTC organizer, *Komen Italia* recruits survivors to attend the event and sets a numerical goal of how many survivors they want to have each year (Personal Interview, Rome, Italy, October 18, 2007). Francisco Bacci elaborated, stating that

We had committed to having 2,000 participants in this first race and hopefully a sizable number of breast cancer survivors. Actually we had almost 6,000 participants in the first year and about 150 breast cancer survivors. And then from there on it's just grown, and grown, and grown every year. In 2007 we held our 8th race in Rome and we had 35,000 participants, 2,000 survivors coming from all over Italy (Personal Interview, Rome, Italy, October 16, 2007)

The survivors are an important part of these events, as they serve as proof that undergoing routine medical surveillance saves lives. At the RFTC in Bologna in 2007 and 2008, medical professionals from local hospitals and medical centers, as well as medical professionals who serve on the board of *Komen Italia*, spoke on stage after the race about the importance of early detection and how early detection saves lives. The breast cancer survivors, wearing pink shirts and baseball caps provided by Neutrogena, the official sponsor of survivors at the Race in Bologna, were seated in a special section directly in front of the stage, while other supporters and participants surrounded them in a standing section. In speaking about early detection and the importance of getting routine mammograms and performing self-exams, doctors often gestured toward the survivors while stating that they are the proof that early detection and subsequent medical intervention saves lives.

Figure 7.8. Survivor Seating Area at the Closing Ceremony after the Race



Source: Personal Photo, Race for the Cure, Bologna, Italy, October 28, 2008

Avon's *Global Connection Ribbon Tour* spreads a similar message, celebrating survivorship as evidence that awareness, early detection, and personal vigilance save lives. At the GCRT event in Malaysia, for example, the visiting survivor from Japan, who was diagnosed with breast cancer in 2004, shared her experience, ending her speech by saying "there is life after breast cancer, but you must have early detection and regular screening" (Avon Foundation 2007). Early detection, often interchanged with the term "prevention" at biomedical breast cancer advocacy events, therefore, is presented not as preventing breast cancer *per se*, but as preventing death from breast cancer.

Death from breast cancer at these events is portrayed as resulting from a lack of awareness about breast cancer, which in turn leads to late-stage diagnosis, and unnecessary, or preventable had it been caught earlier, death from breast cancer. In addition to the presence of survivors at events, stories of death from breast cancer are used to emphasize the importance of early detection. For example, at the 2008 Avon WAWBC event in Estonia, an Avon representative recounted the story of losing her mother to breast cancer, stating, "I can not stress enough, the importance of early detection to save lives" (Avon Foundation 2008).

By providing medical screening through events and campaigns and praising survivors as proof that personal vigilance with regard to regular breast cancer screening saves lives through early detection, biomedical breast cancer advocacy organizations are globally promoting a form of advocacy that upholds medical surveillance and individual responsibility as paramount in confronting breast cancer. As argued by King (2006, 104),

While breast cancer survivors are celebrated for their courage and strength within this model, their success at survivorship is seen to depend on their submission to mainstream scientific knowledge and reliance on doctors and scientists to protect them from death. They—and the public at large—are told to obtain regular screenings, demand insurance coverage for mammograms, explore a range of treatment options, and talk to other survivors, but they are discouraged from questioning the underlying structures and guiding assumptions of the cancer-industrial complex.

CREATING AT-RISK IDENTITIES

Globalizing processes of biomedicalization encompass the shift toward “surveillance medicine,” which dissolves previous categories of “healthy” and “ill” persons in favor of new categories of “at-risk-individuals, communities, and populations, using strategies of pathologization and vigilance” (Clarke et al. 2005, 22). According to Clarke and Oleson (1999, 14), “surveillance medicine is creating a new culture of risk and new burdens of health care consumption that particularly implicate women.” As the slogan on the back of the 2007 *Race for the Cure* shirts in Lansing, MI stated “The greatest risk factors for getting breast cancer are being a woman and getting older,” thereby constructing all women as being on a “risk continuum,” in which they are always at risk due to their gender, and at increasing levels of risk as they age and based on any other risk factors that they may have (Klawiter 2002).

Being “at risk” is now being transformed into “requiring biomedical prevention/intervention” (Clarke et al. 2005, 22). Processes of biomedicalization also

transform the concepts of health, risk and surveillance, bringing discourses of risk to the forefront of medical attention. Whereas processes of medicalization redefined social problems as medical illnesses, disabilities and/or diseases, processes of biomedicalization have redefined health so that the lack of symptoms does not necessarily indicate the lack of illness or potential illness. Therefore, health must be maintained through biomedical surveillance and risk assessment (Clarke et al. 2005, 446). Individuals who may otherwise appear and feel healthy are defined as “at risk” based on family history, personal behaviors, and/or results from genetic testing. Risk is then managed through “processes of surveillance, screening, and routine measurements of health indicators” (Clarke et al. 2005, 448). Through biomedical screening, breast cancer was “reinvented as an invisible risk and symptom-less disease that required continuous bodily vigilance and surveillance” (Klawiter 2008, 38). According to Klawiter (2008, 38),

Breast self-exam, clinical exam, and mammographic screening were heavily promoted and discursively constructed as the moral duty of every woman. As this occurred, the temporary sick role for symptomatic women was replaced by a permanent “risk role” for all women. Biomedicalization thus reconstituted healthy, asymptomatic women as risky subjects and transformed the disease from an either-or condition to a breast cancer continuum.

Over the past twenty-five years, biomedical breast cancer advocates have stressed the permanent “risk role” for women, emphasizing that all women are at risk for breast cancer, even though some women may be at greater risk than others. The message of the 1 in 8 lifetime risk of breast cancer is ubiquitous in the US, which is largely due to the efforts of biomedical breast cancer advocacy organizations. It is pertinent to note that most women in the US overestimate their risk of breast cancer and underestimate their risk of heart disease, diabetes, and other more prevalent diseases (Phillips et al. 1999). In order to responsibly respond to the 1 in 8 breast cancer risk statistic, women in the US


have learned the appropriate behaviors, largely due to biomedical breast cancer campaigns. Not only do women know that they are supposed to abide by the trilogy of self-exams, clinical exams, and mammograms, but they are also encouraged by reminders from SGKC and their corporate sponsors to remind other women to comply (NCI 2009). These “risk messages” are now being promoted globally by SGKC and the Avon Foundation, facilitating the creation of new “at risk” identities among women who, in many cases depending on their geographic location, may not need to be concerned about their breast cancer risk, or may have other health-related issues with which to be more concerned.

Just as in the US, SGKC and the Avon Foundation are now disseminating risk information regarding breast cancer in other countries. Figure 7.9 is an excerpt from a *Komen Puerto Rico* pamphlet about breast cancer. The page on the left in Figure 7.9 is entitled *Conceptos Basicos Sobre la Salud del Seno*, which translates to “Basic Concepts About Breast Health.” The basic concepts include information regarding breast cancer statistics, breast cancer risk, and SGKC’s recommendations for dealing with risk. The first section entitled *Conozca la realidad sobre el cancer de seno* (“Know the reality about breast cancer”) states that breast cancer is the main cause of death among Hispanic women, breast cancer is the most common form of cancer among Hispanic women, and when breast cancer is detected early, at a localized stage, chances of survival are much better than when it is detected at an advanced stage.³³ This information is followed by the section entitled *Corro el riesgo de tener cancer de seno?* (“Do I run the risk of having breast cancer?”), which states that all women run the risk of having breast cancer, that the greatest risk factor is being a woman and that risk increases with age, that many women

³³ Breast cancer is not the main cause of death among Hispanic women, heart disease is (CDC 2004)

who get breast cancer don't have any additional risk factors and that even though it is more common for women to get breast cancer after the age of 40, younger women can also get breast cancer. Finally, it mentions that while rare, men can also get breast cancer. In the next section SGKC recommends dealing with the risk of breast cancer that comes with being a woman by being vigilant when it comes to self-exams, clinical exams and mammograms in order to catch breast cancer at its earliest stage, thereby increasing the likelihood of survival. The page on the right consists of questions and answers regarding the implications of family history, alcohol use, contraceptive pills, exercise, and fibrocystic breasts for breast cancer risk. Notably, the risk factors mentioned are all individual risk factors, which in the case of alcohol use, birth control pill use, and exercise are in the woman's control. While family history and fibrocystic breasts are not within a woman's control directly, the advice given places responsibility on the woman to know her family history, discuss this history with her doctor, and seek additional medical screening if recommended. For fibrocystic breasts, which do not increase breast cancer risk but may make detecting a lump through self-exams more difficult, the advice given places the responsibility on the woman to know her breasts well, so that if a change occurs, she will be able to detect it. The provided information, therefore, defines all women as "at-risk" for breast cancer and as personally responsible for mitigating this risk by adhering to the trilogy of self-exams, clinical exams, and mammography, without reference to access to care or insurance coverage.

Figure 7.9. Breast Cancer Risk Information




Conceptos Básicos Sobre la Salud del Seno

Conozca la realidad
sobre el cáncer de seno.


- El cáncer de seno es la causa principal de muerte entre las mujeres hispanas.
- El cáncer de seno es el cáncer más común entre las mujeres hispanas.
- Cuando el cáncer de seno se detecta temprano y se limita al área del seno, las oportunidades de sobrevivir son mucho mayores.

**¿Corro el riesgo de tener
cáncer de seno?**

- Todas las mujeres corren el riesgo de tener cáncer de seno.
- El ser mujer es el factor de riesgo número uno para el cáncer de seno. Su riesgo de tener cáncer de seno aumenta con la edad.
- Muchas mujeres que han tenido cáncer de seno no tienen ningún factor adicional de riesgo.
- Aunque el cáncer de seno es más común en mujeres mayores de 40 años, las mujeres más jóvenes también pueden desarrollar cáncer de seno.
- Los hombres también pueden tener cáncer de seno pero es raro. Es aproximadamente 100 veces más común en mujeres.



susan g.
komen
FOR THE
cure



**Susan G. Komen for the Cure
recomienda lo siguiente:**

1. Hágase una mamografía (examen del seno con rayos X) cada año desde los 40 años.
 - Si usted tiene menos de 40 años, y alguien en su familia ha tenido cáncer de seno, o está preocupada por la salud de sus senos, hable con su doctor.
2. Hágase un examen clínico de los senos por su doctor o enfermera por lo menos cada 3 años desde los 20 años de edad, y cada año después de los 40 años.
3. Hágase un autoexamen del seno cada mes a partir de los 20 años de edad.
 - Familiarícese con sus senos. Infórmele a su doctor o enfermera sobre cualquier cambio.

Para más información llame al: 1-800-462-9273 o visite www.komen.org

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Source: *Komen Puerto Rico*, October 16, 2007

Figure 7.10. Excerpt from Avon Foundation's Resource Guide in Puerto Rico

WHAT EVERYONE SHOULD KNOW ABOUT BREAST CANCER

Important U.S. facts:

- Approximately 214,640 people in the U.S. will be diagnosed with invasive breast cancer this year – including 1,720 men.
- 40,970 women and 460 men will die from the disease annually.
- One person is diagnosed approximately every 3 minutes, and one person dies of breast cancer approximately every 14 minutes
- People over the age of 50 account for 77% of breast cancer cases.
- Breast cancer is the most commonly diagnosed cancer among Hispanic women and is the leading cause of cancer deaths among this group.
- Breast cancer is the most common cancer among African-American women, but ranks second to lung cancer in cause of cancer deaths.
- White, non-Hispanic women are more likely to develop breast cancer but African-American women are more likely to die from it.

Your history and habits:

All are at risk of getting breast cancer. Below are some factors that increase your risk:

- **Gender** – men can get breast cancer, but they account for only about 1% of cases.
- **Aging** – only about 5% of breast cancer diagnoses are under age 40 and approximately 18% are in their 40s, while more than three-quarters of new cases are diagnosed after age 50.
- **Menstruation and reproductive history** – risk is increased by onset of menstruation before age 12, menopause after 50, first child after 30 or no children.
- **Family history of breast cancer increases risk** – especially if close relatives are diagnosed before the age of 50. A first degree relative (mother, sister, daughter) with breast cancer approximately doubles the risk of breast cancer.
- **Diet and weight** – being overweight is linked to a higher risk of breast cancer, especially after menopause.

Sources: American Cancer Society and The National Cancer Institute.

Source: *Avon Puerto Rico*, October 16, 2007

Similarly, Figure 7.10 is an excerpt from Avon Foundation's Resource Guide, which is distributed throughout the world with every purchase of an *Avon Breast Cancer Crusade* product. This particular resource guide is distributed throughout the Caribbean in Spanish and English. The information provided is based on US breast cancer statistics with an emphasis on Hispanic women's breast cancer risk. Like the SGKC educational

pamphlet, Avon's resource guide also stresses the fact that *all* women are at risk for breast cancer, while certain women may have an increased risk based on family history of breast cancer, menstruation and reproductive history, and diet and exercise, placing all women on a breast cancer risk continuum.

CONCLUSION

In this chapter, I have argued that through the diffusion of their advocacy events, campaigns and programs, globally expanding biomedical breast cancer advocacy organizations are furthering processes of biomedicalization on a global scale. By raising awareness about early detection and disseminating medical information, biomedical breast cancer organizations are promoting surveillance medicine and creating new at-risk identities among women across the globe. Biomedical breast cancer advocacy organizations are playing a significant role in establishing a biomedical understanding of breast cancer outside of the US by engaging in awareness-raising activities and disseminating medical information about breast cancer.

This chapter demonstrates how advocacy organizations can act as agents of globalization. While most social movement literature focuses on how advocacy organizations respond to globalization, biomedical breast cancer advocacy organizations are an example of how these organizations also contribute to globalization. As shown in this chapter, biomedical breast cancer advocacy organizations are actively promoting a particular brand of health advocacy, "awareness advocacy," which is often unfamiliar to the countries within which they are expanding. In addition to spreading a specific type of health advocacy, SGKC and the Avon Foundation, through their breast cancer events, campaigns and programs, are also furthering processes of biomedicalization.

Culturally transplanting messages of breast cancer awareness, education, and screening, while not all bad, does have significant implications for processes of biomedicalization, the political economy of health and illness, and individual women. By creating new “at risk” identities among women globally and advocating for increased medical screening, biomedical breast cancer advocacy organizations are generating profits for medical institutions, as well as medical experts, who own screening technologies. Additionally, in the process of creating “at risk” identities, while promoting awareness and medical surveillance, SGKC and the Avon Foundation are expanding the market for breast cancer-related preventative pharmaceuticals and medical screening equipment, which will be discussed further in Chapter 8. As has occurred in the US, where breast cancer risk is actually relatively high compared to most of the world, the cultural transplantation of awareness and risk messages may skew women’s perceptions of their health risks and affect health priorities in countries where breast cancer may necessitate such attention. Finally, the focus on individual vigilance with regard to breast cancer risk and assessment neglects healthcare infrastructures, which may or may not, depending on the country, have the ability to properly treat breast cancer when it does occur. Providing access to free screening to medically underserved communities ignores the broader issue of why they are underserved to begin with and whether or not they will have access to treatment should they find out that they do in fact have breast cancer. Finally, this form of advocacy is globally promoting an approach to cancer that relies on the saving graces of medical technology, while ignoring issues of prevention and causes of breast cancer altogether.

Much of the literature on biomedicalization has focused on the role of medical professionals and the pharmaceutical industry in promoting processes of biomedicalization in order to monitor “at-risk” individuals, communities, and populations and increase profits, respectively. By examining the globally proliferating activities of biomedical breast cancer advocacy organizations in this chapter, I have demonstrated that biomedical advocacy organizations are also contributing to processes of biomedicalization and need to be accounted for not only by social movement scholars, but also by sociologists of health and illness interested in the global expansion of processes of biomedicalization.

CHAPTER 8

THE GLOBAL DIFFUSION OF CAUSE-RELATED MARKETING VIA BIOMEDICAL BREAST CANCER ADVOCACY ORGANIZATIONS

While I focused on biomedical breast cancer advocacy organizations' promotion of individual responsibility to "take charge" of one's health by submitting to surveillance medicine in Chapter 7, in this chapter I address the organizations' promotion of individual and corporate responsibility to raise funds in support of biomedical breast cancer research and treatment. Focusing on cause-related marketing, the predominant form of fundraising that SGKC and the Avon Foundation are expanding internationally, I argue that biomedical breast cancer advocacy organizations are globally expanding a hybrid form of "corporate advocacy" that relies on the participation of "consumer advocates." While this form of advocacy, having been promoted by SGKC and the Avon Foundation for over 20 years, has become ubiquitous in the US as an increasing number of corporations adopt cause-related marketing strategies, it is often being introduced into other countries for the first time, or at least at an early stage in its development.

Further, I argue that the global promotion of this form of corporate advocacy is significant within the global political economy of health and illness because it champions corporatized and individualized solutions to health-related problems. The global expansion of cause-related marketing and corporate-advocate partnerships as new forms of health advocacy that create corporate-advocate and consumer-advocate identities is significant in that it detracts from health advocacy aimed at reforming healthcare systems, problematizing unequal access to care, and questioning the causes of diseases. Instead, corporate advocacy, via cause-related marketing campaigns, raises money for a specific disease, based on the participation of consumer-advocates, who through their

engagement in corporate-sponsored events (i.e., by paying a registration fee) and their purchase of designated products fund these endeavors.

While SGKC and the Avon Foundation are not in the business of cutting public expenditures on healthcare, their approach to breast cancer advocacy complements neoliberal agendas by proposing corporate (advocacy) and individual (consumer) solutions to breast cancer. As defined by King (2006, xxvi), neoliberalism is “a philosophy and a set of economic and political policies aimed at cutting expenditures on public goods such as education, healthcare, and income assistance in order to enhance corporate profit rates.” The exclusively biomedical approach to breast cancer advocacy being promoted by SGKC and the Avon Foundation potentially enhances corporate profit rates. In addition to benefits that accrue to companies, including the Avon Company, the final section of this chapter addresses the allocation of funds raised through fundraising events and cause-related marketing internationally demonstrating that medical researchers, cancer research centers, pharmaceutical and medical technology companies benefit.

A BRIEF HISTORY OF CAUSE-RELATED MARKETING

Cause-related marketing emerged in the mid-1980s as a strategic marketing tool for differentiating a brand and adding value to it (Pringle 1999). According to Carol Cone, founder and CEO of Cone Communications, “Companies and brands associate themselves with a cause as a means to build the reputation of a brand, increase profit, develop employee loyalty to the company, and add to their reputation as good corporate citizens” (Carol Cone as quoted in King 2006, 9). According to King (2006, 9), since the 1990s, cause-related marketing has

evolved from what were mostly relatively short-term commitments of one- or two-month promotions with a charitable organization at the end of which the corporation donated a portion of its profits—to major long-term commitments to an issue through an alliance that links the company or brand name with the issue in the consumer's mind.

Given the state of competition among companies, in addition to trying to gain an edge by cutting prices, increasing advertising, and improving technology, a growing number of companies are utilizing long-term cause-related marketing strategies to “attract the attention and loyalty of the consumer, who is understood to be increasingly adept at reading marketing messages and dissecting the meaning and symbolism of any particular commercial or advertisement” (Pringle 1999, 12).

Cause-related marketing campaigns have been proliferating in the US since the early 1990s. In addition to breast cancer cause-related marketing campaigns, there are similar campaigns for diabetes, heart disease in women, multiple sclerosis, and ovarian cancer, just to name a few. While cause-related marketing is becoming increasingly common in the US, forcing brands to compete more aggressively for brand recognition and customer loyalty, cause-related marketing campaigns are in the early stages of expanding internationally (King 2006). According to King (2006, 10), “in so-called developing markets the priority for marketers and brands is to achieve rapid gains in consumer ‘penetration’ and market share.” Therefore, while companies promoting cause-related marketing campaigns in the US may only hope to secure customer loyalty, in developing markets “the battle is all about acquiring new customers before the competition does” (Pringle 1999, 14).

Although cause-related marketing campaigns around a variety of issues exist in the US, breast cancer is often singled out as being an ideal cause. Marketing experts have

“labeled breast cancer ‘a dream cause’ and pointed to the success of corporate campaigns against the disease as a way to encourage other companies to pursue cause-related marketing” (King 2006, 14). According to King (2006, 111),

Breast cancer became a philanthropic cause par excellence not simply because of effective political organizing at the grassroots level, but because of an informal alliance of large corporations (particularly pharmaceutical companies, mammography equipment manufacturers, and cosmetics producers), major cancer charities, the state, and the media that emerged at around the same time and was able to capitalize on growing public interest in the disease.

The “popularity” of breast cancer among corporations has produced “intense competition as corporations struggle, in the words of Avon’s Joanne Mazurki, “to gain ownership over the issue” (King 2006, 14).

Both SGKC and the Avon Foundation are noted for being particularly adept at marketing breast cancer. Nancy Brinker is often credited with pioneering cause-related marketing, as demonstrated in the following excerpt from *TIME Magazine*’s article on the “100 Most Influential People,”

Not only did Ambassador Brinker found the organization that has become synonymous with breast cancer globally, she brought the disease out of the shadows of secrecy and shame in large part by launching Komen for the Cure’s well-known and emulated Susan G. Komen Race for the Cure Series®, the world’s largest and most successful education and fundraising event for a charity and *the precursor to the booming cause-related marketing movement*. Susan G. Komen for the Cure is *known as a pioneer in the cause-related marketing industry, and thanks to Ambassador Brinker’s pioneering efforts, the organization boasts partnerships with more than 170 companies*” (my emphasis, SGKC 2008).

Similarly, as emphasized by Gabriella Lopez at Avon Puerto Rico,

As a tagline of our Company we say we are the company for women because [breast cancer] is a disease that is affecting mostly women so they [Avon Foundation] adopt that. And [Avon] was *the first company I think that start with this movement* of awareness and doing something to increase the awareness of breast cancer and *raising money and everything like that* (my emphasis, Personal Interview, Caguas, Puerto Rico, September 14, 2007).

Given the strong histories and successes that SGKC and the Avon Foundation have had with cause-related marketing in the US, it is not surprising that these two organizations in particular would lead the way toward cause-related marketing campaigns on an international scale.

GLOBAL EXPANSION OF CAUSE-RELATED MARKETING

Walking down store-lined streets and browsing grocery stores, coffee shops, drug stores, department stores and boutiques in Rome and Bologna, Italy and San Juan, Puerto Rico during September and October of 2007 and 2008 differed drastically from my experience with the ever-proliferating pink products lining the shelves in a variety of stores in the US during Breast Cancer Awareness Month (BCAM). During October in the US, without purposely seeking pink products, I am routinely inundated with cause-related marketing campaigns promoting the purchase of food, wine, tea, clothing, cosmetics, cars, and airline tickets, just to name a few, as a form of corporate- and consumer-advocacy, to benefit biomedical breast cancer research. Based on my research experience in Puerto Rico and Italy as well as documentary analysis, cause-related marketing is not nearly as prevalent internationally as it is in the US, although it seems to be gaining ground quickly particularly in Western European countries, and biomedical breast cancer advocacy organizations are often at the forefront of cause-related marketing campaigns globally.

SGKC and the Avon Foundation, with very few cultural adaptations, are expanding their cause-related marketing campaigns internationally. The Avon Company incorporates cause-related marketing in their product brochures, expanding their cause-related marketing of breast cancer products to over 50 countries.

Figure 8.1. Avon Breast Cancer Crusade Products



Cruzada contra el cáncer del seno

Únase a la lucha para ayudar a combatir el cáncer del seno
Desde el año 2000, en Puerto Rico se ha recaudado y donado la suma de \$190,238 a la Sociedad Americana del Cáncer, Capítulo de Puerto Rico, para su programa de mamografías a bajo costo, a mujeres de escasos recursos económicos.

El 100% de la venta neta se donará a la Cruzada Avon Contra el Cáncer del Seno.

*Con la compra de 2 productos del Cáncer del Seno recibirá el **Breast Health Resource Guide**.* (Guía para la Salud del Seno), con valiosa información sobre cómo conservar la salud del seno.*

**Cantidades limitadas mientras duren.*



NUEVO

BREAST CANCER CRUSADE LOCKET NECKLACE
 Precioso colgante con un foto de la familia que siempre recordará. Se puede cambiar una foto. Cadena de 17" (incluye extensión de 3").

Demo: 5.00

Suaviza y protege tus labios

NUEVO



Humectante labial
AVON BREAST CANCER CRUSADE
Moisturizing Lip Treatment with SPF 15
 Humecta sus labios y los protege del sol. Peso neto 1.5 oz. 607-573

Demo: 99c

Suaviza e hidrata mientras duerme



APLIQUE EL TRATAMIENTO
FOOT WORKS Overnight Treatment
 Tratamiento intensivo que hidrata sus pies mientras duerme. Suaviza la piel. Algodón 4.4 oz. 695-394

Demo: 4.99

USE LAS MEDIAS POR LA NOCHE PARA SELLAR LA HUMECTACIÓN CRUSADE SOCKS
 Medias. Se lavan a máquina. De algodón 100% transpirables. Para mujeres de tallas 9-11. 491-926

Demo: 1.99



Únete a la Marcha Por Una Causa 2007 de la Sociedad Americana del Cáncer de Puerto Rico, a llevarse a cabo el sábado 6 de octubre a partir de las 3:00 p.m. en el Parque del Tercer Milenio en Puerta de Tierra, San Juan.
¡Contamos contigo!

Qué Hay de Nuevo C-21-07

Avon Products, Inc.

026.0007 97810

Source: Avon Puerto Rico, October 14, 2007

Figure 8.1 is an example of the breast cancer crusade page in Avon brochures. These products are featured in the brochures during four campaigns throughout the year, and this is consistent in all countries where Avon sells its products. The products are mostly

the same, but are described in the country's native language. The campaign not only consists of the selling of the products by Avon representatives via the brochure. The Avon Foundation also launches a media campaign to promote the breast cancer-related products. Rather than advertising through the Avon Company, the Avon Foundation is often able to receive media coverage free of cost or at a reduced cost given the organization's non-profit status. As explained by Gabriella Lopez,

We also made a media tour that started last week. We start a month early because the brochure starts in October, but these [What's New] brochures start one month early. We have representatives with already this brochure in their hands so we wanted to start the campaign really early in the media so they can deliver the products, or we have customers that asked for, I saw the product on the TV and do you have it, yes I have it. Not to wait to October to have that. So that's the same thing with this commercial, we are going to be on air the last two weeks of September and the first two weeks of October, because these brochures are out. So we were on the radio and in morning news and we also started receiving some coverage in the media in beauty magazines, they are going to be showing some images of the products in October (Personal Interview, Caguas, Puerto Rico, September 14, 2007).

The Avon Breast Cancer Crusade, therefore, draws media attention for the Avon Company, emphasizing the Company's commitment to women based on its "corporate advocacy." While companies, including Avon, engaging in cause-related marketing campaigns hope to bolster their profit via increased brand recognition and loyalty, the funds garnered through the sale of breast cancer products usually benefit a breast cancer NGO, allowing consumers to feel good about their purchases.³⁴

In addition to Avon's cause-related marketing campaigns in Puerto Rico, *Komen Puerto Rico* is also expanding cause-related marketing efforts on the island. As shown in Figure 8.2, *Komen Puerto Rico* and Mazola developed a corporate-advocate partnership through SGKC's *Bake for the Cure* campaign. The advertisement, appearing during

³⁴ Specifics about the allocation of funds will be discussed in a later section of this chapter.

Breast Cancer Awareness Month in *El Nueva Dia* presents *Komen Puerto Rico* and Mazola as “united” in the fight against breast cancer, an example of corporate advocacy.

Figure 8.2. Mazola Cause-Related Marketing Advertisement in Puerto Rico*



Source: *El Nuevo Dia*, San Juan, Puerto Rico, Wednesday, October 1, 2008

*The text in the advertisement reads, *Podemos! Unete a Mazola en la Lucha Contra el Cancer del Seno. Este año donaremos \$250,000 a la fundación Susan G. Komen for the Cure. Juntos hacemos la diferencia. Bake for the Cure benefits Susan G. Komen for the Cure. www.bakefortheure.com. This translates to We Can! Unite with Mazola in the fight against breast cancer. This year we are donating \$250,000 to the foundation Susan G. Komen for the Cure. Together we can make the difference.*

In Italy, cause-related marketing is beginning to take off as well, primarily due to the efforts of *Komen Italia*. Rather than reinventing the wheel, *Komen Italia* began introducing breast cancer cause-related marketing campaigns in Italy in partnership with

multinational corporations that were already engaging in cause-related marketing campaigns with SGKC in the US. According to Rosa Valentino,

We started with a project with KitchenAid as in the US, with a big blender, it's one of these multi-function blenders for the kitchen and I think it costs 299 euro, and for each blender sold, we get 99 euros (Personal Interview, Rome, Italy, October 15, 2007).

In Italy, breast cancer NGOs not engaging in cause-related marketing campaigns often have trouble staying afloat, while *Komen Italia*, since its inception in 2000, has taken off, becoming financially stable and even expanding beyond Rome to Bologna and Bari in 2007. As Celia Barolo, a member of *Europa Donna* in Italy stated,

It is very, very difficult right now to have enough money to be present because in Italy, in Europe, but mainly in Italy, we don't have a public, we don't have an individual, or citizen feeling to give to the association.... This is different from America. In America it is normal that you send money to somebody, you must trust of course, but it's normal for you. In Italy, no. It's very very difficult. You can collect money if you organize a big event, so the Komen race is an example, but at the beginning it was very, very difficult, but now it is the seventh or eighth edition, by now its becoming different. But it took time, and time, and time. So it's difficult for a small organization to have enough money to be present where you must be present (Personal Interview, Rome, Italy, October 16, 2007).

As this statement demonstrates, SGKC's forms of advocacy were not familiar to many Italians at first. Multiple people with whom I spoke in Italy explained to me that the non-profit sector, and the notion of donating money to an organization, like a breast cancer non-profit, is foreign to Italians, and only recently gaining legitimacy. Celia Barolo said this is because in Italy, unlike in the US, Italians can rely on, or at least historically have been able to rely on, their government for basic services like healthcare and education. Therefore, the concept of donating money to a non-profit to help with these types of needs seemed unnecessary. Nevertheless, given that SGKC has extensive financial resources, rather than altering its form of corporate advocacy to culturally "fit" in Italy, it

held *Race for the Cure* fundraising events annually and promoted cause-related marketing campaigns, and over time, and a relatively short amount of time at that, they became successful in Italy, normalizing a new form of corporate advocacy reliant on the participation of consumer advocates.

RESPONSES TO CAUSE-RELATED MARKETING AS A NEW FORM OF ADVOCACY

Given the introduction and early successes of breast cancer cause-related marketing in Puerto Rico and Italy, it would seem that other breast cancer organizations might model cause-related marketing fundraising strategies. My findings indicate that while corporations are likely to jump on the cause-related marketing bandwagon, some governmental and non-governmental organizations have had mixed responses. For example, *Europa Donna*, the pan-European breast cancer advocacy organization, has not chosen to emulate SGKC's form of fundraising advocacy, despite acknowledging *Komen Italia*'s success in promoting this form of advocacy in Italy. According to Celia Barolo, this is because the organizations are fundamentally different in their approaches to breast cancer. As she maintained,

They [*Komen Italia* and *Europa Donna*] are two very different kinds of work, of course the main objective is to make more and more curable breast cancer, but of course, ending breast cancer is the goal of everyone who works in this field, but how we work is absolutely different because one is an advocacy movement, *Europa Donna* is an advocacy movement, for advocacy and lobbying and *Komen* is a raising funds movement. And of course the breast cancer problems and issues are in the program of the *Komen* but how they reach some result is absolutely different because we want to reach a result in a way of the thinking of the people of, of the women. As *Europa Donna* we want to push the politicians to do something in favor of women, to increase the diffusion of the public breast cancer screening program for example. In our country, the screening program, the public screening program covers 60 percent of the Italian territory, but only for the women aged 50 to 69 with the biannual mammography because we adopted the breast cancer screening program project from Northern Europe, from Norway, from Sweden, and so on (Personal Interview, Rome, Italy, October 16, 2007).

Europa Donna, therefore, does not direct its energy toward fundraising for breast cancer, as *Komen Italia* does. Rather, members of *Europa Donna* describe themselves as “advocates” and “lobbyists” working to reform national healthcare coverage and improve the national screening program. They thereby distinguish their organization as a true advocacy organization, different from *Komen Italia*, which they refer to as a fundraising movement.

While some breast cancer NGOs may not pursue cause-related marketing, other organizations are following suit, developing their own corporate-advocate campaigns. The *Lega Italiana per la Lotta contro i Tumori* (LILT), an Italian anti-cancer governmental organization run by the Italian Department of Health recently began engaging in cause-related marketing campaigns. As Rosa Valentino of *Komen Italia* put it,

In Italy there's a big campaign [during Breast Cancer Awareness Month] with the LILT, *Lega Italiana per la Lotta contro i Tumori*. It is another national association and they made in October a program with Estee Lauder. I think it is the same in the US, a pink ribbon campaign (Personal Interview, Rome, Italy, October 15, 2007).

A store front advertisement from the cause-related marketing partnership between LILT and Estee Lauder is pictured in Figure 8.3. The main text in the advertisement reads *Mondo Rosa: Un Mondo Senza Cancro al Seno*, which translates to “Pink World: A World without Breast Cancer.” By including information about the organization next to the products for sale, which are also pink and have the breast cancer pink ribbon on them, corporate advocacy is demonstrated. Consumers who purchase this product, then, become consumer advocates, by utilizing their consumption to financially benefit a cause.

Figure 8.3. LILT and Estee Lauder Cause-Related Marketing Campaign in Italy



Source: Personal Photo, Rome, Italy, October 2008

SGKC's and Avon Foundation's cause-related marketing campaigns are rapidly expanding internationally, particularly as an increasing number of corporations are participating in cause-related marketing initiatives. *Komen Italia*, for example, solicits new companies each year, increasing the number of corporate sponsors for their events and breast cancer cause-related marketing campaigns that support their organization. For example, Rosa Valentino described the organization's arrangement with a new corporate sponsor,

We have another new sponsor, Stardust, it's an Italian [cosmetics] company, and they're sponsor of the races, and also with them we make a social marketed project because every month they choose two of their products and 0.50 euro of each product sold goes to Komen, for one year. And right now we raised something like 15,000 euro with these products (Personal Interview, Rome, Italy, October 15, 2007).

While it was relatively rare, in comparison to the US, to encounter cause-related marketing campaigns in Italy, while in Bologna, I came across Sosushi, an Italian sushi restaurant that was a sponsor of the Bologna *Race for the Cure* and also engaged in cause-related marketing by providing a “menu rosa,” or “pink menu,” as shown in Figure 8.4, donating two euro to *Komen Italia* from each sale of an item on the menu rosa. As a relatively new restaurant, launched in multiple locations in Italy in 2006, Sosushi was having a difficult time introducing Japanese food into the Italian diet (Cecelia Dilletta, Personal Interview, October 18, 2007). Because of this, the owners of Sosushi were seeking ways to connect with Italians and bring new customers into the restaurants to at least try sushi. Partnering with *Komen Italia* provided Sosushi with an opportunity to draw women into their restaurant through their cause-related marketing campaign, which according to the text on Sosushi’s menu demonstrates the restaurant’s commitment to women through its partnership with *Komen Italia*, and then emphasizing the health benefits of sushi, particularly for women concerned with a healthy diet once women are willing to try it.

sosushi test

il primo sushi test italiano
per la prevenzione dei tumori al seno

il sosushi test è un'attività di fund raising che si svolge in tutta Italia, in occasione della Giornata Nazionale del Tumore al Seno (11 settembre).

il sosushi test è un'attività di fund raising che si svolge in tutta Italia, in occasione della Giornata Nazionale del Tumore al Seno (11 settembre).

bologna lab1
via F. Testi 1 - Bologna
tel. 051/2611111
11.30-14.30
18.30-22.30

bologna lab2
via S. Giacomo 1 - Bologna
tel. 051/2611111
11.30-14.30
18.30-22.30

menu rosa



scegliendo il menu rosa

aiuti a sostenere la Komen Italia Onlus

sosushi donerà 2€ per ogni menu rosa acquistato

con i fondi verranno realizzati progetti per la lotta contro i tumori al seno


sosushi for women

"sosushi e Komen Italia insieme per la lotta contro i tumori del seno"

sosushi, da sempre vicino all'universo femminile, alla sua sensibilità e al suo gusto, ha deciso di scendere in campo a favore della Komen Italia Onlus (www.komen.it), associazione operativa in tutto il mondo, affermatasi nel tempo per la sua grande serietà ed il suo impegno concreto nella prevenzione e nella lotta contro i tumori al seno, malattia che in Italia colpisce ogni anno 36.000 donne.

Il team di sosushi con numerose iniziative di fund raising, come il Menù Rosa e cene di beneficenza, donerà almeno 10.000 euro entro il 1 settembre 2009 all'associazione.

Inoltre sosushi, sostenendo e sponsorizzando la "Race for the Cure", maratona che la Komen Italia organizza ogni anno a Roma, Bari ed ora anche a Bologna (il 28 di settembre ai Giardini Margherita), si impegna, dimostrandosi partner amico e sensibile, a divulgarne il messaggio e le importanti attività svolte dall'associazione.



sosushi.it

*The translation of text in the upper half of the advertisement reads: Sosushi Test. You've never tasted sushi? Aren't you curious? Present this coupon at the Sosushi laboratory in Bologna. Taste our specialty while helping *Komen Italia*. This way you can eat eat, eat Sosushi and in doing so make an important contribution to women's health! By choosing an item from the pink menu, you help support *Komen Italia*.

Sosushi donates 2 euros for every pink menu item purchased. The funds support projects in the struggle against breast cancer. The translation of the lower half of the text reads: Sosushi and *Komen Italia* are working together in the struggle against breast cancer. Sosushi, always in touch with the feminine universe, decided to make a concrete effort on the ground for *Komen Italia* (www.komen.it), an association that operates all over the world, known for its concrete engagement for the prevention of and in the struggle against breast cancer, an illness that affects 36,000 women a year in Italy. The team of Sosushi, with numerous fundraising initiatives, like the Pink Menu and charity dinners, will donate at least 10,000 euros to Komen Italia by September 1, 2009. Besides Sosushi supporting and sponsoring the “Race for the Cure” run that Komen Italia organizes every year in Rome, Bari, and now in Bologna (on September 28th in the Margharita Gardens), we have also pledged, as a sensitive partner and friend to the association, to spread the important message of Komen Italia.

SGKC and the Avon Foundation are, of course, not only expanding cause-related marketing in Italy and Puerto Rico. Breast cancer cause-related marketing campaigns are developing all over the world through these organizations. For example, in Bulgaria,

Popular television star, Natalia Simeonova was announced as *Avon Bulgaria*’s new breast cancer crusade spokesperson, and she introduced the alliance between Avon and United Colors of Benetton in creating a pink t-shirt to benefit the breast cancer cause (Avon Foundation 2007).

Additionally, *Avon India* reported tremendous success with its *Kiss Goodbye to Breast Cancer* campaign in 2005. According to the organization’s website, “The month-long campaign in 2005 raised over 5,000 US dollars, selling more than 90,000 lipsticks” (Avon Foundation 2006). SGKC, rather than directly initiating cause-related marketing campaigns in countries without SGKC affiliates, teaches advocates about Komen’s brand of advocacy via the *Course for the Cure*, which is currently active in ten countries.

According to Sara Friedman of SGKC, the *Course for the Cure*

has a fundraising component, talking about how they can learn to raise funds through you know, connecting events, doing corporate sponsorship, grant writing, and *cause-related marketing campaigns, of course* (my emphasis, Telephone Interview, November 16, 2008).

Therefore, while cause-related marketing may be culturally unfamiliar at first and may still be shunned as a lesser form of advocacy by some NGOs, SGKC and the Avon

Foundation are largely experiencing success in transplanting cause-related marketing advocacy strategies internationally.

GLOBAL PROLIFERATION OF BREAST CANCER CAUSE-RELATED MARKETING

Although in some countries, SGKC and the Avon Foundation are directly involved in leading the cause-related marketing trend, in other countries, particularly Western European countries, companies and other breast cancer NGOs have adopted this trend from US breast cancer organizations on their own. As Kathleen McDonald, an advocate with *Europa Donna* in Ireland, described Breast Cancer Awareness Month in Ireland,

There are all sorts of things happening now, you have, like one of our department stores had a pink party and they had a whole lot of pink things, everything from balloons decorating the place in pink to pink night dresses, pink purses, pink gloves, pink umbrellas, and you see this all over the place and sometimes it might be to raise funds for the Cancer Society, other times it might be for the Mary Kettering Foundation, but there is a plethora of these kinds of things that different companies initiate and every year seems to spawn a few more and they all seem to have the basic...of something in pink (Telephone Interview, October 15, 2008).

As her description shows, while SGKC and the Avon Foundation pioneered cause-related marketing in the US and are directly expanding it as an advocacy technique globally, in some cases corporations have adopted the marketing technique without urging from these organizations.

Another example of such marketing is the international expansion of Fashion Targets Breast Cancer (FTBC). Fashion Targets Breast Cancer is an NGO founded by the Council of Fashion Designers of America (CFDA) in the US in 1994. According to the organization's literature,

Fashion Targets Breast Cancer is the U.S. fashion industry's response to breast cancer - a widely recognized effort that raises public awareness and funds to

support breast cancer research, education, screening and patient care. The campaign has become an ongoing initiative of the CFDA Foundations - the philanthropic division of the Council of Fashion Designers of America (CFDA), which represents over 300 of America's leading fashion designers. *Since its launch, Fashion Targets Breast Cancer has become the worldwide fashion community's singular and most successful response to breast cancer - an issue of vital importance to its primary consumers: women* (my emphasis, FTBC 2009).

Like other companies that engage in breast cancer cause-related marketing, the CFDA recognizes breast cancer as an important issue to its largely female consumer-base.

Although the US fashion industry developed FTBC, given the global nature of corporations, it was in the interest of the fashion designers, who sell their clothes internationally, to extend the FTBC campaign to other countries. To do this,

The CFDA Foundation licenses the Fashion Targets Breast Cancer name and logo to leading breast cancer organizations in individual countries. The CFDA Foundation recommends that approximately one-third of the proceeds from merchandise sales accrue to the charity beneficiary (FTBC 2009).

FTBC campaigns currently operate in about ten countries, promoting cause-related marketing to raise funds for breast cancer during BCAM (FTBC 2009). Table 8.1 delineates the international expansion of FTBC. Through this expansion, FTBC, like SGKC and the Avon Foundation, is globally expanding a form of corporate- and consumer-based breast cancer advocacy, which is an unfamiliar concept in many countries. For example, FTBC unsuccessfully launched its campaign in Japan in 2003, as stated by the NGO on their website,

FTBC Japan was launched in the spring of 2003, featuring world renowned model, Ai Tominaga, and benefiting the Japan Cancer Society. *At the time, the concept of philanthropic sales of merchandise was new to Japan. However, in recent years, Japanese women have begun to embrace this new approach to a public health concern* (my emphasis, FTBC 2009).

While the FTBC cancelled the campaign after the unsuccessful 2003 launch, it was re-launched in 2008 as there seemed to be a shift in which Japanese women, unsupportive of this unfamiliar form of advocacy only a few years ago, are now more receptive to it. Part of the reason for this shift in acceptance may have been the increasing cause-related marketing activities of the Avon Foundation in Japan from 2005 to 2008, with their *Walk Around the World for Breast Cancer* events and cause-related marketing campaigns. Perhaps, as in Italy where *Komen Italia*'s brand of corporate advocacy was initially foreign, but increasingly accepted with repeated exposure, Japanese women have adapted to this "new approach to a public health concern" (FTBC 2009).

Table 8.1. International Expansion of Fashion Targets Breast Cancer Cause-Related Marketing Campaign*

Country	Year Established	Funds Raised	Allocation of Funds
United States	1994	\$40 million raised by all campaigns (US and international) combined	Not specified
Brazil	1995	Not specified	Instituto Brasileiro de Controlo do Cancer (IBCC)
United Kingdom	1996	9.5 million pounds	Breakthrough Breast Cancer-a breast cancer NGO
Canada	2001	\$750,000 (as of 2006)	Rethink Breast Cancer-innovative breast cancer education, research and support programs

Table 8.1 (Continued)

Greece	2001	Not specified	Inaugurated a Breast Cancer Centre dedicated to provide free breast cancer screening to women ages 45-64. All running costs, salaries and equipment are funded by FTBC Greece. The next goal is to equip the Center with a state-of-the-art Digital Mammography Unit.
Japan	2003 (cancelled due to lack of interest and re-launched in 2008)	Not specified	Japan Cancer Society; free mammograms at launch of FTBC event; raise public awareness support breast cancer research, education, screening and patient care in Japan
Ireland	2005	287,000 euro (as of 2007)	Irish Cancer Society and <i>Europa Donna</i> Ireland
Australia	2005	\$20 million	Support new research into young women diagnosed with breast cancer
Portugal	2006	500,000 euro	Funding the fight against breast cancer in Portugal

Source: Fashion Targets Breast Cancer (FTBC 2009)

*Turkey and Cyprus were also mentioned on the website as having FTBC programs, but no specifics were provided.

Therefore, in addition to the efforts of SGKÇ and the Avon Foundation, other organizations and corporations are implementing cause-related marketing campaigns internationally. Although corporate advocacy is at times initially culturally unfamiliar, as cause-related marketing strategies proliferate and persist, it seems that these campaigns

are becoming successful even in countries where they initially faltered only a few years ago.

THE ALLOCATION OF FUNDS

While cause-related marketing campaigns benefit participating corporations by developing brand recognition and loyalty, potentially increasing their profit, a portion of funds amassed through corporate advocacy are allocated to “support the cause” in some way. I found that the allocation of breast-cancer related cause-marketing funds largely benefit established biomedical NGOs as well as medical researchers, pharmaceutical and medical technology companies, and cancer research centers, thereby strengthening the biomedical approach to breast cancer.

Although a variety of NGOs addressing breast cancer often exist within a country, the larger, more well-established NGOs receive more funding from cause-related marketing campaigns. As described by Gabriella Lopez, the Avon representative in charge of the breast cancer crusade at *Avon Puerto Rico*,

So they [Avon associates] receive this brochure and they can order products from here so they have a way to demo to the customers and we also include the breast cancer products right over here. We have plenty of products, necklaces, lip balm, um, overnight treatment for the foots [sic], fragrance and socks. One hundred percent of the net income of these products is going to the breast cancer crusade and then this money stays in Puerto Rico. We donate this money to *Sociedad Americana del Cancer* and this year we are adding one, another organization, and that is Susan G. Komen (Personal Interview, Caguas, Puerto Rico, September 14, 2007).

While smaller breast cancer NGOs, such as *Mujeres sin Tiempo*, that provide patient services, such as transportation to and from doctor’s appointments or chemotherapy, advice regarding healthcare coverage, and individual and family counseling services, exist in Puerto Rico, the Avon Foundation donates funds to the two largest and most

financially successful breast cancer-related non-profits, namely the American Cancer Society of Puerto Rico and, more recently, *Komen Puerto Rico*. Gabriella Lopez explained the selection of organizations as based on the organizations' ability to improve the lives of individual women who are confronting breast cancer. In her words,

With this money the American Cancer Society, they have a program that they use the money to give mammographies [mammograms] to women that ask for it. They have five offices around the island and the person, the only thing that she needs to do is go to his [her] doctor, the doctor gave the order to make the mammography, and then she with that order go to the American Cancer Society, they give you like a check or coupon and then she goes with that coupon back, it's the way that she pays to do the mammography (Personal Interview, Caguas, Puerto Rico, September 14, 2007).

Although the American Cancer Society of Puerto Rico provides access to free screening for Puerto Rican women, they do not actually provide services to women who have breast cancer. Gabriella Lopez specifically stated that the Avon Foundation did not previously donate to *Komen Puerto Rico* because Komen mainly funds medical research, which does not immediately help women who have breast cancer. Despite this comment, she said that they do not donate to smaller organizations because these organizations do not have the resources to help women as much as do the larger organizations, reinforcing the financial success of elite organizations at the expense of grassroots organizations. Breast cancer NGOs like *Mujeres sin Tiempo* in Puerto Rico and *Europa Donna* have trouble financially sustaining themselves and may not attract large donations due to lack of status and name-recognition, as with *Mujeres sin Tiempo*, or because of cultural norms that are not conducive to donating to NGOs, as with *Europa Donna* in Italy.

Table 8.2. Avon Foundation's and SGKC's Allocation of Funds Internationally

Organization	Country	Allocation of Funds
Avon	Argentina	Purchase of mobile mammography unit; Donation to local NGO to maintain and operate the unit
Avon	Australia	Local NGOs; Clinical trial research program; Community support through exercise and counseling
Avon	Bosnia	Purchase of digital mammography machine for a medical clinic
Avon	Canada	Donation to local NGO
Avon	Czech Republic	Donation to local NGOs for screening tests, rehabilitation treatment, purchase of medical devices, educational brochures, and to help fund the operation of a toll-free breast cancer help line
Avon	Dominican Republic	Donation to local NGOs for early detection tests, medical treatment, and support groups for underserved cancer patients; Donation to hospitals that provide care for cancer patients
Avon	Ecuador	Donation to local NGO; Purchase of early detection equipment for medical centers
Avon	El Salvador	Funds to equip a pathology lab; Funds to provide care for low-income cancer patients
Avon	El Salvador	Donation to the National Cancer League
Avon	Estonia	Donation to local NGO; purchase of new mammography bus; Funding for breast cancer detection and treatment;
Avon	Finland	Donation to local NGO; Funding for medical research
Avon	France	Donation to breast cancer research center; Funding for medical research
Avon	Germany	Donation to local cancer society for help for breast cancer patients who need financial assistance; Donation to local NGO
Avon	Greece	Purchase of mobile mammography unit
Avon	Guatemala	Donation to National Cancer Society
Avon	Hungary	Donation to the National Health Service and a local NGO; Purchase of mobile mammography van and surgical equipment for medical centers and institutions including the National Oncology Institution, Szent Istvan Hospital and the National Medical Center, Uzsoki Hospital; Funding for breast reconstruction operations
Avon	India	Donation to the Cancer Patients Aid Association for the purchase of a van and free shuttle service for cancer patients
Avon	Italy	Donation to the European Institute of Oncology
Avon	Latvia	Donation of gamma detector equipment to the Latvia Oncology Center
Avon	Lithuania	Donation of mammography machine to the National Institute of Oncology; Donation to the Vilius University Oncology Institute to purchase equipment for breast cancer diagnosis
Avon	Macedonia	Free breast exams throughout Avon events
Avon	Malaysia	Creation of breast prosthesis fund at the University Malay Medical Center; Donated a Breast Cancer Resource Center to the University Malay Medical Center; Donation to the Breast Cancer Welfare Association; Funding of 25 health education workshops

Table 8.2 (Continued)

Avon	Mexico	Donation to a wide range of institutes that provide support for cancer research, treatment, and early detection programs
Avon	Oman	Donation to the National Association for Cancer Awareness
Avon	Philippines	Upgraded breast care services at various provincial hospitals and Manila's Philippine General Hospital; Donation to PGH Breast Care Center and two government hospitals; Donation of ultrasound machines for two government hospitals and salaries and supplies at the PGH Breast Cancer Center
Avon	Poland	Free breast exams throughout Avon events
Avon	Portugal	Donation of digital mammography machine to hospitais da Universidade de Coimbra, a local hospital (Avon Portugal's third equipment donation since 2002)
Avon	Romania	Information Not Available
Avon	Russia	Purchase of contemporary screening and diagnostic equipment across Russia
Avon	Slovenia	Purchase of medical devices for breast reconstruction after mastectomy-donated to the Clinical Center Ljubljana
Avon	South Africa	Donation to Bosom Buddies (breast cancer support group)
Avon	Spain	Donation of more than \$350,000 to Project Avon, a partnership for breast cancer research that it founded with the Scientific Foundation of the Spanish Association Against Cancer
Avon	Turkey	Donation of mammography machine
Avon	Ukraine	Purchase of diagnostic equipment for breast cancer screening; mobile mammography van
Avon	United Arab Emirates	Funding for breast cancer research and awareness
Avon	United Kingdom	Donation to establish the Breakthrough Toby Robins Breast Cancer Research Center (the first breast cancer research facility in the UK); Purchase of new MRI scanner for the Breast Screening Department at Kettering General Hospital; Study on genetic and hormonal risk factors
Avon	Venezuela	Investment in four low-cost breast cancer clinics in Carabobo state
SGKC	United States	Breast cancer research grants to 43 institutions in 13 countries outside of the US; establishment of international affiliates in Germany, Italy and Puerto Rico
SGKC	Mexico	Funding for medical research and clinical resources
SGKC	Global Promise Fund (provides funds to other countries)	Grants to NGOs to develop and implement breast health and breast cancer programs and services
SGKC	Global Expansion Program (Mexico, Costa Rica, Panama, Brazil, Saudi Arabia, Jordan, UAE, Ghana, Romania, Ukraine)	Funding of educational program to teach fundraising and awareness raising advocacy strategies

Table 8.2 (Continued)

SGKC	Italy	Donation to cancer center/hospital; Support for young researchers, scientists, cancer centers, educational programs
SGKC	Puerto Rico	Grant program to fund local breast cancer education, screening and patient support programs
SGKC	Bahamas	Funding cancer research in the Bahamas

Source: Compilation of data from www.komen.org; www.avonfoundation.org; www.komenpr.org; www.komen.it

As shown in Table 8.2, the majority of funds garnered through Avon's and SGKC's cause-related marketing campaigns support biomedical breast cancer research or the purchase of medical technologies. The Avon Foundation, due to its partnerships with local governmental and/or non-governmental organizations in the international locations where it operates, donates funds to a local governmental or non-governmental organization, but often for a specific breast cancer-related medical technology purchase. For example, "the primary goal of" *Avon Estonia*'s fundraising campaigns in 2008 "was to raise money for new mammography equipment" (Avon 2008). Although some of the funding is allocated for breast cancer education programs and patient services, the majority is spent on medical equipment and funneled into biomedical research projects.

The allocation of funds raised internationally by SGKC and the Avon Foundation through the expansion of their corporate advocacy programs demonstrates the role that biomedical health advocacy organizations can play in the global political economy of health and illness. These organizations are financially supporting a biomedical approach to breast cancer, and in doing so on an international scale are often aiding the market expansion of pharmaceutical and medical technology companies as well as creating opportunities for increased international breast cancer research.

CONCLUSION

Political opportunity scholars have addressed the ability of social movements to create opportunities. That is, in addition to responding to exogenous opportunities, collective

action groups have the potential to create or restrain opportunities for allies, countermovements, and other social groups that may be affected by the movement's activities. The creation or restraint of other social actors' opportunities may be purposeful or unintentional. Through their global expansion of corporate advocacy, via cause-related marketing, SGKC and the Avon Foundation have potentially hindered the opportunities of smaller, grassroots breast cancer organizations, while expanding opportunities for other established organizations (e.g., LILT in Italy). At the same time, SGKC and the Avon Foundation are expanding opportunities for corporations, particularly with regard to multinational corporate expansion through cause-marketing campaigns (e.g., the global expansion of clothing brands via the CFDA's Fashion Targets Breast Cancer campaign).

Through their global expansion of corporate advocacy strategies, SGKC and the Avon Foundation are once again demonstrating how social movements can act as globalizing agents. These advocacy organizations are promoting a type of corporate advocacy, which by necessity, creates consumer advocates around the world. Despite initial resistance in some expansion locations (e.g., Italy, Japan), these organizations have managed to persist, due to their significant organizational and financial resources, eventually gaining social acceptance and participation. In addition to globally expanding a *form* of advocacy (i.e., cause-related marketing campaigns), SGKC and the Avon Foundation are promoting a new *type* of advocacy in which corporations participate through the marketing of cause-related products and sponsorship of advocacy events and consumers participate by purchasing cause-related products and participating in corporate-sponsored events.

Finally, the global promotion of this type of advocacy is significant with regard to the global political economy of health and illness. As discussed by Clarke and her colleagues (2005, 446), the “political economy of biomedicalization consists of multinational corporations that are spreading the biomedical paradigm and processes of biomedicalization around the world,” promoting “solutions to health problems [that] are increasingly corporatized and commodified.” By expanding corporate- and consumer-advocacy solutions to breast cancer, these organizations are active participants in the political economy of biomedicalization. In addition to multinational corporations, biomedical health advocacy organizations are actors in defining how health problems are defined, and thereby, how they can be solved. By funding pharmaceutical and medical technology companies, rather than channeling funds to public health programs, SGKC and the Avon Foundation are furthering “corporatized” and “commodified” solutions to global health problems.

CHAPTER 9

CONCLUSIONS

In Chapter 1, I stated that literature on the global expansion of breast cancer advocacy was generally lacking and particularly lacking with regard to engagement with social movement and health and illness theories. My dissertation research begins to fill this gap in the literature. By examining the global expansion of biomedical breast cancer advocacy, via SGKC and the Avon Foundation, in light of social movement and health and illness theories, I conclude in this chapter with my contributions to these literatures.

THEORETICAL IMPLICATIONS

As I stated in Chapter 1, definitions of social movements vary in terms of specifics, social movements are generally understood as collectivities acting at least partially outside of formal institutional channels, with some degree of organization and continuity, for the purpose of “challenging or defending extant authority, whether it is institutionally or culturally based, in the group, organization, society, culture or world order of which they are a part” (Snow et al. 2004, 11). Health social movements in particular have mobilized to challenge medical policy, public health policy and politics, belief systems, medical research and medical practices (Brown 2005, 1). Within the context of globalization, transnational social movements are primarily noted for the challenges they have posed to neoliberal proliferation, environmental degradation, human rights’ violations, crimes against women, war, and misguided development programs (Reitan 2007; Keck 1998; della Porta 2005; Smith 2004). In most cases, therefore, transnational social movements position themselves in opposition to global neoliberal policies.

My inclusion of elite and corporate organizations in the realm of “social movements” is no doubt problematic to some. Nevertheless, I propose that our understanding of social movements needs to evolve as forms of advocacy evolve. By understanding SGKC and the Avon Foundation as forms of “corporate philanthropy,” as Samantha King does, we might miss important opportunities to better understand trends in advocacy, or specifically in this case, trends in health advocacy. As the literature on transnational social movements demonstrated, a bias toward left-leaning and grassroots movements exists in much social movement scholarship. SGKC and the Avon Foundation represent a case in which elite and corporate organizations are co-opting the language of grassroots movements, while promoting their agendas with the full force of their organizational and financial resources. While these organizations are co-opting the language of grassroots social movements that is not to say that they are not advocacy organizations, or should not be understood as social movements in their own right. In fact, these organizations are promoting a form of corporate- and consumer-based advocacy, which has not only become an increasing trend in the US (e.g., in health, environmental, and organic movements), but is now expanding globally through these organizations, seemingly fairly rapidly and successfully. It is important, therefore, for social movement scholars not only to focus on movements that challenge broad social trends, like neoliberal globalization, but also to address movements that complement neoliberal trends, as SGKC and the Avon Foundation do by promoting individual and corporate solutions to breast cancer.

Biomedical breast cancer advocacy organizations also challenge most understandings of social movements by blurring boundaries between, previously thought

of as distinct, social sectors. SGKC and the Avon Foundation demonstrate how elite and corporate advocacy organizations are able to partner with governmental, medical, and corporate sectors, often creating hybridizations of the non-governmental sector and these other entities. Particularly in the development of corporate advocacy, which is the most prominent hybridization of sectors, utilized by SGKC and the Avon Foundation, these organizations are redefining what “counts” as advocacy not only in the US, but globally as well. Finally, by expanding particular forms of advocacy and processes of biomedicalization, SGKC and the Avon Foundation demonstrate the importance of recognizing social movements as not only responding to globalization, but also as agents of globalization in their own right.

The global expansion of biomedical breast cancer advocacy plays a significant role in the global political economy of health and illness, as evidenced by my research findings. Beginning with the global expansion of biomedical breast cancer advocacy organizations in the upper right of the figure and then following the arrows clockwise, I visually display my understanding of the process of the global expansion of biomedical breast cancer advocacy organizations. Because these organizations pursued international markets, they socially constructed a global breast cancer crisis to legitimize their expansion. By socially constructing a global breast cancer crisis and promoting messages of awareness and disseminating information about breast cancer risk, these organizations began contributing to the creation of “at-risk” identities. Additionally, by advancing corporate advocacy and cause-related marketing campaigns, these organizations promoted corporate- and consumer-advocate identities. By promoting

“potentially at-risk” identities to advocacy event participants and through educational materials and media campaigns, while arguing that the solution to breast cancer lies in biomedical research, pharmaceutical and medical technological developments, SGK and the Avon Foundation also created new “biomedical consumers.” These biomedical consumers, through consumer-advocacy, support the allocation of funds to biomedical research, pharmaceutical and medical technology companies. These are the same medical research centers, pharmaceutical and medical technology companies that then fund and participate in biomedical breast cancer events and campaigns, thereby completing the circle in the figure and demonstrating how biomedical advocacy perpetuates itself in the global political economy of health and illness, largely due to the support of biomedical advocacy organizations.

PRACTICAL IMPLICATIONS

As discussed in Chapter 1, there is an increasing trend in disease-specific biomedical health advocacy in the US. With the financial success of biomedical breast cancer advocacy, other health advocates are embracing a similar form of disease-specific advocacy and adopting similar programs of awareness-raising events, corporate-advocate partnerships, and cause-related marketing campaigns. Examples of this can be seen around such diseases as ovarian cancer, heart disease in women, testicular cancer, and spinal muscular atrophy. This form of advocacy, rather than addressing healthcare access and equity on a national or international level, raises awareness about a particular disease, placing it in competition with other diseases for media attention, financial resources, and ultimately, medical attention. As this form of advocacy expands beyond the US, members

of such groups are joining other actors in shaping the global political economy of health and illness by promoting individual and corporate solutions to health problems.

It is highly questionable whether this type advocacy will actually improve people's health. Even in the US, with a 25-year history of breast cancer advocacy, awareness-raising, and fundraising, the breast cancer mortality rate just recently began to decrease slightly and treatment regimens have changed minimally. The main change has been in the increasing number of pharmaceutical interventions in the treatment and/or prevention of breast cancer, which have had mixed results (Klawiter 2002). Lack of access to health insurance and care remain the main factors contributing to late-stage diagnosis and mortality from breast cancer in the US.

Therefore, while SGKC and the Avon Foundation tout their success in combating breast cancer in the US, it has not been made clear that awareness, education, and increased funding of biomedical treatments and interventions are the best way to address breast cancer. By proposing individual solutions to global health inequalities (e.g., by providing free breast cancer screening at events), these organizations omit any critique of the state of access to healthcare in the locations to which they have expanded. By emphasizing awareness, education, and individual responsibility, particularly in countries where not only is there inequality with regard to healthcare, but where there may not be sufficient healthcare infrastructure to adequately diagnose and treat breast cancer, these organizations may be creating educated medical-consumers who lack the resources to be treated if they found that they had the disease (WHO 2008).

APPENDIX

Interview Guide

International Breast Cancer Advocates

1. Name
2. Sex
3. Race/ethnicity
4. Age
5. Education level (degrees)
6. Current work and/or educational status
7. How did you get involved in this organization?
8. How long have you been working with this organization?
9. How long has this organization existed in (location)?
10. What prompted its development?
11. Have you been involved with this organization since its inception?
12. What is the primary focus of this organization?
13. Are there any other organizations that have a similar focus?
 - a. If so, which organizations?
14. What types of activities/events does this organization sponsor or take part in?
15. How have your events and projects been received?
 - a. Turnout?
 - b. What types of responses have you gotten from the public?
16. Do you partner with any other organizations?
 - a. If so, how and why did the partnership develop?

- b. Which organizations?
 - c. What types of things do you do together?
- 17. Have there been any alliances or conflicts with other health organizations?
 - a. If so, regarding what?
- 18. Does your organization have corporate sponsors?
 - a. If so, which corporations?
 - b. How did this come about?
 - c. What role do corporate sponsors/donors play in your organization?
- 19. Are you familiar with the Susan G. Komen for the Cure Foundation, the Avon Breast Cancer Crusade, or the Breast Health Global Initiative?
 - a. If so, what are your perceptions of these organizations?
- 20. Have you or anyone from your organization attended international breast cancer summits/conferences?
 - a. If so, which ones, where, what was the focus, what did you get out of attending?
- 21. Is breast cancer a government health priority in (location)?
 - a. Is it a health priority for women in (location)?
- 22. Are there other women's health issues that are of particular concern?
 - a. If so, like what?
 - b. Is there advocacy/activism around that health issue?
- 23. Is there a stigma surrounding breast cancer?
- 24. When did the pink ribbon symbol begin to appear in (location)?
- 25. Are there ads about breast cancer in magazines, on billboards, on TV?
 - a. If so, when did this start?
 - b. Who sponsors the ads?
- 26. Is there a breast cancer awareness month?
 - a. Which month?

27. What language(s) is information about breast cancer presented in?

Participants at International Breast Cancer Summits

1. Name
2. Sex
3. Race/ethnicity
4. Age
5. Education level (degrees)
6. Current work and/or educational status
7. U.S. delegate or international delegate
 - a. If international, what country?
8. What brought you to this summit?
9. Are you affiliated with SGKC, the Avon Foundation, the Global Breast Health Initiative
 - a. If so, how and why?
 - b. For how long?
10. With any other breast cancer organization?
 - a. If so, which one(s)?
11. In your view, what was the purpose/goal of this summit?
 - a. Was this goal met?
12. What did you do at the summit?
13. What came out of the summit?
14. What will you do regarding breast cancer in your country after attending the summit?
15. (If not US delegate) Is breast cancer a national health priority in your country?

Advocates involved in initiating the global expansion

1. Name
2. Sex
3. Race/ethnicity
4. Age
5. Education level (degrees)
6. Current work and/or educational status
7. How did you get involved in this organization?
8. How long have you been working with this organization?
9. How long has this organization existed?
10. What prompted its development?
11. Have you been involved with this organization since its inception?
12. What is the primary focus of this organization?
13. Are there any other organizations that have a similar focus?
 - a. If so, which organizations?
14. What types of activities/events does this organization sponsor or take part in?
15. How have your events and projects been received?
 - a. Turnout?
 - b. What types of responses have you gotten from the public?
16. Do you partner with any other organizations?
 - a. If so, how did the partnership develop?
 - b. Which organizations?
 - c. What types of things do you do together?
17. Have there been any alliances or conflicts with other health organizations?

- a. If so, regarding what?

18. Does your organization have corporate sponsors?

- a. If so, which corporations?
- b. How did this come about?
- c. What role do corporate sponsors/donors play in your organization?

19. Have you or anyone from your organization attended international breast cancer summits/conferences?

- a. If so, which ones, where, what was the focus, what did you get out of attending?

20. What prompted the decision to expand this organization beyond the U.S.?

21. When was this decision made?

22. Who was involved in making the decision?

23. How were the expansion locations chosen?

24. How are the international affiliates set up?

25. What is the relationship between the U.S. affiliates and the international affiliates?

26. What forms of advocacy are promoted globally?

- a. How was this decided upon?

27. Are there further plans for including more countries?

- a. Which countries?
- b. How was this decision made?

Advocates involved in local breast cancer NGOs

1. Name
2. Sex
3. Race/ethnicity
4. Age

5. Education level (degrees)
6. Current work and/or educational status
7. How did you get involved in this organization?
8. How long have you been working here?
9. How long has this organization existed in (location)?
10. What prompted its development?
11. Have you been involved with this organization since its inception?
12. What is the primary focus of this organization?
13. Are there any other organizations that have a similar focus?
 - a. If so, which organizations?
14. What types of activities/events does this organization sponsor or take part in?
15. Do you partner with any other organizations?
 - a. If so, how did the partnership develop?
 - b. Which organizations?
 - c. What types of things do you do together?
16. Have there been any alliances or conflicts with other health organizations?
 - a. If so, regarding what?
17. Does your organization have corporate sponsors?
 - a. If so, which corporations?
 - b. How did this come about?
18. Are you familiar with the Susan G. Komen for the Cure Foundation, the Avon Breast Cancer Crusade, and/or the Breast Health Global Initiative?
 - a. If so, what are your perceptions of these organizations?
19. Have you or anyone from your organization attended international breast cancer summits/conferences?

- a. If so, which ones, where, what was the focus, what did you get out of attending?
- 20. Is breast cancer a government health priority in (location)?
 - a. Is it a health priority for women in (location)?
- 21. Are there other women's health issues that are of particular concern?
 - a. If so, like what?
 - b. Is there advocacy/activism around that health issue?
- 22. Is there a stigma surrounding breast cancer?
- 23. When did the pink ribbon symbol begin to appear in (location)?
- 24. Are there ads about breast cancer in magazines, on billboards, on TV?
 - a. If so, when did this start?
 - b. Who sponsors the ads?
- 25. Is there a breast cancer awareness month?
 - a. Which month?
- 26. What language is information about breast cancer presented in?

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