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Kathryn Bouskill Date

The Globalization of the Breast Cancer Awareness Campaign in Austria, 2012-2014

by

Kathryn Bouskill
Doctor of Philosophy in Anthropology

Adviser

Peter J. Brown
Department of Anthropology

Peter J. Brown
Chair

Craig Hadley
Committee Member

Chikako Ozawa-de Silva
Committee Member

Kate Winskell
Committee Member

Accepted:

Lisa A. Tedesco
Dean of the Graduate School

Date

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Kathryn Bouskill

M.A., Emory University, 2012
B.A., University of Notre Dame, 2008

Advisor: Peter J. Brown, Ph.D.

An abstract of
A dissertation submitted to the Faculty of the Graduate School
of Emory University in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Anthropology
2015

Abstract

Despite billions of research dollars, therapeutic advancements, and the widespread adoption of mammography screening technologies, breast cancer remains a threat to women's lives and wellbeing. Globally, experiences and outcomes of breast cancer are shaped by the structural and sociocultural contexts in which a woman is diagnosed. In the last decade, the globalization of the American-style breast cancer awareness campaign and its iconic pink ribbon have added new dimensions to the illness experience of breast cancer, as well as notions of breast cancer risk and prevention. This dissertation employs ethnographic methods to explore the globalization of the breast cancer awareness campaign in Austria from 2012-2014. It focuses on the example of *Pink Ribbon Austria,* which was founded in 2006 by the Austrian Cancer Society and the multinational cosmetics company Estee Lauder. The stated goals of the campaign were to create solidarity and support for those with cancer, de-stigmatize the disease, and increase awareness for breast cancer prevention and screening among 'at-risk' women. In spite of these worthy aims, this research demonstrates how the globalization of the campaign is paradoxically distracting attention away from critical shortcomings in breast cancer prevention and screening, and is doing little to address long-term psychosocial and physical health issues related to breast cancer.

Although breast cancer awareness campaigns are new in Austria, they have long been part of the American cultural landscape. The pink ribbon stands as a symbol of hope for a cure for breast cancer as well as a metaphor for encouraging women to be cheerful, heroic, feminine, and forthright about having breast cancer. The campaigns emphasize women's personal control over breast cancer through the use of mammographic screening, despite the epidemiological facts showing that the procedure has limited overall benefits and known harms. Previous anthropological research has examined the complicated relationship that American women with breast cancer have with the style and corporatization of the breast cancer awareness campaign. In one respect, the campaign created a new social identity of the breast cancer 'survivor,' which helped de-stigmatize the disease and enables women to seek social support. However, women resist the unrelenting optimism and cheerfulness of the campaigns as well inadequate depictions of the challenges of a life-threatening illness. The campaign in the

United States has also been criticized for its corporatization through ‘cause-marketing,’ lack of attention to breast cancer disparities, and the reality that the medical community is far from finding a cure for the disease.

This ethnography examines the global flow of breast cancer awareness campaigns in the particular case of Austria. More importantly, it explores how new discourses of breast cancer have affected the perception of risk, health behaviors, and the actual illness experience of women with the disease. Austria presents an interesting comparative context for exploring the globalization of the campaign, not only for the cultural tradition of keeping grave illnesses like cancer private, but also for the need to question the purpose and motives behind bringing awareness for breast cancer into a welfare state with a preexisting excellent healthcare infrastructure.

In regard to increasing ‘awareness,’ surveys and interviews of 137 Austrian women without breast cancer reveal serious misconceptions regarding breast cancer risk and the purpose of mammograms. Almost two-thirds (n=84) of women mistakenly believed that mammograms prevent breast cancer; this is due blatant misuse of epidemiological data and confusing rhetoric of the breast cancer awareness campaign. Not only does the campaign overestimate the effectiveness of mammograms in saving lives, but also conflates the terms *Vorsorge* (prevention) and *Früherkennung* (early detection).

Narrative interviews on the illness experience with 55 women undergoing treatment for breast cancer also revealed a suite of psychosocial issues that are not addressed by the campaign, despite the stated goals of de-stigmatization as well as increased solidarity and support for those with the disease. For example, 57% (n=31) of the sample believed that emotional distress stemming from problems of family instability, marital conflict and women’s problems in fulfilling expected gender roles caused their cancer. Interviews discovered that the emphasis on personal responsibility to control breast cancer through prevention and screening contributes to the unwarranted feelings of guilt from those with the disease. Finally, the sexualized visual imagery of the campaign and the inability for women with breast cancer to attend key *Pink Ribbon Austria* events creates a sense of exclusivity that fails to establish a sense of solidarity for women with breast cancer.

Overall, this dissertation concerns how the feminization and sexualization, corporatization, and the misuse of epidemiological data within breast cancer awareness campaigns is spreading, in turn creating gains for the biomedical community and companies involved in 'cause-marketing.' Finally, this case study from Austria explores the impact of this recent phenomenon in public health on women's breast cancer illness experiences and perceptions of risk. This process masks both sociocultural differences between societies in regard to cancer as well as breast cancer disparities through its use of the pink ribbon and creation of a homogenous breast cancer 'survivor.'

This work was supported by the Department of Anthropology at Emory University, the Fulbright Foundation/Austrian American Educational Exchange, and the Comprehensive Cancer Center of Vienna.

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ACKNOWLEDGEMENTS

As the proverb goes, it takes a village to raise a child. It takes a global village to become an anthropologist. This dissertation belongs to the incredible educators, friends, and family members who have provided invaluable help along the way.

My biggest thanks are to my committee at Emory University. I have been incredibly fortunate to have Peter Brown as my advisor and mentor. Peter's intellectual curiosity and his devotion to his students' scholarly development and personal wellbeing are unmatched. Committee members Kate Winskell, Craig Hadley, and Chikako Ozawa-de Silva were a wonderful and generous source of academic and personal support throughout the entire process. My thanks to Michael Kramer in the Department of Epidemiology for his enthusiasm, patience, and openness to interdisciplinary research. Special thanks as well to my friends I made at Emory, especially Bonnie Kaiser, Claire-Marie Hefner, Lesley Jo Weaver, Beth Turner, Jenny Mascaro, Michelle Parsons, Shunyuan Zhang, Jen Sweeney, Amanda Mummert, Bisan Salhi, Amy Cobden, Tawni Tidwell, Josh Robinson, and Molly Zuckerman. It was so rewarding to work with scholars who are committed to producing scholarship that is not only theoretically stimulating but also provides concrete contributions with the potential to improve health and wellbeing around the world.

The Department of Anthropology and the Department of Epidemiology at Emory University consistently provides a congenial environment where students can work to their fullest potential. I am grateful to the staff in the Department of Anthropology, especially Lora McDonald, who was always patient, helpful, and accommodating. My thanks to Frances Pici, who at the eleventh hour helped out a fellow Buffalonian. Special thanks to the members of the Department of German Studies who gave up a seat in their classes to an overzealous graduate student. Many wonderful faculty members selflessly helped me at the professional, scholarly, and personal levels, including the late George Armelagos, the late Maximillian Aue, Peter Höyng, Carol Worthman, Michael Kramer, Hiram Maxim, Melvin Konner, Liv Nilsson Stutz, Bradd Shore, David Nugent, and Michael Peletz. They were all part of making my time at Emory University productive and fulfilling.

My thanks to those who nurtured an appreciation for the discipline of Anthropology, starting with Marcus and Kristine Miranda. At the University of Notre Dame, Daniel Lende and Vania Smith-Oka provided invaluable mentorship throughout my first research projects. They, as well as James McKenna and Agustín Fuentes encouraged me to pursue a doctoral degree in Anthropology. At Notre Dame, I met Vera

Profit, who became a dear friend, mentor, and enduring connection to Vienna. I am indebted to her for her friendship.

This project would not have been possible without the support of many friends and colleagues in Austria. Natalija Frank's belief in this project is the reason I was able to work in Vienna. She is an unsung hero in cancer care. Kristina Gugerbauer and our great group of friends patiently taught me German and always made me feel at home. In Margret Jäger I found a compassionate colleague and friend always willing to share helpful insights on this work. Georg Trattnig had an unwavering support for my research and was with me every step of the way. Lonnie Johnson and his dynamic team at the Austrian American Educational Commission provided an institutional home for me in the field. I would be hard-pressed to find a group more dedicated to the mission of the Fulbright Commission.

My parents Rick and Elizabeth taught me to feel comfortable in any social situation and to listen intently to everyone's story. Their influence is woven throughout this work. As a child, my mother took me along to her volunteer work at the Roswell Park Cancer Institute and showed me how important and rewarding it is to try to better the lives of those affected by cancer. My aunt Colleen Burns is also a steadfast volunteer, and I greatly appreciated her genuine interest in this research.

Many wonderful friends and family have opened their doors to me throughout my education and made me feel at home. They are (in reverse chronological order): the Zdrahal family, the Gugerbauer family, the Linthwaite family, the Phillips family, the Anthony family, and Gina Maldonado-Gomez. I am indebted to you and hope I can someday reciprocate. Thank you for your incredible kindness and generosity.

This work is dedicated to the many women affected by breast cancer who graciously gave their time and energy to this research in hopes of bettering the lives of others affected by the disease. *Thank you.*

PREFACE

In the United States, each October over the last thirty years has been devoted to raising awareness for breast cancer. Symbolized by the iconic pink ribbon, the breast cancer awareness campaign has become an American cultural mainstay. American supermarkets, parks, schools, post offices, and so forth are dotted with pink ribbons in the name of raising awareness for the most commonly diagnosed cancer among women in the United States. The pervasiveness of pink ribbons reflects an interesting paradox where breast cancer appears to be a part of the public consciousness, when in reality the campaign does little to draw attention to the struggles inherent to facing a grave illness and the major health disparities in regard to breast cancer mortality. As the campaign globalizes into novel contexts, discourses of breast cancer are expanding. But is all of this talk speaking truth to the reality of breast cancer?

This dissertation presents an ethnographic and social epidemiological case study of this paradox in Austria in light of a recently implemented breast cancer awareness campaign. This work questions what it means to be 'aware' of breast cancer from multiple vantage points, including women living with the disease, those at risk for developing the disease, and the stakeholders and promoters of the public health awareness campaign. A central theme throughout the work is how the expansion of 'awareness' for breast cancer is paradoxically distracting attention away from key issues in breast cancer prevention and is doing little to address long-term psychosocial and physical health issues related to breast cancer. In addition, this work questions the appropriateness of importing American constructions of breast cancer awareness into culturally discordant contexts. This research also documents the consequences of and resistance to the neoliberal bent in public health campaigns, including increasing corporatization and an emphasis on personal responsibility in controlling one's risk for cancer. Medical anthropology is well poised to make significant theoretical and applied contributions to understanding how macro-level factors, such as the corporatization of the breast cancer awareness campaign, are impacting the lived experience of breast cancer.

Breast cancer is, like most cancers, complex and diverse. In fact, to say breast *cancers* more accurately depicts the ever-expanding subtypes of malignant growths originating in the breast tissue. Like many forms of cancer, breast cancer differs widely in etiology (causes), latency, aggressiveness, prognosis, and effective measures to manage the disease. For instance, 'triple negative' breast cancers tend to strike younger, premenopausal women, are treated with radical mastectomies, and present limited chemotherapeutic options, while estrogen receptor-positive breast cancers tend to affect postmenopausal women, are often treated with a lumpectomy (partial removal of the breast tissue) and radiation, and are less frequently treated with chemotherapy. Only 5-10% of breast cancer cases can be attributed to genetic mutations, meaning that most cases of breast cancer are caused by an indeterminable interaction between genetics, epigenetics, environmental, and bio-behavioral factors.

The complexity of breast cancer biology is mirrored in lived experiences of those faced with the diagnosis. In many ways, the complicated nature of breast cancer reflects aspects common to all cancer experiences. For instance, cancer is widely portrayed in and out of the clinic as disorderly, ambiguous, and defying the lines between self and other (Heurtin-Roberts 2009; McMullin & Weiner 2009). Another overarching issue is the fact that cancer can often be managed, but rarely cured. This reality prohibits those once diagnosed with cancer from living a life fully free of the disease. The state of being ‘not-sick-but-not-well’ is one of being betwixt and between, or what anthropologists call a state of *liminality.* Liminality generally refers to a transitional and temporary phase between two states, identities or roles; however, the case of cancer remission simply prolongs the state of liminality. Anthropologist Paul Stoller writes of his experience with lymphoma, “Once you enter the village of the sick…you can never fully return to the village of the healthy” (2009:35), meaning that the fear and unpredictability of cancer recurrence become intrinsic parts of life following a diagnosis. Thus, those confronted with a cancer diagnosis often experience permanent changes in their lives.

What these changes are, what they mean, and how they are enacted all depend upon the social and cultural contexts in which someone gets sick. Although there are similarities in cancer illness experiences, exploring these illness experiences can also be an effective means of exploring and understanding difference. These variations exist not only in the ways that people personally interpret cancer (and the fear surrounding it) in their lives, but also in the form of disparities in cancer incidence, morbidity and mortality, notions of cancer risk, culturally shaped metaphors of the disease, stigmatization and social ‘othering’ of those with the disease, and the appropriate ways that cancer should (or should not) be treated within medical systems. Medical anthropology is well positioned to use cancer as a lens through which to decipher differences and draw comparisons within broader political economic and sociocultural processes and the macro and the micro, and to resist homogenization of cancer illness experiences in an increasingly globalized world.

There are a few particular aspects of breast cancer that make it a compelling subject within medical anthropology. One obvious factor is the cultural valence of breasts and the ties of breasts to motherhood, reproduction, sexual attraction, and aesthetics (Smith 2014). Breasts can both foster life through breastfeeding and take life through cancer. The potential loss or deformation of the breasts, key signifiers of femininity, complicates gender roles and meanings of womanhood. The connection of breast cancer to women's gender often creates a tension between lay and biomedical understandings of breast cancer and how people make sense of it within the broader context of their lives. In addition, breast cancer also brings the distinction between disease and illness to the fore, the former attending to a physiological abnormality and the latter describing how the afflicted and their social networks subjectively live with symptoms and disability (Kleinman 1988; Young 1982).

Another unique aspect of breast cancer is its widespread presence in the public sphere and its symbolic representation through the pink ribbon. This is particularly the case in the United States, where the pink ribbons have become a part of the American cultural landscape, appearing in contexts as far ranging as National Football League fields to yogurt lids. Under the auspices of the breast cancer awareness campaign, women with breast cancer are portrayed as survivors who paradoxically remain cheerful and feminine while fearlessly 'battling' breast cancer. The primary objectives of the campaign are 1.) finding a cure for the disease, 2.) promoting prevention and mammographic screening, and 3.) providing support for those affected by the disease. The secondary objective comes in forms of profits made from campaign stakeholders, including medical personnel conducting mammographic screening and companies selling pink ribbon products. Despite the questionable collateral profits of the campaign, its cultural ubiquity has had a profound impact on the ways in which American women experience breast cancer. As the movement globalizes to places as widespread as Saudi Arabia[1] and France, it is critical to examine the means, practices, and objectives at hand in establishing the campaign in novel contexts, and to ask what is at stake for the growing number of women affected by breast cancer. A critical medical anthropological perspective is helpful for not only calling into question the assumptions and motives of the breast cancer awareness campaign, but for grounding these critiques within nuanced ethnographic accounts that privilege the voices and needs of those affected by breast cancer.

Following the Breast Cancer Awareness Campaign into Austria

This work describes the globalization of the breast cancer awareness campaign in Austria, where traditionally breast cancer is a private and taboo topic. Although organizations in Austria had sporadically used the pink ribbon since 2002, it has only within recent years gained a more widespread presence. This research period from 2012-2014 captured the ramped-up rollout of the main campaign under the name *Pink Ribbon Austria*. These increased efforts also coincided with the enactment of a universal breast cancer screening program in Austria, which ended abruptly only six months after it started. Then in May 2013, Hollywood star Angelina Jolie came forward with her decision to have a prophylactic mastectomy after discovering that she is a carrier of a genetic mutation that greatly increases her risk for developing breast cancer. During the

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[1] Samantha King (2010) describes the diplomatic agenda behind the globalization of the pink ribbon campaign into Saudi Arabia. I failed to find any information on the campaign in Saudi Arabia since 2010.

research period, it was nearly impossible not to hear of breast cancer in the media, see posters advertising the screening program, or overhear people talking about Jolie's 'brave' decision.

The fact that breast cancer was on the public's radar was a recent and perhaps fleeting phenomenon. In fact, it was the *lack* of breast cancer in the public realm that initially piqued my interest in performing fieldwork in Austria. From 2006-2008, I performed ethnographic data on coping mechanisms and social support among women with breast cancer in the Midwestern United States. I analyzed much of these ethnographic data during the summers of 2008-2011 while living with an Austrian-American family in Vienna. One theme that emerged from the data was the complicated relationship American women with breast cancer have with the awareness campaign, the pink ribbons, and the idea of being a survivor. On the one hand, the destigmatization of breast cancer opened up the social spaces where women could bond and seek support in one another. But at the same time, women resisted the cultural expectation to be constantly cheerful and strong, especially when life is anything but 'in the pink.' They felt as if the campaign did not always accurately reflect the struggles they endured. In short, women with breast cancer perceive both benefits and drawbacks to the cultural prominence of breast cancer in the United States (Bouskill 2012; Kaiser 2008).

As I engaged in everyday life in Vienna, I realized that talking about my research on experiences of cancer often ended a conversation, as if people simply did not want to hear the word cancer. I became struck by the lack of pink ribbons, which prompted me to ask others if they had seen it, heard of it, or ever bought any pink ribbon products. "Oh, do you mean the red ribbon for AIDS?" people often replied, often referring to the red ribbons associated with the *Life Ball* for HIV/AIDS awareness and support. The Life Ball has been a Viennese institution for twenty years and is the largest charity event in Europe to support those with HIV/AIDS. After clarifying, many answered, “no, the pink one for breast cancer– never heard of it.” This surprised me, especially considering that in 2008, approximately 5,000 women in Austria were diagnosed with breast cancer, while only about 20 women were diagnosed with HIV/AIDS (Statistik Austria 2014).

When I began to inquire about the cultural aspects of cancer in 2008, neighbors and acquaintances explained, “If someone has cancer, it’s very intimate. It’s no one’s business but the family and close friends.” It was difficult to know if cancer was just private, taboo, or both, but it was clear that one key aspect of Austrian social life was withholding personal details, ‘keeping a stiff upper lip,’ and not being forthright with problems. At the same time, I continued thinking about the contested relationship women with breast cancer have to the widespread campaign and the pink ribbons in the United States, and pondered over what it would be like to experience breast cancer in a context where it is the most frequently diagnosed cancer among women, but where instead of being encouraged to be forthright with the illness, women were expected to keep breast cancer private. Moreover, I began to reflect on how Austrian women with breast cancer conceptualized and embodied their illness experience without ‘pink ribbon culture’ and the social label of being a survivor.

I remained cognizant of these differences as I returned to Vienna the following summers. By summer 2010 however, the pink ribbons had seemingly entered into the Austrian market, appearing on pretzel boxes, cosmetic cases, bottles of rosé wine, and even a pink ribbon-sponsored iconic Viennese streetcar (figure 1.1). It was clear that I would have to rethink my original question about the experience of breast cancer in a context where such symbolic representations of the disease were absent. I began to think instead of what the global flow of the pink ribbon would mean for women with breast cancer who had never encountered it, how they would interpret it, and how public forms of support for breast cancer fit in with the Austrian cultural norm of keeping a cancer diagnosis private. Most importantly, I wanted to understand how well this iteration of the globalized campaign achieved the goal of raising awareness for breast cancer prevention and screening, as well as the needs of women with the disease.

On another level, the idea of bringing an awareness campaign for breast cancer into a country with a top-ranking healthcare system seemed suspect. With well over half of all breast cancer cases found *in situ* or in stage I (and a near quarter in stage II),[2] were women not already getting screened and properly treated? In other words, I found it difficult to reconcile the perceived need to bring support for breast cancer to a country that ostensibly seemed to be doing well in that regard.

Breast cancers that are treatable in countries in Austria remain fatal in others. Ethnographies of cancer (breast cancer among them) depicted impoverished healthcare systems with sparse cancer screening and treatment options, leaving those with cancer in dire situations (Gregg 2003; Jäger 2010), but Austria seemed a far cry away from these contexts. Weeks after the pink streetcar drove by me in Vienna, I participated in a fellowship program in cancer control at the U.S. National Cancer Institute. During the

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[2] These data are from Zielonke et al. 2014. Breast carcinoma *in situ* is a non-invasive form of cancer, but even its classification as a form of cancer is debated. Put simply, stages I & II differ based on the size of the tumor upon presentation and degree of invasion into the surrounding lymph nodes. Stage III refers to larger presentation of the tumor and/or spreading into axillary and more distant lymph nodes. Stage IV, or metastatic/advanced breast cancer, means that cancer has spread to the organs, including the skin, liver, brain, lungs, or other parts of the body.

fellowship, I met a group of Tanzanian oncologists who showed me disturbing photographs of tumors protruding from infected breast tissue and talked about their struggles to provide even basic palliative care for their patients. In reality, I only had to look to the former Yugoslavia and former Allied States of the Soviet Union next to Austria for troubling accounts of dismal cancer care. Meanwhile, Austrian oncologists were heralding the remarkable success of breast reconstruction following a mastectomy, which is covered by the national health insurance. If the motivation was to spread awareness and advocacy and to better the plight of those with breast cancer, Austria was certainly not an obvious place to go. This of course begged the question of what in fact were the motivations behind this iteration of the global flow of the breast cancer awareness campaign. Moreover, what effect was this having on women at-risk for breast cancer, those undergoing treatment, and those continuing to live with the illness?

As mentioned, I spent extensive amount of time in my previous work on breast cancer researching whether American women with breast cancer actually subscribed to the "survivor" label they bore medical and socially, and if they felt it accurately depicted their experiences with the breast cancer. Were cancer metaphors doing more harm than good? Were such awareness campaigns the kind of support women[3] needed? How was the widespread 'awareness' of breast cancer changing the illness experience? Lastly, what are the social, political economic, and biomedical processes driving the global flow of breast cancer awareness?

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[3] Breast cancer also occurs in men, albeit far less frequently. The annual prevalence of breast cancer among men in Europe for instance is 1 in 100,000, and breast cancer among men accounts for less than 1% of all breast cancer cases (Fentiman et al. 2006). For the sake of simplicity and also the scope of this dissertation, I will refer only to women with breast cancer.

These are not trivial questions. In the United States, the introduction of the pink ribbon changed how women interfaced with the disease and how women could give a voice to their affliction. While women with breast cancer need not live in shame and secrecy, many encounter unwanted pressure to conform to life as a hero-survivor (Kaiser 2008; Sulik 2012). Thus, for all that the ribbons and their label of survivorship enable, so too can they obscure the reality of hardship, worry, and angst experienced by women with breast cancer. On a political-economic level, breast cancer is profitable for politicians, doctors, the pharmaceutical and biotechnological industries, and stakeholders marketing pink ribbon products. One main motivation for this work was to explore the less obvious power dynamics behind seemingly harmless and apolitical pink ribbons.[4]

With these new factors in mind, I set out to explore what happens when an intimate illness goes public in a new setting. In addition, I needed to inquire about who or what was behind the global flow and their motivations. The pink ribbon in the United States is big business, often translating to major profits for the pharmaceutical industry, radiologists, and the host of companies selling pink ribbon products.[5] What are the implications of branding breast cancer and shipping the brand into new contexts? Can this still be considered advocacy if it was not imported by the community of sufferers it

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[4] Samantha King (2010) provides an excellent commentary on the erasure of inequality, gender dimensions, and political and financial motives in the globalization of the breast cancer awareness campaign under the auspices of the US-Middle East Partnership for Breast Cancer Awareness. The US-Middle East Partnership for Breast Cancer awareness was established in 2006. Both Susan G. Komen and the Avon Foundation competed over a share of the new Middle Eastern market. As stated, I have not found any information on the Partnership since 2010 and assume it has ended.

[5] Iconoclastic biomedical practitioners Franz Fischl and Andreas Feiertag have also criticized breast cancer screening and care in Austria as little more than a means to make profits (i.e. big business, German: *Wirtschaftsfaktor*) (Fischl & Feiertag 2005). The authors purport that the "business of oncology" plays up to women's fears and anxieties and purposefully exaggerates breast cancer risk and the benefits of screening for its own gain.

seeks to help (see Packard et al. 2004)? What other advocacy groups have emerged and what are the means with which they engage in breast cancer advocacy?

Figure 1.1 A Viennese streetcar in the Alsergrund district.

This work also looks critically at the stakeholders involved in the globalization of breast cancer awareness and their motives in seeking to corporatize women's health in order to offer a political-economic perspective on this latest global flow. It also reveals the persistence of *eminence*-based medicine, as opposed to *evidence*-based medicine, and the ways in which cultures conceptualize cancer more broadly. Evidence-based medicine is to the application of findings from robust research trials (often including double-blind randomized control trials) to medical decision-making and public health policies. In contrast, *eminence*-based medicine refers to the reliance of personal opinions and clinical experience of prestigious (often older) practitioners. Evidence-based medicine offers the most rational and efficient means of carrying out healthcare delivery, but it can (and often does) diverge from traditional clinical practice. This dissertation uses the example of mammographic screening to show how evidence-based medicine is at odds with eminence-based medicine, and how this clash affects the construction of discourses surrounding the early detection of breast cancer.

This case study looks at what is lost, gained, warped, made visible and invisible in the global flow of breast cancer awareness campaigns. I achieve this particularly by examining what this means for women at risk for breast cancer and those already affected by the disease. These women are ostensibly in the center of the global constellation of actors behind the spread of the pink ribbon. The globalization of the breast cancer awareness campaign— including its biomedical assumptions, its branded symbol, and emphasis on femininity and beauty— is masking key sociocultural differences in how women live out breast cancer illness experiences.

CHAPTER ONE: INTRODUCTION

Breast Cancer Awareness in the United States

It is inevitable that by simply importing the pink ribbon, the rich and multifaceted history of the campaign and its antecedents get left behind, lose their meaning, or gain new meanings in the process. This brief introduction to the history of the breast cancer awareness campaign and the rise of the pink ribbon in the United States is intended to serve as a point of comparison of the campaign in the American and Austrian contexts, which will be an important feature of the themes presented in this dissertation and the broader issues at hand in the globalization of women's health campaigns.

Early forms of Awareness

It is commonly assumed that breast cancer in the United States remained stigmatized and out of the public eye until the spread of the pink ribbon and the establishment of powerful advocacy groups like the National Breast Cancer Coalition and Susan G. Komen for the Cure in the 1980s. In some ways, the notion that breast cancer was stigmatized until recent decades is accurate. For example, in his "biography of cancer," oncologist Siddhartha Mukherjee tells the story of Manhattan socialite Fanny Rosenow, who in the 1950s attempted to advertise for a breast cancer support group in the New York Times. Her request was denied by New York Times editorial board, which cited their policy to print neither the word "breast" nor "cancer" (2010: 26). Even well into the 1970s, breast cancer was interpreted as a shameful disease, made worse by its dominant metaphor of being associated with weak women who lacked the ability the properly express their emotions (Sontag 1990 [1979]).

However, this portrayal that breast cancer awareness and grassroots activism is a recent phenomenon is only a partial truth. In reality, laywomen had been working towards breast cancer awareness and educating themselves on cancer for the better part of the 20th century (Klawiter 2008). In fact, efforts to publicize breast cancer in the U.S. began in 1913 with the establishment of the American Society for Cancer Control (now the American Cancer Society), which prioritized education about breast cancer signs and symptoms (Lerner 2002). Women's magazines in the U.S. dating back to 1929 were already publishing dozens articles to educate women on the signs and symptoms of cancer, and to encourage women to seek immediate attention if they discovered a suspicious lump in their breasts (Black 1995). In 1936, the American Society for the Control of Cancer founded the Women's Field Army, which 'enlisted' women from across the United States to donate one dollar, hold regular lectures on women and cancer, and hand out pamphlets proclaiming that "cancer can be cured" if women seek immediate medical attention for any signs and symptoms of cancer, including breast cancer (Anderson 2004; Murciano-Goroff 2015). Only two years after the start of the Women's Field Army, participation rose from 15,000 to nearly 150,000 women who donned khaki uniforms and took to the streets in the name of "waging war on cancer" (American Cancer Society 2014). Throughout the 1950s, various women's organizations formed in order to continue educating women and to foster rehabilitation efforts for those who survived breast cancer (Lerner 2002). Women's organization and mobilization with physicians and the American Society for Cancer Control reflects the notion that most women have always had to learn how to be pragmatic with their health and use the tools available to them to benefit themselves (Lock & Kaufert 1998: 2).

Unfortunately, the only tool available to women until the mid-1970s was the surgeon's knife through a radical mastectomy, which involved complete removal of the breast tissue and parts of the chest wall in an effort to prevent the spread of breast cancer (Roses et al. 2009). The drastic procedure was performed irrespective of the size of the lump and medical non-disclosure of the severity of the tumor was the norm, meaning that women were often unaware of their prognosis (Klawiter 2008). Following the procedure, women were expected to quietly return to their normal lives and duties post-haste. The loss of breasts and torso mobility from the surgery was debilitating and shameful, which arguably hindered the widespread participation on the part of women with breast cancer. The longstanding expectation was that breast cancer was curable, but only if a woman did not delay in obtaining treatment and only if she fully obeyed the orders of the presiding oncologist (*ibid.*). This was the guiding principle of the first wave of breast cancer awareness in the U.S., which began with the establishment of American Society for the Control of Cancer in 1913 and lasted until the late 1970s (Lerner 2002).

However, mortality rates failed to uphold the promise that seeking immediate treatment would cure breast cancer. The percentage of women who survived five years after their diagnosis had increased from 60% in 1950 to 68% in 1973 (Doll & Peto 1981). However, at the same time, mortality rates from breast cancer in women under 65 reportedly increased (*ibid.*).[6] The radical mastectomy it seemed failed to cure breast cancer. This increasing realization was perhaps the reason why organizations to support

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[6] I use early cancer epidemiology statistics cautiously due to the recognized methodological errors in gathering data. For instance, in cases of metastasis, it is unclear if death is reported as a result of the original cancer site (i.e. breast) or a site of metastasis (i.e. lung) (Doll & Peto 1981).

breast cancer awareness within the U.S. waned throughout the 1960s in early 1970s (Lerner 2002). In other words, the slogan to ‘seek early treatment to cure breast cancer’ was no longer convincing.

A few key developments occurred throughout the 1970s and 80s that spurred a change in the way breast cancer awareness was conceptualized and practiced in the United States. To start, in 1971 Richard Nixon declared “war on cancer.” The lunar landing two years prior had secured America’s status as a pioneer of scientific development and conveyed a sense of hubris that America could use its scientific prowess to end the dreaded disease (Mukherjee 2010). By signing the bill, Nixon secured billions of research dollars to propel the National Cancer Institute and to quell the rising impatience with the lack of progress in cancer research. Additionally, the idea of declaring war on cancer underscores the ideal of protecting something greater than the individual, which is central to the American ethos. In addition, there is a peculiar positive quality of war and military metaphors in the States, which makes it particularly recognizable to donors and to people in a community looking to support a cause. Agreeing to declare a metaphoric war on cancer (or drugs, poverty, or terror) is the glue that upholds the mobilization, the camaraderie, and the intense efforts together. Without that kind of declaration, the discourse falls apart. To think that the over forty-four years later the American public is still hopefully awaiting a cure (i.e. victory in the war) speaks volumes to the impact of these cultural ideas.

Another factor that contributed to changes in breast cancer awareness was the rise of the Women’s Health Initiative and Third Wave Feminism, which helped women to gain a voice, acknowledge their bodies, health and agency, and to fight back against patriarchy, including the unquestioned nondisclosure[7] that took place in medical settings (Sherwin 1998). Women with breast cancer began to "question the authority of the overwhelmingly male medical profession" and to cast doubt on the practice of radical mastectomies as the only treatment for breast cancer (Lerner 2002: 226). For instance, journalist Rose Kusher published an investigative report in which she criticized the practice of radical mastectomies without the consent of the patient (Leopold 2000). American women in general were gaining a stronger voice, and breast cancer was one issue where women wanted to speak out. Politicians were starting to oblige, as evidenced by the "war on cancer" and the prioritization of breast cancer in the National Cancer Institute (Klawiter 2008). In addition, breast cancer care was a popular bipartisan and noncontroversial approach to garnering support from female voters, especially following the polarizing landmark Supreme Court decision on abortion from the Roe vs. Wade case (Mukherjee 2010).

A major catalyst in changing the discourse and practice of breast cancer awareness was the rise in mammographic screening as common practice. Mammograms presented an opportunity to screen breast tissue using x-rays in order to detect any abnormal growths before they could be felt. The idea that breast tumors could and *should* be found as early as possible (i.e. in their asymptomatic phase) changed the frame of responsible behavior for breast cancer. In this new wave of breast cancer awareness, the

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[7] Disclosure in oncology practices cross-culturally is illustrative of not only the cultural context in which the doctor and patient are situated, but also the availability of proper and adequate treatment (Good et al. 1993). The perpetuation of a lack of adequate cancer technologies has sustained the association between cancer and death, leading many medical practitioners to perceive cancer disclosure as a far worse psychological burden than not knowing (Gregg 2003). This approach is supported both ethically and legally by many non-Western cultures; however, studies demonstrate that as treatment options improve and hope for cancer survival becomes a possibility, the commonality of disclosure and cancer communication increases (Mitchell 1998).

discourse of treating breast cancer at the doctor's discretion gave way a new discourse of risk and surveillance. Klawiter's (2008) term for this new wave of discourse for breast cancer is "the regime of biomedicalization," which signifies how women's healthy breast tissue was transformed into a source of risk that needed to be under constant surveillance. In this regime, controlling breast cancer was no longer about seeking early treatment for palpable tumors, but rather was conceptualized as finding an "invisible risk and symptomless disease that required continuous bodily vigilance and surveillance" (Klawiter 2008: 37).

In 1974, First Lady Betty Ford and Second Lady Happy Rockefeller made this new practice of controlling breast cancer a mainstream issue by publicly crediting their successful treatment of breast cancer to detecting their tumors early via mammographic screening (Sherwin 2006). This highly publicized outing was instrumental in destigmatizing breast cancer. In addition, women almost began overnight to demand mammograms, leading to long waiting lists in radiology clinics (Klawiter 2008) and spikes in breast cancer incidence throughout the early 1970s (Doll & Peto 1981; Pollack & Horm 1980).

Using x-rays to examine breast tissue was not a new phenomenon in the mid-1970s per se. In fact, x-rays had infrequently been used to diagnose (i.e. not screen) tumors of the breast since the 1930s, and early use of mammograms to screen asymptomatic breast tissue began in the 1950s (Bassett & Gold 1988). In 1963, the National Cancer Institute sponsored the Health Insurance Plan study that examined the effects of combining physical exams and mammography in reducing breast cancer mortality among New Yorkers (Kaufert 1998, 2000). In 1972, the American Cancer

Society launched a considerably larger study called the Breast Cancer Detection and Demonstration Project. This study provided more robust data to confirm mammographic screening as an efficient means of detecting tumors and preventing deaths (Baker 1982). However, data gathered by experts at the National Cancer Institute throughout the 1970s showed that ionizing radiation emitted through mammographic screening could have been carcinogenic, at least to younger women (Aronowitz 2007). In 1977, the opposing sides– one in favor of making mammography standard clinical practice and one arguing in favor of conducting more randomized control trials to decipher the benefits and harms of the method– convened a panel to review the conflicting evidence from the existing clinical trials (National Institutes of Health 1977). Although the members of the panel were still in disagreement over how to implement mammographic screening, they reached a consensus on the most contentious issue of when to start screening:

> "The panel acknowledged that mammographic techniques have improved markedly in recent years, with smaller, and presumably earlier, lesions now being detected. The advantage of mammography lies in the fact that appropriate therapy may be administered at an earlier stage of breast cancer, which presumably improves prognosis. Moreover, radiation dosage has been decreased significantly…The panel found no convincing justification for routine mammographic screening for women under 50 years of age. This does not imply, however, that physical examination and breast self-examination are not important for women of any age." (National Institutes of Health 1977)

Despite the agreement to recommend screening for women over 50 (and those with family and history over 40), both women and physicians were skeptical. The sense was that if detecting breast cancer earlier meant a better prognosis, why would it not be good practice for all women? Messages surrounding mammography have since the early 1980s been as overt as this American Cancer Society's advertisement: "If you are over 35 and have not had a mammogram, you need your head examined." Clearly, the sense was and is that not having a regular mammogram is irresponsible, reckless, and immoral, despite the fact that mammograms have long been a disputed method of screening for breast cancer (Kaufert 1996, 2000).

By the late 1970s, the rise in chemotherapy and estrogen receptor blockers to treat breast cancer changed the outlook for women diagnosed with cancer. Women were no longer without question given a radical mastectomy and sent on their way; instead, adjuvant chemotherapeutic and radiation therapies became instituted, in turn making treatment longer, more complicated, and harder to contain within women's private lives (Klawiter 2004). A large-scale randomized clinical trial conducted in the 1980s also proved that a lumpectomy and radiation treatment in early-stage breast cancers was an effective course of treatment (Fisher et al. 1989). These findings meant that most women were no longer subjected to the stigmatizing effects of the radical mastectomy. This factor, together with the celebrity outings and the galvanizing effects of the Women's Health Movement and Third Wave Feminism expanded women's collective power and networking (Kaufert 1996, 2000). In addition, the screening of asymptomatic women made 'healthy' women aware of their breast cancer risk and opened up new social spaces to bring breast cancer into the public consciousness.

Women's organizations to raise awareness for breast cancer were making a comeback by incorporating 'healthy' women into the discourse on controlling risk through mammographic screening (Sulik 2012). At the same time, a new identity of the 'breast cancer survivor' was crystallizing. Under the label survivor, women with breast cancer were encouraged to take on the disease as a source of strength in their lives, rather than to simply put it behind them (Klawiter 2008). The new "regime of biomedicalization" of breast cancer turned healthy women's breasts into places of pending risk, as women with breast cancer were touted as 'survivors' (Klawiter 2008). With this new identity, women began to rally around breast cancer in newly formed organizations such as The Susan G. Komen Breast Cancer Foundation (now Susan G. Komen for the Cure) (1982) and the National Alliance of Breast Cancer Organizations (1986).

In addition to these new roles, women's organizations were picking up steam by partnering with corporations under the framework of cause marketing. Cause marketing came to the fore in the mid-1980s as a marketing strategy to sell consumers the products they were seeking and the additional perk of the feeling they had done something good (King 2001). Cause marketing fit well to the rise in neoliberal economic practice, which emphasizes consumption as a civic virtue (Rose 1999). The frontrunner in taking on the corporatized approach to awareness was the Susan G. Komen Breast Cancer Foundation, which helped to transform cause marketing for breast cancer into a profitable, widespread business strategy (King 2001). The pharmaceutical industry caught on quickly to the rapid cultural changes in attitudes toward breast cancer, amendments in standard breast cancer treatment, and stagnant progress in finding a cure. In 1985, AstraZeneca, a subsidiary of Imperial Chemical and manufacturer of popular chemotherapy drugs like Tamoxifen, founded and copyrighted National Breast Cancer Awareness Month (Schrader-Frechette 2007). Pharmaceutical companies rallied behind the mantra of "finding the cure," which allowed them to dispel conflicts of interests and promote a positive message of hope. It made no difference to the industry, considering that a cure for breast cancer hardly seemed imminent (*ibid.*). Soon after, the cosmetics industry, followed by corporations across various industries joined the marketing sensation and began to sell products in the name of supporting breast cancer (Sulik 2012). Breast cancer awareness had gone from a grassroots "Women's Field Army" to a widespread corporatized marketing tool.

Breast Cancer in the Current American Cultural Landscape

The rise in breast cancer awareness organizations, increased political attention, and the merging of breast cancer awareness with corporate interests had immense power in solidifying the breast cancer survivor identity and expanding the public presence of breast cancer support (Klawiter 2000). What solidified the visibility of breast cancer as a key emerging health issue was the creation of the pink ribbon. "Ribbon culture," or the use of a colored ribbon to symbolize awareness and support for a given cause, had long been intelligible to the American public (Moore 2007). For instance, a yellow ribbon was used to represent support American troops during the Gulf War.[8]

Recognizing the collective symbolism tied to the yellow ribbon, the activist organization Visual AIDS created its own red ribbon to boost the cultural consciousness for those affected by HIV/AIDS (King 2006). The color red symbolized the need to cut the red tape (i.e. excessive bureaucracy) that hindered action during the HIV/AIDS epidemic (Packard et al. 2004). It was also intended to promote a militant response to the complacency and seeming lack of urgency in the epidemic (Parker 2000). The militancy

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[8] A yellow handkerchief, scarf, or ribbon had already long meant that was one grieving the absence of a loved one, possibly dating back to the Civil War (Parsons 1991). Popular examples included John Wayne's 1949 film "She wore a Yellow Ribbon" and Tony Orlando's 1973 hit song, "Tie a yellow ribbon 'round the ole oak tree." During the Iranian hostage crisis, the yellow ribbon quickly became a symbol of support to bring the hostages home safely. At the start of the first Gulf War, the yellow ribbons resurfaced as a means of showing support to bring the troops back home safely.

gave way to the mainstream, and the first red ribbon U.S. postage stamp hit production lines in 1993. The HIV/AIDS campaign and its red ribbon served as an example for other "communities of suffering," (Packard et al. 2004), including those pushing for breast cancer awareness. Interestingly, federal spending for breast cancer had already increased immensely from $40 million in 1981 to $407 million in 1993 (King 2010). It seems politicians had caught on to the galvanization and strength of women's organizations as platforms to spread scientific and medical developments. It was also certainly an advantage that breast cancer was a politically and socially neutral investment for the government, as opposed to HIV/AIDS.

By the early 1991, the Susan G. Komen, the largest organization for breast cancer education, advocacy, and social events, had already made pink their trademark color.[9] While Komen's platform of treating cancer appealed to some, others affected by breast cancer gravitated towards the National Breast Cancer Coalition, whose color remains maroon and who promises to end breast cancer through better prevention research. The National Breast Cancer Coalition wanted to follow the lead of their politically charged contemporaries in the HIV/AIDS movement by demanding answers and better funding, and empowering themselves by learning the fundamentals of epidemiology and medicine. Meanwhile, grassroots initiatives had started to crop up, including that led by 68-year old Charlotte Haley, who passed out peach-colored ribbons to influence local and national legislators to make breast cancer prevention, not treatment, a top priority (King 2006).

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[9] The Susan G. Komen Foundation has routinely come under fire. Issues include *pinkwashing*, or the branding of potentially carcinogenic products with a pink ribbon (Sulik 2012). Founder Nancy Brinker also officially stepped down after a falling out when the foundation stopped supporting Planned Parenthood in the United States. According to charitable watch group Charity Navigator, Brinker's annual salary (despite stepping down) is around $685,000, which is well above the norm for CEOs of charitable organizations much larger than Komen (see Sulik 2012 for more critique of the Susan G. Komen Foundation).

The women's magazine *Self* together with cosmetics mogul and breast cancer 'survivor' Evelyn Lauder (of Estee Lauder) approached Haley, who rejected Estee Lauder's commercial approach and declined to allow the magazine to reproduce her idea (Fernandez 1998). For *Self* and Lauder, the solution was simple: they needed to change the color, and settled on pink (*ibid.*). According to Estee Lauder's website, the Estee Lauder Breast Cancer Awareness Campaign has since 1992 spread into seventy countries around the world and raised $53 million dollars for breast cancer research and education (BCACampaign.com). In fact, it is the Estee Lauder version of the breast cancer awareness campaign that is currently present in Austria and is described throughout this dissertation.

There is no copyright on the pink ribbon, meaning that it can be used by companies as far ranging as Avon Cosmetics to the National Football League. Throughout the late 1990s and 2000s, "pink ribbon culture" expanded widely within American public life, from U.S. postal stamps, to the largest 5K running race in the world, to the entire month of October devoted to breast cancer awareness (King 2006; Sulik 2012). Although there are multiple sects of the breast cancer awareness campaign, the dominant mode is symbolized by the iconic pink ribbon, relies upon biomedicine, private industry and consumerism, and emphasizes agency, valorization, survivorship, optimism, and femininity (Klawiter 1999; Sulik 2012). Paradoxically, the 'fight against breast cancer' and the 'war on cancer' are softer, friendlier, and *pink.*

The Problems with Pink

Despite the ubiquity of breast cancer awareness, it is not universally endorsed and has been critiqued from various angles ranging from the power dynamics of cause marketing to the emphasis on individual agency. One general critique is obvious: with billions of dollars donated and spent on research and education, why is breast cancer still a major threat to women's health? There are ethical implications to asserting that we will have a cure if we just 'fight hard enough' when there is little scientific evidence to suggest that a panacea for breast cancer will be found if more research dollars are donated.

The ubiquity of the pink ribbon stands in stark contrast to the shame and secrecy once suffered by those with the disease (Lerner 2000; Lorde 1980; Sulik 2012). In the U.S., women with breast cancer thankfully no longer need to fear that a breast cancer diagnosis will be stigmatized as shameful (Klawiter 2008). This outward discussion of breast cancer has been a major factor in reducing the stigma of breast cancer, and it enables survivors to take more control over their illness experiences, thereby alleviating feelings of helplessness and hopelessness in the face of breast cancer. In the popular notion, the pink ribbon stands not only a symbol of hope for an elusive cure for breast cancer and raising awareness for mammograms, but also as a metaphor for encouraging "hero-survivors" to be valiantly and aggressively at war with cancer, while paradoxically remaining cheerful, hyper-feminine, and optimistic (King 2006; Mathews 2009; Sulik 2012). This conceptual framework reflects the power of cultural influences on how the afflicted describe and embody the illness experience of breast cancer.

There is a call for attention to the serious aspects of breast cancer and the fact that dealing with breast cancer is a time of "uncertainty, obscurity, and ambiguity" (Skott 2002:230), which is not adequately reflected within the cheerfulness of the breast cancer awareness campaign. This issue is particularly salient to women with metastatic breast cancer, who unfortunately face much poorer prognoses. Behind these dominant cultural metaphors of optimism and survivorship, there is a world of uncertainty and a constant negotiation of self-identity among those with breast cancer (DeShazer 2013). Because of this, some women either reject or modify the meaning of being a survivor in ways that counter and alter the underlying messages of the awareness campaign (Kaiser 2008). This in turn begs the question of whom the campaign is representing, what it is promoting, and if it is actually creating a sense of support.

Promoting annual mammographic screening as unequivocal healthy behavior for women over 40 also raises ethical issues. Recent robust epidemiological studies have failed to show a benefit of screening women under 50. From a public health standpoint, regular mammographic screening of asymptomatic women has a limited benefit in terms of mortality reduction. It also comes along with a host of potential harms, including costly and burdensome biopsies as well as false or missed diagnoses. In an article published in December 2014 in the Journal of the American Medical Association, the estimated harms and benefits of annual mammographic screening over ten years of 10,000 50-year old women are as follows: 302 will be diagnosed as having breast cancer, 173 will survive with treatment regardless of screening, 10 deaths will be averted, 57 unnecessary diagnoses will be made, 62 deaths will occur despite having been screened, and 940 will have an unnecessary biopsy (Jin 2014, figure 1.2.). It is noteworthy that breast cancer advocates from a host of orientations have not used these unbiased data as a motivation to demand a more reliable method for screening. This appears to represent the unwavering trust in biomedical progress within the ‘fight against breast cancer,’ as well as a blatant misuse and misinterpretation of statistics.

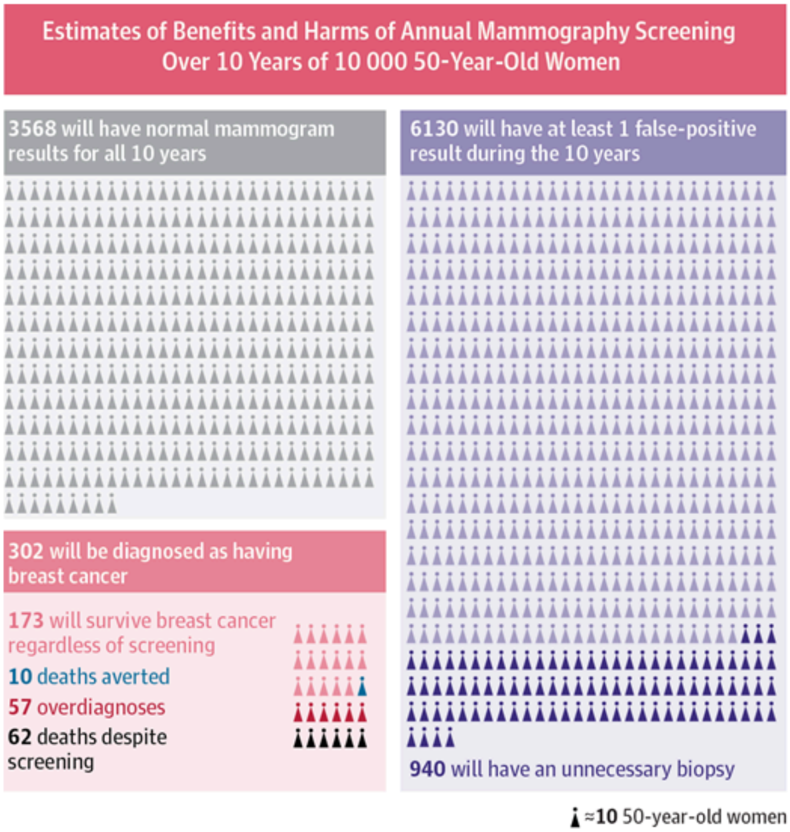

Figure 1.2 The estimated benefits and harms of annual mammographic screening. This graphic is reproduced from Jin 2014.

The dominant breast cancer awareness campaign, symbolized by the pink ribbons, is also criticized for its emphasis on traditional tropes of beauty and promoting an image of survivors with full heads of hair and intact breasts. This emphasis on femininity is incongruous to women who have to come to terms with losing their hair and breasts. The other issue is pink ribbon kitsch, including everything from infantilizing teddy bears (Ehrenreich 2009, Varga 2009) to handguns (King 2006). In addition, slogans like “save the *tatas*,” while trying to come across as humorous and light, send the message that breasts are more important than women, or that a woman’s life could be equated with her breasts.

Corporations sponsoring pink ribbons have questionable conflicts of interest, so much that a counter-campaign *Think Before you Pink* formed in 2002 to urge people to be critical of the commercialization of the disease and to make companies selling pink ribbon-products be more transparent about *how* they actually support breast cancer (Harvey & Strahilevitz 2009; Moore 2007; Sulik 2012). 'Pinkwashing,' which is analogous to 'greenwashing,'[10] or the spread of disinformation to feign an environmentally responsible image, is also present in certain pink ribbon products. Pinkwashing happens when companies that can contribute to cancer risk disseminate or sell products, or financially support breast cancer awareness organizations (Pezzullo 2003). A recent example is hydraulic fracturing mogul Baker Hughes donating a massive sum to Susan G. Komen and manufacturing one thousand pink ribbon drill bits under the slogan "doing our *bit* for the cure" (Baker Hughes 2014). It can also refer to companies that appear to be donating to breast cancer organizations, when in fact they profit from women undergoing treatment for breast cancer. In a broader sense, it refers to misleading consumers who believe that they are making a donation to breast cancer research, when in fact only a nominal amount from a sale will be donated.

Strong criticism is also levied against the movement for its "tyranny of cheerfulness," (King 2006) which can obscure the reality of hardship that women with breast cancer endure, stigmatize those who express their frustrations with having breast cancer, reinforce stereotypical expectations of femininity, and create the illusion that passive social interaction (i.e. purchasing products with pink ribbons) creates real social change (Jain 2007, 2013; Varga 2009). To be the naysayer of ostensible efforts to end breast cancer is an unpopular position. That has not stopped social media sites and news

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[10] Greenwashing is spreading misinformation or selling products that present an environmentally responsible image, while actually incurring damage to the environment.

reports, notably among them the New York Times, from whistleblowing activities and inviting social commentary on all of the serious aspects of breast cancer that get obscured within the popular portrayals of the disease (Sulik 2012).

While the survivor label is deeply meaningful to many living with cancer, it can also be seen as problematic. For one, it is troublesome to attach the term to many who will eventually pass away from the disease. Did they not 'fight' or 'think positively' enough? Are they somehow weaker than those who survive longer? In my interviews among American women with breast cancer, some reported the expectations of being a hero-survivor burdensome, particularly at a time when breast cancer poses a major challenge in life. The felt as though it was at times difficult to speak out about their worries and fears. One woman told me how she received a bracelet with pink ribbon charms and the word 'survivor' on it from a well-meaning friend after finishing chemotherapy. After initially hiding it in a corner of a closet, she eventually gave them back to the sender. She explained to me, "My friend could not understand why I didn't want it. I hate that stuff. I know what I went through, and I don't need a ribbon to tell me I'm strong. *I'm* the one who has to live with the fact that this cancer could come back no matter what I do. But of course, I came out looking like the bad guy." In other words, the issue is that the presence of pink ribbons on postal stamps, yogurt lids, or bumper stickers does not actually provide opportunities to truly cope with the immense stress and pain that breast cancer engenders. The cheerful, light atmosphere of the campaign also does not always allow for women to openly express these difficulties.

Gayle Sulik writes, "Pink ribbon culture is geared more toward encouraging people to feel good about the cause than to acknowledge the often difficult and un-pretty realities of a breast cancer diagnosis" (2012: 18). With the feel good, fun and cheerful campaign, it is easy to overlook major issues in breast cancer disparities in the U.S. One major issue that is often overlooked by the breast cancer awareness campaign is the startling disparities in breast cancer mortality in the U.S. (Sulik 2012). For instance, breast cancer incidence rates among non-Hispanic white women in the U.S. are consistently higher than rates among black women. Despite lower incidence rates, black women have higher rates of breast cancer mortality than white women (Siegel et al. 2014).[11] Anthropologist Suzanne Heurtin-Roberts critiques the discourse of disparities in the U.S. for its link to "very real divisions of power and status in U.S. society that result in the alienation and disenfranchisement of particular groups on the basis of ethnicity and economics" (2009: 199). While some use genetic reductionism to explain breast cancer disparities (see Carey et al. 2006), others caution against ignoring structural factors such as lack of access to treatment in exchange for privileging the genetics and the reification of race (Dai 2010). This issue is given very little attention and funding within "pink ribbon culture" (Sulik 2012).

This is obviously only a small fragment of the history of how breast cancer became socio-politicized and a major part of the American cultural landscape. The works of Maren Klawiter (2008), Jackie Stacey (1997), Ellen Leopold (1999), Barron Lerner (2001), Samantha King (2006), Gayle Sulik (2012), Robert A. Aronowitz (2007), Barbara Ehrenreich (2009), S. Lochlann Jain (2007, 2013), and Mary DeShazer (2013) all provide excellent overviews of breast cancer in the United States. This description is intended to

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[11] In 2014, incidence rates of breast cancer among black women were 118.4 and 127.3 (per 100,000 population) among non-Hispanic white women. Mortality rates among black women were 30.8 as compared to 22.7 (per 100,000 population) among white women. Five-year survival rates increased among white women from 76% from 1975-1977 to 92% from 2003-2009, while rates among black women only increased from 62% to 79% within the same time periods (Siegel et al. 2014).

illustrate the particular political and cultural aspects, including the grassroots initiatives that went into the breast cancer awareness campaign in the United States. The idea of spreading an idea so rooted in American cultural, historical, and political underpinnings points to a potential discordance and tension when implemented in different contexts. As the breast cancer awareness campaign and its pink ribbons globalize, it is important to recall that the constituent parts of its history do not always get carried along with it. This point reverts back to the question of what a women's health campaign actually intends to do when it is not driven by the community of sufferers it seeks to benefit. This leads to a skeptical view of the homogenization of sociocultural representations of breast cancer through the global branding of the pink ribbon.

Julie Livingstone writes, "a woman in North America with breast cancer will experience her disease at least partially in relationship to a set of expectations around what breast cancer is and what treatment might entail, further crystallizing some boundary around this disease." (2012:53). Experiences of cancer, while individual, are highly influenced by the sociocultural and political economic contexts in which someone gets sick. In the U.S., these "sets of expectations around what breast cancer is" elicit the ideas that shape how to respond to the disease in preventative and therapeutic means, in risk perception, how one copes, and the identities of those enduring breast cancer. At the same time, these expectations come with significant historical, cultural, and political baggage that at times reflect and other times obscure the illness experience of cancer (Coreil et al. 2004; Kaiser 2008; Mathews 2000). This dissertation looks at the broader social processes that are breaking down these cultural, historical, political, and medical boundaries, and what that can signal about emerging trends in women's health.

Theoretical Orientation

Critical Medical Anthropology

The strength of a medical anthropological approach is the ability to connect multiple social, cultural, and structural processes with in-depth and personalized accounts of sickness and healing. This research draws through two prominent orientations– critical medical anthropology and experiential/interpretivist medical anthropology– to understand the various ways in which women respond to the neoliberal underpinnings of modern biomedical and public health paradigms.

Critical medical anthropology emerged out of the key social and economic theoretical developments of the late 20th century, including world systems theory and the rise in Marxist/materialist anthropology, as a means to understand the social production of health and sickness. Thus, the critical medical anthropological approach sees the "structure of social relationships that give rise to and empower particular cultural constructions" of illness (Baer, Singer & Susser 2003:34). Furthermore, the critical approach calls into question the effects of biomedicine's profit-driven endeavors and how the state fosters corporate involvement within biomedical practice (*ibid.*).

Critical medical anthropology likewise encompasses poststructuralist theory that rejects biomedicine as an objective, value-free, and static enterprise. Foucault's notion of *biopower* (1980) has been a particularly useful device for understanding how the power of the state and biomedicine is exercised through the surveillance of bodies. This insight on the objectification and discipline of the body has profoundly impacted how medical anthropology conceptualizes the body within webs of power and knowledge (Lock 1993).

Feminist-oriented critical medical anthropologists have also exposed the ways in which women resist biomedical constructions, metaphors and discourse surrounding the body (Martin 1987; Rapp 1988).

Anthropologists have drawn upon this notion to understand how power of the state is exercised through the regulatory and disciplinary practices employed on the body politic. In the biomedical conception, health problems are objectified as technological problems, thereby making biomedical technologies tools for implementing surveillance over bodies (Lock & Nyugen 2010). The concept of risk within epidemiological statistics and public health has also been subsumed into biopower (Lupton 2003; Petersen & Lupton 1996). Statistical models of risk based on population-wide estimates function as a technology of governance that decontextualizes lived experience and reconstructs the body as source of vulnerability and pending danger (Lock 1996; Lock & Nyugen 2010). For instance, the history of the breast cancer awareness campaign in the U.S. demonstrates how control over women's bodies has changed drastically since the early 1900s from one of seeking early treatment to proactively searching for breast cancer though the use of mammograms.

This work strives to synthetize critical medical anthropology within an experiential analysis of how women draw upon intersubjectivity and cultural norms of gender to make sense of breast cancer within the broader contexts of their lives. Thus, it takes on a meaning-centered and a critical approach (Good 1994). This coalescence owes much to the groundbreaking work of Margaret Lock and Nancy Scheper-Hughes (1987), who suggest three angles through which "the mindful body" can be explored, including the phenomenologically experienced body-self, the social body which stands at the nexus of nature, culture, and society, and the body-politic, which represents the body as a product of social and political control. I strive to overlap these units of analysis, including the individual subjective and the macrosocial, as a means of elucidating how the broader processes within the world system come to bear on the process of meaning making and how they can obscure illness-related suffering.

Anthropology of Cancer

Ethnographies of cancer are at the core of the critical and experiential approaches within medical anthropology. How cancer develops, is diagnosed and treated, and shapes the lives of those affected is both reflective of and shaped by micro and macro social, cultural, and political economic processes. At the same time, cancer remains a largely unexplained and incomprehensible disease that stems from a complex interaction between factors both internal and external to the body. The complexity of the condition evokes universal ontological aspects of the human condition, including intersubjectivity, risk, danger, curing, healing, and the fragility of life.

Medical anthropologists have given attention to the cultural meanings, metaphors, and social identities that order and organize the anxiety surrounding cancer (Balshem 1993; Chavez et al. 2001; Gordon & Paci 1997; Hunt 1998; Kleinman 1988; Weiner 1999). Metaphors offer insights into the ways that people with cancer come to terms with the newfound social and cultural worlds encountered after a diagnosis (McMullin & Weiner 2009). Likewise, delineating and comparing cancer metaphors can also shed light on the suffering incurred from global cancer disparities. Anthropological work also grasps how people regain a sense of agency and find new possibilities that chronic and complex diseases like cancer cast onto an individual's life (Honkasalo 2008). Hence, an interpretive and experiential approach to anthropological work on cancer can reflect the deeply meaningful ways that cancer changes lives.

One means of understanding how people experience cancer is through sociocultural representations of cancer. Susan Sontag's seminal work (1990[1978]) on the metaphors of tuberculosis and cancer demonstrated that the ways with which people live out their illness is inherently shaped by sociocultural representations and constructions that are subject to change over time (see also Thorne & Murray 2000). Moscovici (1984) solidified a theory of social representations in which coherent ideas surrounding particular social phenomena, such as cancer, become commonsensical and direct the modes of behavior and the ways in which people orient themselves within everyday life. Social representations vary based on their origin and purpose. For instance, a hegemonic social representation is often shared by and reflects the dominant social group, and has the ability to more broadly influence how society thinks of a particular social artifact (*ibid.*). Social psychologist Michael Murray (2002) introduced the concept that narratives are in constant negotiation with broader representations of illness. Mark Nichter also extended theoretical perspectives on social representations to reflect the principles of critical medical anthropology within studies of global health, namely, to understand representations as socially constructed and situated within unequal power dynamics (2008). He writes,

> "The popularity of representations and the rationalities [representations] propagate beg examination given cultural heterogeneity, unequal distribution of knowledge and power within societies, contests of meaning and the subtle and not-so-subtle agendas of stakeholders" (2008: 5).

The fact that “Breast Cancer Awareness Month” is the brainchild of pharmaceutical giant AstraZeneca (Schrader-Frechette 2007) is a prime example of how representations are tied to stakeholder interests and hierarchies of power. Thus, sociocultural representations of cancer, like that of “pink ribbon culture,” or the idea of survivorship, call for an analysis of the motivations driving these representations (Thorne & Murray 2000). Throughout this dissertation, I oscillate between the construction of the breast cancer awareness campaign as a novel representation within Austria and experience-near accounts of breast cancer. Narratives allow social scientists to ascertain the degree to which someone with cancer ascribes to or rejects a representation of cancer (Murray 2002), while Nichter’s insights direct anthropologists to go upstream and situate representations– and people’s ability to speak for or against them– within broader webs of power.

The anthropology of cancer is a rich venue for exposing the authoritative knowledge of biomedicine and the ways in which biomedicine conceptualizes and acts upon risk, prevention, and the proper ways to ‘survive’ cancer (Chavez et al. 1995; Good et al. 1990; Good 1995; Lock 1996). The fear and dread surrounding cancer, in addition to its persistent deviance and resistance to fit into straightforward, Fordist terms of the body make it a target for the biomedical gaze (Weiss 1997). The construction of the body as a place of pending danger medicalizes a healthy body and reorients it under the control of biomedicine, despite the fact that the screening for most cancers remains inefficient, and that genetics hardly represent the complex etiology of cancer in most cases. Using surveillance as a means of controlling the deviant, cancerous body (Kaufert 1996, 2000; Keating & Cambrosio 2000) is a hallmark of biopower (Foucault 1978, 1991). Screening as a technology of governance and biopower labels bodies as permanently risky and subjected to the constant supervision of biomedicine. In the exercise of biopower, installing modes of surveillance ensures the productivity of the body politic.

The link to control and productivity makes the rise in cancer screening also reflective of the integration of public health within the current neoliberal paradigm (Petersen & Lupton 1996). Rather than simply a set of practices or policies, neoliberalism is a Weltanschauung in which each actor is assumed to have personal responsibility over their success, health, and wellbeing (Chavez 2009; Heurtin-Roberts 2009; Lyon-Callo 2004). It is this orientation that allows not only for the diffusion of cavalier search-and destroy surveillance methods like mammography, but also the notion that screening is responsible, rational behavior.

The discourse of risk control within public health assumes that individuals can constantly be taking actions to mitigate disease and maximize their health (Lupton 1993). It follows that people who choose to not take actions to reduce adverse health events are placing themselves in danger, incurring costs in the healthcare system, and reducing their ability to be productive citizens (Lupton 1995, 2003). Within the risk control paradigm, the availability of mammography to detect breast cancer in its earliest stages has transformed the disease into a silent but perpetual threat to women's bodies (Lupton 1995). It follows that women whose breast cancers are detected in more advanced stages did not follow the imperative to have their breasts screened often enough, thus implying carelessness, lack of responsibility, and a moral failure to correct the body's deviance.

Examining this neoliberal leaning within public health is particularly compelling within critical medical anthropology due to the persistent failure of screening (such as mammography or PSA tests) to prevent deaths from cancer.[12] In relation to this work, Lock & Nguyen assert that an ethnographic approach enables an evaluation of taken-for-granted, epistemological assumptions of knowledge and truth in calling for medical anthropological work that examines "the way in which scientists, health policy-makers, and publics are all caught up in culturally informed realities that are sometimes mutually reinforcing, and at other times divisive" (2010: 1505). In other words, the unequivocal promotion of screening for cancer as simply moral behavior is a biomedical and public health construction. This points to the subjective and interest-laden construction of knowledge of cancer and the ways in which epidemiological statistics can be wielded to suit the interests of biomedicine and public health.

The concept of 'survivorship' also presents a facet of the forms of erasure incurred by the neoliberal turn in treating cancer. For instance, the breast cancer awareness campaign labels women with breast cancer as 'survivors,' and in turn transformed the social expectation to not speak publicly about one's personal illness into a moral duty of being optimistic, strong, and outspoken in informing other women to attend screening (Ehrenreich 2009, Willig 2011). Furthermore, in many European

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[12] Statistics for prostate cancer are inconclusive with regards to reduction in mortality (Eckersberger et al. 2009). The debates over mortality rates and screening for breast cancer persist, but very optimistic estimates report a reduction in mortality of 10 women per 100,000 women over the age of 50 who attend regular screening (Jin 2014). There are also limited benefits for annual mammograms for women under 50, which prompted the American Cancer Society under the direction of Dr. Otis Webb Brawley to change the official recommendations on when and how often women should receive mammograms. In personal communication with Dr. Brawley following a presentation at the National Cancer Institute, he explained how both the American public and American clinicians strongly resisted the change in the recommendations despite the statistics, and the recommendation was reversed. In addition to showing the misinterpretation of epidemiological statistics (Gifford 1986; Gigenrenzer 2002), I believe this shows the unflinching belief on the part of Americans in the benevolence and duty of biomedicine to take all necessary steps to control cancer.

nations, state-run cancer rehabilitation clinics foster the idea that if patients govern themselves by setting goals, they can and should return to their productive pre-cancer selves (Hansen and Tjørnhøj-Thomsen 2008). The emphasis on being a 'productive survivor' however does not reflect the vicissitudes and ambiguity inherent to living with cancer (McMullin & Weiner 2009). Controlling the norms of conduct through survivorship is a form of governance (Foucault 1991; Rose 1999) that forces those with cancer to repress their struggles with treatment side effects and fears over cancer recurrence and to take individual responsibility for their health (however tenuous that state of health may be).

The turn towards charitable campaigns and cause marketing for cancer presents another avenue to explore the influence of neoliberalism on experiences of cancer. Nikolas Rose (1999) outlines how the neoliberal market spurred the diffusion of power from political and non-political actors into everyday, civic life in local communities. In her aptly titled book on cause-marketing strategies for breast cancer *Pink Ribbons, Inc.*, Samantha King builds on Rose's insights to show how proper citizenship is about achieving civic duty though the consumption of cause-related products. In buying or wearing products to 'support' cancer, the rational, responsible citizen contributes to the broader mission of finding the 'cure' for cancer while displaying a persona of being an ethical consumer. These factors together show how the sale of pink ribbon products with the intention of 'buying into a cure' and striving to help women with breast cancer in the local community wind up reinforcing the neoliberal paradigm. In a similar vein, the spread of charitable campaigns to provide help for those with cancer also reflects the current post-welfare state in which care for others is interpreted as moral, civic duty, rather than the responsibility of the state (King 2010). The fact that Austria, among many other European nations, is considered a welfare state also presents an interesting facet within the corporatization of cancer campaigns. This is due to the general expectation that care for cancer is the responsibility of the state, not a charity or individual donations. Thus, depoliticized consumption and charitable donations have become commonsense, moral means for people to handle the ‘problem of cancer’ without ever having to confront the real issues at hand or demand political answers for the persistence of cancer disparities and the relative inefficacy of cancer screening and therapies.

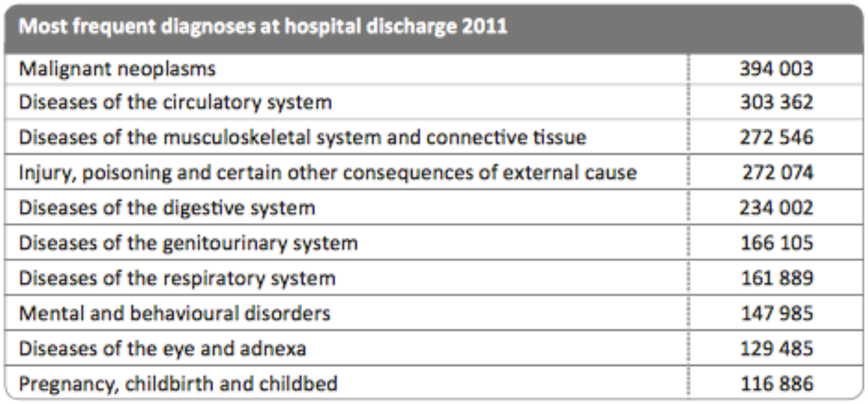
This dissertation seeks to engage with these multiple perspectives on the anthropology of cancer and critical medical anthropology more broadly. In doing so, I aim to answer the call to for anthropologists to perform ethnographic work on the “technologies of governance” within the globalization health policies (Castro & Singer 2004; Nichter 2008). However, I also strive throughout to use the strength of the ethnographic approach to ground critiques of broader social and political economics within on-the-ground lived experience of breast cancer. In doing so, this work presents an in-depth account of how the global, neoliberal paradigm is shaping the social artifacts of breast cancer and what this means for women with and without breast cancer. Although the spread of the breast cancer awareness campaign and the pink ribbon function to streamline and homogenize experiences of breast cancer, I am reminded of McMullin & Weiner’s (2009) call to use cancer as a means to elucidate and understand difference at individual, sociocultural, and political economic levels. This approach invites anthropologists to ask not only what is masked by the spread of the pink ribbon and breast cancer awareness, but also to point out how people regain agency and assert their needs, even when they stand in contrast to the aims of the campaign. Thus, an anthropological view can draw from the lived experience of breast cancer to point out the limits of the neoliberal approach to promote personal responsibility and to convince people that consumerism translates to activism. Medical anthropologists can call into question the idea that public health campaigns such as the breast cancer awareness campaign are mutually beneficial by examining directly how much each side profits. By striving to show how and where the campaign fails, this work uses multiple forms of data (see Appendix A) to shed light on opportunities to holistically improve women's health and wellbeing.

Breast Cancer in the Austrian Context

What follows is a brief description of breast cancer epidemiology, as well as the treatment and early detection methods available within Austria. While breast cancer is a significant public health threat among women in Austria, treatment and supplemental care for breast cancer is on a global scale very good. The rise in private health insurance, in addition to the centrality of the breast cancer awareness campaign within the Ministry of Health and Austrian Cancer Society, set the stage for understanding how the (post)-welfare state of Austria is becoming increasing corporatized and privatized, and what that means for the experience of breast cancer and conceptualizations (and misunderstandings) of breast cancer risk.

Economic and Demographic Factors

Austria (population: 8.46 million) is a small (84,000-km^2), landlocked democratic republic in central Europe. Sixty-six percent of people in Austria live in urban regions throughout Austria's nine provinces. Austria's gross domestic product per capita is approximately $50,430, making Austria one of the wealthiest nations in the world (World Bank 2015). Life expectancy for women is 83.3 and for men is 78 (Statistik Austria 2015). The age structure however is increasingly aging and birth rates remain below replacement level. The percent GDP spent on social security and medical services is approximately 11% and those legally living in Austria receive excellent social security (World Bank 2015; Ministry of Health 2013).



Most frequent diagnoses at hospital discharge 2011	
Malignant neoplasms	394 003
Diseases of the circulatory system	303 362
Diseases of the musculoskeletal system and connective tissue	272 546
Injury, poisoning and certain other consequences of external cause	272 074
Diseases of the digestive system	234 002
Diseases of the genitourinary system	166 105
Diseases of the respiratory system	161 889
Mental and behavioural disorders	147 985
Diseases of the eye and adnexa	129 485
Pregnancy, childbirth and childbed	116 886

Source: BMG 2012, calculations: GÖG/ÖBIG

Table 1.1 Most frequent diagnoses at hospital discharge in 2011, as cited in *The Austrian Health Care System, Key Facts, updated version 2013* (Ministry of Health 2013)

Breast Cancer Statistics

As shown in table 1.1, malignant neoplasms, or cancers, were the most frequent diagnoses at hospital discharge in 2011. In general, cancer statistics in Austria reflect those of other high-income nations, meaning that cancer a serious and costly public health issue. Breast cancer is the most frequently diagnosed cancer among women, followed by lung and colon cancer (Zielonke et al. 2014). Approximately 5,000 women are diagnosed with breast cancer each year and there are currently over 64,000 women living with breast cancer (*ibid.*). The age-standardized incidence rate for breast cancer is 90.7 (per 100,000 women per year), which falls below the average in the European Union (EU) of 108.8 (Ferlay et al. 2013). Although incidence rates have increased since 1986, mortality rates have started to decline (Zielonke et al. 2014). The latest estimate for the breast cancer mortality rate is 21.3 (per 100,000 women), which is roughly on par on with the E.U. average of 22.4 (*ibid.*), meaning that the incidence to mortality ratio is slightly worse than the EU average. Survival is also improving, and now on average 84.7% of women diagnosed with breast cancer will survive at least five years after their initial diagnosis (*ibid.*).

Privatization of the Healthcare System

While the healthcare system in Austria is one of the best in the world, access to healthcare is not equally distributed. One cause for this is the increasing privatization of the Austrian two-tiered healthcare system, which consists of compulsory government health insurance as well as an option to enroll in any number of private insurance plans, or *Zusatzversicherung*, at an increased cost. Current estimates indicate that 34% of the population has some form of private health insurance (Versicherungsverband Österreich 2013). Even without a plan, patients can offer to pay for medical services out-of-pocket with the potential to receive a partial rebate from the state. Although it is technically illegal to offer better care to those with private insurance, those with the additional coverage have shorter wait times and longer clinical visits with medical practitioners.

Breast Cancer Screening and Care

Out of Austria's 273 hospitals, none are dedicated specifically to cancer treatment. Furthermore, there are only four teaching hospitals with cancer clinics. Only about half of women with breast cancer are treated in quality-certified breast health centers (Neunteufel 2015). The current aim of the Certification Commission is to have all breast health centers certified by 2016, but this may be unrealistic given the fact that some provinces have no certified centers (*ibid.*). In my experience, women diagnosed with breast cancer were often unwilling to travel to the nearest certified clinic or teaching hospital to seek treatment. Care for breast cancer is therefore relatively varied if a woman is diagnosed in an urban or rural region.

Patients can participate in clinical studies sponsored by groups such as the Austrian Breast and Colorectal Cancer Study Group, which work in clinics across Austria. In an effort to increase overall access to care for those in rural regions, all cancer patients can obtain a free taxi service to attend treatment (figure 1.2). All patients also have a right to receive psychological therapy, a stay in a health resort (*Kur*) or oncologic rehabilitation, obtain partial reimbursement for a wig, and be treated with certain forms of complementary medicine. Breast cancer patients can also obtain breast prostheses (see Bouskill & Jäger forthcoming).

Figure 1.2. Patients ride in the 'cancer treatment taxi' in the rural region of Northern Styria to a clinic in the small city of Bruck an der Mur.

The Austrian Cancer Society (*Österreichische Krebshilfe*) is a not-for-profit organization that works with the government to inform the public about cancer prevention and screening, provide help for patients and their families, and enable continuing education for doctors. The federal Austrian Cancer Society is also home to *Pink Ribbon Austria*, which has been its central project and arguably receives the most attention from the organization. Pink Ribbon Austria is the leader of the breast cancer awareness campaign, and the manager of the campaign informed me that she would like the Austrian Cancer Society to hold a monopoly on the use of the pink ribbon in Austria. The breast cancer awareness campaign, sponsored by Pink Ribbon Austria, is the main focus of this research. The Austrian Cancer Society depends on charitable donations from a host of sponsors. Sponsors also have the ability to donate exclusively to campaigns like Pink Ribbon Austria to ensure that funds are devoted only to breast cancer. The Austrian Cancer Society and Pink Ribbon Austria are headquartered in

Vienna, but the Cancer Society has regional offices in the nine Austrian provinces. Its specific duties for patients include offering informational materials and events, psychological therapy, dietary consultation, and securing financial assistance for those in need throughout their treatment. In addition, psychosocial support is available through regional cancer self-help groups, which have existed for decades, but are not very well attended. The Austrian Cancer Society also recently developed a computer application to offer information on various forms of cancer, help patients keep track of their therapy, write a diary, and even listen to relaxing music.

In addition to spreading information on breast cancer and providing financial assistance for women with breast cancer, the Austrian Cancer Society/Pink Ribbon Austria devotes a significant amount of energy to the secondary prevention of cancer through early detection or screening. The consensus among health policy scholars is that Austrian society is not oriented towards primary preventive health measures for cancer (Jäger 2011). Given these challenges and the relatively low influence personal behavioral factors have on breast cancer risk, the Ministry of Health together with the Austrian Cancer Society has focused on secondary, rather than primary preventive strategies. It is important to note that prevention in this sense is the prevention of death. Primary prevention refers to the prevention of the development of a disease or condition. Secondary prevention refers to finding a disease or condition before symptoms arise. Tertiary prevention is the control of a disease or condition so that no further harm is done. Quaternary prevention refers to palliative care to prevent the spread of pain and discomfort. Most importantly, secondary prevention through screening does not prevent the development of breast cancer; however, as shown in chapter four, this appears to be a major misconception among Austrian women.

In 2005, the Ministry of Health (MOH) also restructured the program *Vorsorge Neu* (English: Prevention Revamped) in order to promote cancer-screening tests, including mammography. Overall participation in screening programs for mammography is low, especially in lower socioeconomic groups and those from an immigrant background in comparison to those born in Austria (Brunner-Ziegler et al. 2013; Wimmer-Puchinger, Wolf, & Engleder 2006). After multiple delays throughout 2013, in January 2014 the MOH enacted a universal breast cancer-screening program, whereby women aged 45-69 received an invitation by post to attend mammographic screening by a certified radiologist every two years. Women between 40-44 and 70-74 could opt in if they chose. Due to extremely low attendance, poor advertising, political pressure, and confusion over the purpose of the exam, the program was cut in Summer 2014, only months after its initial enactment. An invitation is no longer required, women can attend screening annually starting at age 40, and women over 75 can continue to attend screening. However, these concessions (i.e. attending mammographic screening at 40) go against current public health guidelines for mammograms (Jin 2014).

The MOH also offers genetic testing for those at high risk for the two genetic mutations known to dramatically increase breast cancer risk, BRCA I and BRCA II. Women must fulfill certain criteria in order to be eligible for the test without cost, including a certain number of breast or ovarian cancer cases in her family, or cases of cancer before a certain age. Those who test positive can opt for mastectomy and oophorectomy (removal of the ovaries) and breast reconstruction.

On a global scale, Austria offers excellent care and security for those diagnosed with breast cancer. The main issue is in access to the top-notch care, meaning that most receive very good care, while some (mostly those in urban areas/near teaching hospitals) receive excellent care. Many of the pros and cons of breast cancer care in Austria, including concrete areas for improvement, are discussed in chapter three.

Chapter Overview and Key Questions

The following chapter takes a closer look at cultural constructions of cancer. Cultural constructions of cancer impact the ways in which people interpret and react to a diagnosis and create social labels for those with cancer. These also shape and are shaped by institutional actions towards controlling cancer through research and systematic preventative measures. In particular, it looks at the cultural schema with which meanings and metaphors of cancer arise in the United States and Austria. In addition, this exploratory section sets the stage for understanding the particular American cultural constructions of cancer that have contributed to the wide success of the cancer awareness campaigns and the ‘fight against cancer’ in the United States. This is coupled with Austrian constructions of cancer, in which I draw from cultural historians, casual conversations, literature, the media, and the Catholic ‘sensibility’ pervading Austrian society. Although this view is gradually losing hold, the traditional Austrian cultural reaction to cancer is rooted in a resignation to fate and the private aspects of suffering. This comparison serves as a framework for understanding why some of the key facets of the American-style breast cancer awareness campaign, including the idea of being forthright and taking on a survivor identity, are discordant in Austria. The following questions are addressed in chapter two:

›What are the cultural constructions of and responses to cancer in Austria? What metaphors are used to comprehend cancer? How do these responses differ from American reactions to cancer, and what can that say about the tensions in bringing a campaign rooted in the American cultural construction of cancer into a novel context?

As phenomena such as the breast cancer awareness campaign globalize, they inherently take on new forms, aims, and meanings (Appadurai 1996, 2001). While the campaign has retained many of its recognizable symbols and messages, the ways women with breast cancer engage with and are portrayed by the campaign have changed significantly throughout its global flow into Austria. This section begins by juxtaposing the use of the pink ribbon at a posh Viennese gala with mourners wearing it at the funeral of a 28-year old woman who died of breast cancer. The former intends to show the exclusivity of the campaign and how the absence of women going through the disease at the gala event undoes any real advocacy or awareness for the disease. In contrast, funeral mourners wearing the pink ribbon on their lapels demonstrates how the symbol has become a global means of showing that people are united in caring, suffering, and grieving the lives that are taken by the disease. Throughout this descriptive chapter, I draw from examples of pink ribbon products, events, and media campaigns to describe the *Pink Ribbon Austria* awareness campaign and its on-the-ground enactment. Pink Ribbon Austria fits into Austria's history of charitable organizations, which tend to not actively or systematically engage the communities of suffering they seek to aid; however, no other community of suffering in Austria is as populated as the community of women living with breast cancer. Women with breast cancer took issue with the exclusivity of the campaign. Participant observation confirmed this exclusivity in terms of accessibility of campaign events, cost and applicability of pink ribbon products, and the sexualized images used by the campaign. In short, the campaign fails to connect with women affected by breast cancer and promotes a misleading representation of breast cancer that is highly incongruent with the breast cancer illness experience. Chapter three covers these questions:

›How is the global flow of breast cancer advocacy being interpreted, re-worked, and re-made in new contexts? How are Austrian women with breast cancer responding to the breast cancer awareness campaign and publicity surrounding breast cancer? How well do the images, symbols, and products of the campaign reflect the illness experiences of women with breast cancer? How well does the campaign address the needs and gaps in breast cancer care in Austria? How are the neoliberal underpinnings of the campaign exercised within this particular global flow?

Chapter four explores the discourse of risk and personal responsibility as it pertains to breast cancer within the recent neoliberal turn in public health. I incorporate epidemiological data on breast cancer risk to demonstrate how little is known about the etiology of the disease. I then compare this lack of knowledge to ethnographic data collected at multiple breast cancer informational sessions (most in conjunction with the breast cancer awareness campaign), which continually emphasized personal behavior in order to reduce the risk for breast cancer. This chapter also presents the results of a survey distributed among Austrian women without breast cancer to assess understandings of breast cancer risk and the purpose of mammographic screening. I speculate as to why women appear to be misinformed in regard to these factors and substantiate my hypotheses using images, claims, and materials used in the campaign. I draw upon reactions from women with breast cancer to infer that the discourse of personal responsibility to control one’s risk for breast cancer is not only misguided, but also creates an unnecessary sense of guilt among women with breast cancer. Overall, this chapter shows how the many informational sessions guided by the rhetoric of risk serve the aims of the breast cancer awareness campaign at the expense of addressing women's needs. The following questions are addressed throughout this chapter:

›What messages are being promoted by the biomedical community and interest groups in regard to breast cancer prevention, screening, and treatment? How accurate are these messages given our current epidemiological knowledge of breast cancer? How are these messages interpreted by women 'at risk' for breast cancer and women who have breast cancer? How do women with breast cancer respond to discourse of risk, especially considering how much remains unknown about the etiology of breast cancer?

Like most forms of cancer, breast cancer lacks a clear etiology. Diseases with ambiguous causalities create gaps that allow for the afflicted to create their own understandings of illness within the contexts of their lives and life histories. Exploring the question "why did breast cancer happen to me?" is a subjective and intersubjective experience. I hypothesized that Austrian women would not report a definite underlying cause for their cancer, but rather would see cancer as an uncontrollable fate that is part of the human condition. Contrary to this hypothesis, more than half of the women who took part in semi-structured, narrative interviews believed emotional distress caused their cancer. Emotional distress emerged from tensions in fulfilling their social roles as women, mothers, wives, daughters, and workers and a lack of harmony within their lives. I describe this belief in relation to the continued stigmatization of women with breast cancer and social support following the diagnosis more broadly. I describe differences in beliefs about breast cancer across age. In addition, I show how the emotional distress explanation plays into making positive changes in one's life following a diagnosis. Overall, this chapter shows how the campaign does little to speak to the experience of breast cancer and meaningful beliefs women hold about its cause. The questions below are explored in this chapter:

›How do women with breast cancer interpret the cause of their cancer? What does this say about gender relations? How do beliefs about cancer etiology and stigmatization affect support seeking for breast cancer? What actions do women take following their diagnosis? How do women's illness narratives speak against the idea that one can control breast cancer? What are biomedical perspectives on the link between emotional distress and the onset of cancer?

Chapter six describes data from a social epidemiological project investigating the impact of breast cancer among long-term survivors. An estimated 64,000 women living in Austria have been treated for breast cancer, and the number of breast cancer survivors is expected to increase (Zielonke et al. 2014). While some studies show that a cancer diagnosis can initiate positive changes in one's life, another body of literature reveals long-term disruptions caused by the diagnosis, side effects of treatment, and survivorship on body image, self-esteem, sexual function and health, career issues and financial problems (Zebrack 2008). With the number of breast cancer survivors increasing, it is important to be able to examine the relationship between various treatments, sociodemographic factors, and the perceived impact of cancer on survivor quality of life. The findings show that an overall positive perception of the impact of cancer can contribute to improved physical health-related quality of life. However, a perceived overall negative impact of cancer can worsen both physical and mental health-related quality of life. Surprisingly, perceiving an overall positive impact of cancer did not have an effect on mental health-related quality of life. These initial findings point to the need for further investigation and more attention to the growing population of breast cancer survivors. Long-term survivors are rarely discussed within the breast cancer awareness campaign, despite their growing numbers and important mental and physical health needs. The following questions are addressed in this chapter:

›What are the long-term impacts of living with breast cancer? How are these factors addressed within the breast cancer awareness campaign? How can we begin to think about ways to encourage a more positive impact (or even neutral) impact of cancer in order to improve long-term health among survivors? What can medical anthropology contribute to studies of breast cancer survivorship?

Overall, this dissertation looks at the dimensions of the global spread of the breast cancer awareness campaign into Austria from the following vantage points: a cultural level (cultural responses to and representations of cancer), women 'at risk' for breast cancer, women undergoing treatment for breast cancer, and long-term survivors.[13] The concluding remarks draw from these perspectives to offer recommendations to improve approaches to controlling breast cancer. Lastly, I suggest future directions for critical medical anthropologists, anthropologists of public health, and anthropologists of women's health to critique the current trend of corporatizing, marketing, sexualizing, and homogenizing cancer illness experiences and women's health more broadly.

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[13] A brief note on my perspectives as a researcher throughout this dissertation: I have experience in basic science research in oncology and have performed years of volunteer work with patient organizations. In addition to my education in Medical Anthropology, I have also received a Master of Public Health degree with a specialization in Epidemiology. First and foremost I am a medical anthropologist; however, readers may notice that my analysis is influenced by my dual training and my background experience in volunteering with cancer patients.

CHAPTER TWO: CANCER AS A FIGHT, CANCER AS FATE: COMPARING CULTURAL RESPONSES TO CANCER

In the fall of 2013, president of the Austrian National Council Barbara Prammer announced, “Yes, I have cancer” in a press conference. With her statement, she became one of the first prominent Austrian politicians to be forthcoming and public with her diagnosis.[14] Prammer, who was respected in Austria, provided few details, except that she would continue to hold office,[15] which her doctors emphasized was an absolutely sound decision, that she would “fight,” and that “this is not a reason to give up” (*Kurier*, September 24, 2013). While the diagnosis came as a shock to the active and lively Prammer, the press likewise was shocked that she would be candid with her disease and would take such a great stride toward “countering the stigmatization of cancer patients.” Even her oncologist noted what an “unusual step” Prammer took in being forthcoming with her diagnosis. This was echoed by a fellow long-term politician who hoped for a “change in the current mentality [of cancer],” noting “in Austria, you can be anything except ill, because a disease will be seen from everyone as a weakness.”

Interestingly, the paper mentioned, “If Prammer were an American top politician, we would know precisely what type of cancer she has and what her plans for therapy are.”[16] This reflects in part the American expectation that politicians should lead transparent lives, as well as the openness and forthrightness with which Americans

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[14] Political journalist Kurt Kuch, who passed away in early January 2015 of lung cancer, was also an outspoken advocate for speaking out about cancer and leading the current anti-smoking campaign. In February 2015, Minister of Health Sabine Oberhauser also came forth with her cancer diagnosis and publically appeared in the media without a wig following chemotherapy treatment.

[15] As of July 2014, Barbara Prammer announced that she would unfortunately have to give up her duties for the time being due to complications with her treatment for cancer and an infection.

[16] This sentiment was later echoed following Prammer’s death in an interview between oncologist Professor Christoph Zielinski and Armin Wolf from the Austrian Broadcasting Corporation (*ORF*, August 4, 2014).

address cancer. In other words, the American style of openness in regard to cancer is a source of bewilderment for Austrians, who are more likely to wish to retain their privacy following a cancer diagnosis. Prammer instead was praised for her efforts in trying to lift "cancer's persistent aura of deadliness." The press was right; if Prammer were American, the nation would have likely known the intricate details of her form of cancer and prognosis right from her hospital room. But most of all, she would be heralded as a hero, not just for being forthcoming with her cancer, but simply by nature of having cancer and proclaiming that she would fight. Why would it be so extraordinary to be open with a cancer diagnosis in Austria? Why would someone be valorized for having cancer in the United States?

Barbara Prammer lost her life to cancer in August 2014, just ten months after her diagnosis. The sad news came as a shock to those who had assumed, as her doctors emphasized following her diagnosis, that she could continue to work and would recover.[17] Through the end of the summer, the nation mourned the death of the political pioneer, and confronted the general anxiety surrounding cancer in a host of media reports and interviews.

This work explores the constructions of cancer in Austria and the United States and how these differences can shape the illness experience and social labels of those affected by the disease. By constructions of cancer I mean the metaphorical, visual, historical, structural, political, cultural and discursive ways in which cancer is represented and how people react to it (see Skuse 2014; Thorne & Murray 2000; Willig 2011). The

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[17] Prammer passed away on August 2, 2014. After her death, the press broke the news that Prammer was diagnosed with pancreatic cancer, which is an aggressive form of cancer that is associated with high mortality rates (Yadav & Lowenfels 2013). It is puzzling that she and her doctors proclaimed that she could continue to hold her position in office given the nature of her diagnosis. This does however reflect the traditional cultural response of shutting cancer out and not discussing (nor valorizing) it.

breast cancer awareness campaign is rooted in American conceptualizations of cancer, which are colliding with traditional Austrian conceptualizations of and reactions to cancer. An exploration of cancer metaphors, socially ascribed roles of those with the disease, and discourses of cancer shed light on variations within cancer illness experiences. The globalization of the breast cancer awareness campaign is introducing novel ways to conceptualize the disease in Austria, while simultaneously downplaying the sociocultural particulars of living with breast cancer. The focus is on the United States and Austria because the breast cancer awareness movement grew out of the dominant construction of cancer within the United States before its subsequent globalization and implementation in the Austrian context.

Culture and Cancer

Despite wide variation in the forms and severity of cancer, screening and treatment availability, and the demographics of those affected, one common thread throughout experiences of cancer is the need to make sense of the disease. The complexity of cancer does not lend itself to straightforward explanations of its onset, prognosis, or recovery. Much of this meaning-making is related to the fact that biomedicine lacks both clear etiologic models for the host of diseases grouped under the term cancer and completely effective means of treating them. Unlike heart disease, cancer cannot be explained in Fordist or mechanical terms of the body (Weiss 1997). Heart disease is often interpreted as the inevitable degradation of the body's machinery and is not as ridden with meaning as cancer is. In contrast, cancer is seen as a pandemic symbolizing the anxiety of the postmodern, late capitalist era whereby the disease breaks down boundaries between self and other within the body and defies rational explanations of causality (*ibid.*). In many ways, how cultures grapple with cancer mirrors how they respond to the anxieties engendered by globalization and rapid social change.

Anthropology engages with the struggle to provide explanations for cancer, the expression of cancer metaphors, cancer disparities, stigma, and the altered social identities of those with cancer (McMullin & Weiner 2009).[18] Cancer is only one such disease subject to various different cultural interpretations. For instance, mental illness is also strongly shaped by cultural beliefs (Ozawa-de Silva 1996).

Cultural responses and representations of cancer are rooted in historical, sociopolitical, and sociocultural contexts. Instead of being static, these meanings of cancer are in dynamic interchange with sociocultural representations of illness and health and can change over time (Murray 2002; Weiner 2009; Winskell et al. 2011, 2013). Cultural constructions of cancer shape the ways in which people react to those facing a cancer diagnosis and how those with cancer make sense of the disease in their lives. Tapping into the uncertainty of cancer invokes questions that touch on universal mysteries of life, suffering, and the inevitability that death can strike unexpectedly.

The chapter is intended to give a broad overview of the cultural schema with which people react to and make sense of cancer. Furthermore, it sets the stage for understanding the nuanced ways that women with breast cancer interpret, contest, and amend these metaphors within their individual illness narratives. While this chapter

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[18] I purposefully resist calling those with cancer ‘cancer patients’ or ‘cancer survivors.’ One can still struggle or worry over cancer and yet not be a patient, and others resist the hero metaphor inherent to being a ‘survivor.’ It is my place as an anthropologist to critique these labels, not to assign them. In this work, I only use the term patient as it is used in the biomedical context, as this reflects both the literature, and the idea that a patient is under the care of the biomedical practitioner.

mentions commonalities in global metaphors of cancer, the emphasis is on Austrian cultural attitudes towards cancer, illness, and death. Interspersed throughout are distinctions and differences in relation to American constructions of cancer, which help to set the stage for understanding the tensions and discordances inherent in transporting the breast cancer awareness campaign into the Austrian context. The chapter begins with an explanation of how metaphors infuse meaning into the illness experience, followed by a survey of metaphors of cancer and the theoretical underpinnings of why cancer is subjected to an excess of meaning, one result of which is its transformation into metaphors, and another is stigmatization. The chapter follows by exploring the dominant and traditional constructions of cancer in the United States and Austria, and why these constructions are contextually shaped. I continue with an in-depth description of the cultural models of cancer, illness, and death. This is supplemented by a survey of articles reviewed from the popular Austrian news magazine *News*, as well as the views of women with breast cancer.

As the breast cancer awareness campaign globalizes, the constructions of cancer in which it is rooted can be discordant with local ways of responding to and representing cancer. For example, the unrelenting optimism and survivor identity that are tied with American constructions of cancer are culturally incongruous with traditional Austrian ways of handling the hardship of cancer. The cultural exchange through the globalization of the breast cancer awareness campaign is creating novel constructions that arguably poorly reflect the lived experienced of breast cancer. These discordances point back to the overarching research question: What is the sense behind the globalization the breast cancer awareness campaign into Austria? To what degree does it adequately reflect the illness experience of breast cancer?

While culture plays a significant role in shaping concepts of health and illness, I not want to lean so far into modern anthropology's interpretive turn as to conflate what Farmer (2004) calls "structural violence" for cultural difference, particularly in regard to cancer treatment and cultural models of cancer (Chavez et al. 1995; Hunt 2001). In other words, that which can be misinterpreted as a cultural belief often stems from a manifestation of material poverty, oppression, and gender politics (Gregg 2003). In addition, I operate under the assumption that dominant cultural constructions of health and illness are real, and such constructions impact human health (Broesch & Hadley 2012; Dressler & Bindon 2000; Gravlee 2009). Insights from cognitive anthropology demonstrate how these constructions are operationalized as "cultural models" (D'Andrade & Strauss 1992; D'Andrade 1995), which Dressler notes are, "a blueprint, or schematic," adding that how cultural models are "realized in practice will depend on the conditions in which individual try to implement the cultural models distributed in their society" (Dressler 2011: 128. It is important to note that these cultural models are neither static nor uncontested, and it is critical to understand the distribution of cultural beliefs when striving to understand health outcomes (Coreil et al. 2004, 2012; Broesch & Hadley 2012). These cultural concepts act as a template for how to make sense of cancer. An individual interpretation will inherently stand in relation to a dominant cultural construction of cancer through agreement, modification, or rejection. In regard to cancer, such constructions are rarely neutral or mundane, but rather elicit deeper ontological questions that are shaped by a sociocultural context.

Cancer as more than a disease

Nearly forty years ago, famed writer and social critic Susan Sontag learned she had advanced breast cancer. Shocked by her diagnosis and the damning stigmatization she encountered as a result, Sontag published a polemical treatise on the burden caused by the metaphors used to describe, assign, and stigmatize the 'dreaded' diseases, including historically tuberculosis and currently cancer. Disease, the physical disorder within the body, comprises only part of the suffering endured by the ill, she contended. The other insult is the social suffering invoked by the metaphors and meanings assigned to diseases, and in her case, the interpretation of breast cancer as a "disease of insufficient passion," among women who cannot adequately express their emotions, and cancer more broadly as a synonym for evil and scourge (Sontag 1990[1977]: 24). This excess of meaning through the use of metaphor is a means of controlling the fear of a disease where "causality is murky, and for which treatment is ineffectual" (*ibid*: 58). Through metaphor, cancer is transformed from a physiological disorder into an interpersonal problem that places an additional burden on the sick. Sontag's aim was to elucidate the metaphors attached to diseases like cancer so that those diagnosed can reside in the "kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped" (1990[1977]: 4). Sontag's hope was that as more effective treatments for cancer and more fundamental understandings of its etiology developed, the disease would rid itself of its excess of meaning. Unfortunately, science and biomedicine have failed to fully understand cancer etiology and produce effective therapies for most cancers. Cancer remains a representation of a bodily and social disorder, a breakdown of boundaries, and a lack of control from within. A central reason for the weighty metaphors and excess of meaning of cancer is the universal struggle for control over the body and bodily deviance (McMullin & Weiner 2009; Weiss 1997).

Foucault outlined how modernity and the modern age of biomedicine "replaced salvation" as the manifestation of a moral life (1975: 198). Good (1994) elaborated on this by demonstrating how biomedicine claims to offer healing through both physiological and soteriological dimensions, and how the advent of biomedical screening and treatment brought morality into illness and healing (*ibid.*). Because cancer is a hallmark of a lack of bodily control and discernible borders, blurred lines between self and other, it is particularly vulnerable to biomedical control.

The process of controlling the angst and enigma surrounding cancer creates the double burden of being diseased and ill. Medical anthropology draws a distinction between the biological aspects of being sick (disease) and the socioculturally constructed lived experience of being sick, healing, and meaning-making (illness), the latter of which is inextricably tied to sociocultural conditions (Brown, Gregg & Ballard 1994; Young 1982). Disease is a deviation from a biomedically-defined state of normality, whereas illness reflects the sociocultural and cognitive constructions of mental and bodily distress (Kleinman 1978). People living with cancer face both disease and illness, in addition to permanent changes to their identities, as well as social roles and responsibilities (Garro 1994; Good 1994; Hunt 2001; Jackson 2005). As Hunt succinctly states, a chronic disease "does not permit one to go on living in an undisputed, familiar world (2001: 88; see also Good 1994). The fragility of cancer remission prohibits a return to state of full health, which can stand as a representation for the indeterminacies and imponderables of daily life.

One way of accessing the illness experience of cancer is through an analysis of the metaphors used in association with a particular condition. The ways we comprehend and engage with experiences in life, from the mundane to the exceptional, are largely shaped by the use of metaphor (Lakoff & Johnson 1980). With metaphor, we begin to comprehend experiences, add value to them, and redirect our actions and thought processes in regard to them. Clifford Geertz explained how “in metaphor one has, of course, a stratification of meaning, in which an incongruity of sense on one level produces in an influx of significance on another” (1973: 210). Metaphors redirect phenomena in a way that we might believe is comprehensible (Lakoff & Johnson 1980). Thus, it turns that which is incomprehensible into something that can be cognitively grasped. As philosopher Paul Ricouer aptly noted, “the metaphor is not the enigma but the solution of the enigma” (1978:146). It also directs the actions we take toward a particular illness. For example, when cancer is labeled ‘evil,’ it warrants the act of regular cancer screening to control bodily ‘deviance’ and the pending danger of cancer (Kaufert 1996, 2000; Keating & Cambrosio 2000). Therefore, by abstracting difficult phenomena into metaphors, we envision something concrete, understand it and negotiate a new meaning for it. These new meanings can enable personal agency, as is the case particularly in the U.S. where cancer is perceived as a ‘journey’ or challenge that makes the afflicted stronger (Coreil et al. 2012).

In regard to illness, the use of metaphor is part of a process of making sense of suffering learning to cope with an illness (Gibbs & Franks 2002). To add metaphor to the cancer experience is to cognitively exercise control over the unsettling lack of control over the disease. Overall, illness metaphors are a means of classifying cancer, ordering the chaos of cancer, communicating suffering and fear, and constructing subjectivity (Gibbs & Franks 2002; Kirmayer 1992). In other words, that which is incomprehensible about cancer becomes deflected onto different social and interpersonal planes. Attaching metaphors to such a highly charged, pervasive, severe, and elusive condition like cancer reflects a process of rationalizing the cognitive dissonance of a harmful disease we cannot seem to grasp (Lupton 2003).

One common thread throughout global cancer illness metaphors is the way in which cancer evokes mystery, fear, and a feeling that both the self and society are experiencing a lack of control. In fact, a description of cancer as a loss of control is present across ethnographic accounts including Austria (Jäger 2011; Lammer et al. 2007), China (Lora-Wainright 2010), Mexico (Hunt 1998), Greece (Karakasidou 2009), Italy (MJD Good 1995), Israel (Weiss 1997), Brazil (Gregg 2003), the Czech Republic (Kozikowski 2005); Great Britain (Stacey 1997), United States (Balshem 1993; Schaepe 2011; Sontag 1990[1977]), Latina immigrants in the US (Chavez et al. 1995, 2001), the Czech Republic (Kozokowski 2005) and Slovenia (Ramšak 2008).

Borrowing from Jackson's (2005) insights on chronic pain, cancer invokes a state of being betwixt and between, in both Douglas' sense of "matter out place," (1966), and Turner's (by way of van Gennep) notion of being in a state of liminality, which can create a collective sense of *communitas* among those with cancer (Stoller 2004, 2009; see also Turner 1969). Cancer cells, by nature of them stemming from the self and yet functioning as foreign entities, fit well to the notion of cancer as something 'taboo,' or not fitting into a clearly defined category. (Douglas 1966). Stoller's auto-ethnography builds on Turner's notion of liminality in representing the way in which remission from cancer creates a state of being not sick but not well, as the specter of cancer recurrence looms (2004, 2009). Struggling to embrace liminality demonstrates an attempt to come to terms with the ambiguity and lack of control that cancer instigates in the life course (*ibid.*).

While metaphors shape the frameworks with which people try to grasp the uncontrollable aspects of cancer, they also enact at best new social labels for those living with cancer (McMullin & Weiner 2009). Thus, as Sontag rightly noted, these metaphors can also be harmful, as controlling the fear of cancer can also mean associating those with cancer with a stigmatizing excess of meaning. But as Moerman notes "urging human beings to stop attributing meaning to phenomena is as plausible as urging us to stop breathing" (2002:150). In this sense, Sontag's call to disabuse ourselves of the meaning attached to cancer or interpreting cancer as solely a natural disease dehumanizes suffering and is a "form of self-alienation, of false consciousness" (Scheper-Hughes & Lock 1986: 138). In other words, the point is not to make cancer devoid of meaning, but to mitigate social suffering and remove the blame

The harsh metaphors of cancer as dread and deviance do not exist in isolation; rather, they promote the social distancing away from those with cancer. In contexts where cancer remains stigmatized, both blaming and shaming one for having cancer, those without cancer cope with its unpredictability, dread, and the feeling that it could strike others on a whim by channeling attention away from those with cancer and focusing elsewhere through the process of *othering* (Balshem 1993; Murphy 1987). The control over cancer also arises in one’s social identity through the label of cancer as one’s “master status” (Goffman 1963). Goffman (1963) solidified a theory of stigma as a sociological process through which an individual is marked as unacceptably abnormal within the social milieu, and where one’s mark of difference becomes a point of judgment and exclusion. The stigmatization of those with cancer concretizes the symbolic and metaphoric aspects of cancer into a burdensome illness experience. Stigma then becomes a way for those without cancer to manage the ambiguity and disorder of cancer and demonstrates the ways in which the boundaries of the body become intertwined within the social body (Craddock-Lee 2009; Douglas 1966).

As biomedical technology became a promise for health throughout the last four decades, the stigmatization of cancer began to lift and the “disease of insufficient passion” gave way to metaphors of war and battling a foreign invader (McMullin & Weiner 2009; Ramšak 2008). These physiological aspects lead to the metaphors of cancer as polluting, war-like, plague-like, demonic, monstrous, and contribute to its status as a meaningful, highly charged illness that needs to be proactively controlled (Hunt 1998; McMullin & Weiner 2009). These metaphors of cancer as war set up the body as a struggle over control, and reinforce to those without cancer that their bodies are orderly, functioning, and healthy (Lupton 2003). From another angle of deviance, farmers in Crete see the rise in cancer incidence as a metaphor for the descent of westernization and the expectation that to live the “quality life,” society must modernize and industrialize agriculture, thereby introducing damaging carcinogens (Karakasidou 2009). Cancer in this context signifies the struggle over modernization as deviance within traditional ways of life, the result of which is the inevitability of death (*ibid.*).

Cancer as a fight in the United States

In the United States, war is the dominant metaphor for cancer and other disorders (Napier 2010). In common parlance, Americans speak of those *battling* cancer, those with cancer are labeled medically and socially as *survivors*, and scientists are actively *defeating* cancer. Oncologist Siddhartha Mukherjee meticulously traces the metaphorical shifts in cancer that emerged from the 1950s and into the 1970s. He writes,

> "Every era casts illness in its own image. Society, like the ultimate psychosomatic patient, matches its medical afflictions to its psychological crisis; when a disease touches such a visceral chord, it is often because that chord is already resonating" (2010: 182).

Mukherjee explains how in the 1950s, Americans dealt with threats from external invaders, particularly Cold War-related nuclear obliteration, locating the main threat to society external to American borders. By the 1970s, the fears, and therefore the metaphors had shifted. The Vietnam War had divided the nation and the issues of civil rights and poverty forced people to acknowledge the problems from within. The wholesome, intact ideal of American post-World War II life had decayed and given way to protest and unrest. It was no longer the threat of the nuclear bomb, but rather the invisible threats from within the society and the body itself. Cancer then became a metaphor for danger from within, and an enemy that must be sought out and destroyed.

At the same time, since the end of World War II, this generation enjoyed a level of wealth and prosperity never before experience. This fueled the desire to become and stay healthy and ultimately to evade an early death (Patterson 1987). This generation had seen political leverage successfully put to use to various scientific advancements, including the atomic bomb and the lunar landing (McMullin & Weiner 2009; Patterson

1987). How could they not rally such wealth and scientific progress to defeat cancer once and for all? When President Nixon signed the "war on cancer" bill into effect in 1971, the nation believed strongly that cancer would soon be a thing of the past (Patterson 1987). Political discourse of war appears routinely and clearly resonates with the American public. Nixon's "war on cancer" was preceded by Johnson's "war on poverty" and followed by Reagan's "war on drugs." American children today have no conception of life without the interminable "war on terror." Putting cancer in the same style of political agenda of war shapes the cognitive framework to be one in which cancer is an enemy and something to be punished. Over forty years later, American cancer institutions and advocacy organizations are rallying the community under the slogan, "find the cure," which demonstrates the unwavering hope and belief that scientific progress will prevail over cancer.

The audacity in the American ethos to push the boundaries of science and to deny death as long as possible is tied together with the notions of survivorship, heroism and hope within the American constructions of cancer. Mary Jo Delvecchio Good describes the political economy of hope in which the push for advancements in American oncology works to enhance the sociocultural emphasis on hope in regard to cancer outcomes (1990).[19] To be pessimistic or to give up hope would simply appear un-American and

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[19] Mary-Jo Delvecchio Good et al. (1990) conducted this research on oncology practices among 51 oncologists at Harvard University teaching hospitals, which they equate with perspectives of American oncologists. Harvard physicians emphasized hope, the promise of treatment and technology, and truth-telling (i.e. disclosure) with cancer patients. The biomedical discourse of hope places the patient's control over their treatment compliance within a sense of moral duty. Instilling hope in patients is seen as an absolutely "critical dimension of their care", whereas in Japan and Italy, non-disclosure is (or at the time was) seen as "protective" and "paternalistic" (1990:68). But the degree to which Harvard oncologists represent all American oncologists can be called into question, as McMullin, Chavez & Hubbell (1996) found differences in the cancer discourse among powerful university physicians (Harvard would be at the top of the hierarchy) and community-based physicians.

would go against the individualistic and progressive spirit of the people. The result is that the militaristic offense of American oncology can make a death related to cancer appear to be the fault of the individual of the medical team or a lack of will from the patient (Erwin 1987; Sontag 1990 [1977]; Stoller 2004).

Thus, the American model is one that stresses individual and personal responsibility for recovery from cancer (Balshem 1993; Mathews 2009). A related concept is Talcott Parsons' classic functionalist notion of the "sick role." The sick role is a form of socially sanctioned deviance that exempts a sick person from their daily routines and duties for a short time with the expectation that the sick person will eventually fully recover and return to their normal social roles (Parsons 1951). Parsons (1951) outlined four major components of the sick role, which are summarized well by Lupton (2003:4),

> "Ill persons are exempted from the performance of social obligations which they are normally expected to fulfill; they are not blamed for their condition, and need not feel guilty when they do not fulfill their normal obligations; however, ill people must want to try and get well. If they do not, they can be accused of malingering; and being sick is defined as being in need of medical help to return to 'normality'- the sick must put themselves into the hands of medical practitioners to help them get well again."

As Lieban (1973) rightfully noted, the conceptualization of the "sick role" is grounded in a middle-class, American experience. This was also central to Klawiter's (2008) notion of the breast cancer "regime of medicalization," in which women hid their illness and returned to their duties as quickly as possible. The liminality cancer induces and threat of recurrence– being 'not sick but not well'– challenge the 'sick role' for those with cancer. In part due to decades of activism in the America, those with cancer have finally come

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out of their stigmatized shadows (Mukherjee 2010), but the result was the transformation of the sick role into the survivor role, in which those living with cancer are encouraged to be forthright as a means of getting others to proactively control their risk for cancer.

Hence, instead of dwelling in the liminality and ambiguity of being in remission yet always threatened by cancer recurrence, I suggest that the American notion of *cancer survivorship* is a biomedically- and socially-ascribed means of controlling identity, reconciling the disconnect with the 'sick role,' and transforming those with cancer into 'hero-survivors' who stand as models of courage for the rest of society (Kaiser 2008; Mathews 2009). Being a 'survivor' transforms the culpability within stigma and the ambiguity of 'not sick but not well,' into the duty of being optimistic and feeling a moral imperative to survive (Balshem 1993; Ehrenreich 2009, Willig 2011).[20] In this sense, the survivor label can be interpreted as the other side of the coin from stigma, as both invoke a permanent change to one's identity whereby the fact that the individual has had cancer becomes one's 'master status' in Goffman's sense, and both draw upon an excess of meaning in order to shut out the fear surrounding cancer. But just as Sontag advocated against attaching harmful metaphors to cancer, these hegemonic metaphors of survivorship are also creating particular challenges for those with breast cancer who do see these metaphors and roles as unrepresentative of their illness experience at best and a denial of the actual hardship of going through cancer at worst (Jain 2013; Kaiser 2008; Willig 2011). Worse yet, these hegemonic metaphors can lead to a sense of failure if cancer recurs (Coreil, Wilke & Pintado 2004).

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[20] As described in the introduction, some aspects of survivorship are taken on by some American women with breast cancer (Coreil et al. 2004). Other ethnographies of breast cancer support groups and among those with breast cancer show a rejection or a modification of the survivor role (Kaiser 2008; Mathews 2000, 2009; Sulik 2012). This theme is also discussed in the introduction.

Another prominent metaphor among those with cancer in America draws upon cancer as a "journey" and "inspiration" to explore new meanings in life; thus, the liminality of cancer allows those with cancer to imagine new directions in life and seek out self-actualization (Mathews 2009). Many with cancer also emphasize and practice the discursive act of testimonials, whereby they openly profess how strength and optimism carried them through their experience (Coreil, Wilke & Pintado 2004; Erwin 2009), sometimes even to the point of one-upmanship (Coreil, Wilke & Pintado 2004). Thus, part of the American model is the expectation to not only find the positive aspects of having cancer, but to be forthcoming and open about these revelations to others.

This is of course a broad generalization of cultural models of cancer. Anthropologists have documented numerous examples of how people contest, resist, or modify these cultural models (see Balshem 1993; Bell 2012; Bouskill 2012; DeShazer 2013; Jain 2007, 2013; Kaiser 2008; Klawiter 2008). For example, in my ethnographic research among thirty women with breast cancer in the Midwestern United States, gallows humor became a compelling way to speak back against the portrayal of breast cancer survivors as cheerful and hyper-feminine. In general, people construct their illness experiences and give meaning to cancer in relation to these dominant cultural models (Murray 2002). The following section provides a similar overview of responses and reactions to cancer in Austria, which again are a generalization, but will give a broad impression of how people conceptualize and speak of their cancer illness experiences. It also provides a basis with which to understand how the mentality of cancer has shifted over time due to changes in the political discourse, biomedical innovation and rhetoric of cancer risk, and the corporatization of cancer activism. Although Austria is in the so-called ‘West,’ it presents a different construction of cancer. However, with multiple parties holding a vested interest in making cancer ‘awareness’ public, constructions of cancer are always in a state of flux. This section attends to the traditional and dominant mentality of cancer to provide a basis for understanding how change is happening in the current iteration of the globalization of cancer awareness.

“Time and Chance befall us all”: **Austrian cultural constructions of cancer**

In Austria, traditional metaphors of cancer reflect a construction of cancer that is rooted in a loss of control and in resignation. As this section will demonstrate, various factors, including the American-style model of “hope” in oncology and the awareness that one can continue to live a full life following a diagnosis, are starting to shift the dominant cultural ways of reacting to cancer. Nevertheless, those subscribing to and opposing this almost traditional construction still discuss cancer as an uncontrollable part of one’s fate. This is coupled with a general tendency in Austria to remain reserved and private in regard to one’s illness and to be more accepting of tragedy as a part of life.

That does not keep cancer from being a topic of conversation. In small villages and in Vienna alike, I often heard people talking about others with cancer. At times, the tone was one of concern, while at others it could be interpreted as gossip. Conversations about others with cancer were also seen as a means of showing appreciation for one’s fortune in life, as in “We have it so good. This young mother just lost her life to cancer and left behind young children.” Cancer was also at times quickly dismissed in conversation without much follow-up or detail. For instance, I witnessed an exchange between two friends in their early 50s, Helga und Alexandra,[21] in the locker room of a fitness center. The two women were discussing Helga's mother's cancer diagnosis:

> "You know, I heard she's got pancreatic cancer. [sigh] That's life."
> "Mmhmm."
> "I mean, she's in her 70s. She's at that certain age. Everyone dies, you know?"
> "Are they doing anything for her?"
> "Well, I heard that the issue now is if she'll get the fourth dose of chemotherapy. But she's doing okay, except for all of the thoughts running through her head these days. But I guess that's just how it is."
> "Yep."

The conversation ended and the women switched topics to a recent ski trip. Of course, a snippet from a brief exchange does not tell us about the nuances of how people interpret cancer, and this did appear to be on the extreme end of the Austrian norm of resignation. In addition, Austrians, in particular the Viennese, practice the distinction of "appearing and being," or *schein* und *sein*, which separates one's public persona from one's personal persona. That is to say, these women likely saved their grieving and sadness for their private domains. Thus, this conversation reflected the broader Austrian cultural norm of accepting misfortune as part of the human condition, keeping a stiff upper lip, not grieving in public, and demonstrating a low propensity to seek or offer help.

I often heard from both women with breast cancer and others that cancer is simply "fate," or "misfortune." The concept of accepting fate rather than resisting it and trying to change it is part of a broader ethos of life that situates the locus of control outside of the individual. The idea itself is familiar to traditionally Catholic-based societies such as Austria; however, I do not mean to suggest that Catholicism as an organized religion

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[21] All names throughout this dissertation are pseudonyms.

plays an inherent role in how people conceptualize illness.[22] However, the long tradition of Catholicism does provide a way of organizing the social and cultural milieu. This stands in contrast to the Protestant tradition. Historian Lonnie R. Johnson in his text on the history of Central Europe describes Protestant work ethic as,

> "the belief that serving successfully in this world was indicative of having been chosen by God for the next, a conviction that human action had intrinsic meaning and merits and that success was a sign of having been chosen by the Lord. The tradition of Baroque Roman Catholic religiosity, in comparison, emphasized the omnipotence and glory of God and the vanity of human endeavor, and it contributed in this respect to transmitting values that could be called Mediterranean." (1996:120-121).

Johnson's essential point is that the longstanding Catholic-turned-cultural belief is one in the human inability to grasp or control the nature of human existence, suffering and misfortune, and eventually death.

In a similar vein, Vienna also represents "the paradox of modernity without modernization," whose "dark mother" is destiny, acts of providence, and the higher power (Musner 2009: 259, 280). That is to say, Vienna has become a cosmopolitan city that despite its modern facets, remains anchored to its roots in the Catholic Austro-Hungarian Monarchy (Wodak et al. 2009). Within this context, a Catholic God held Divine Providence, followed closely by the ruling emperor of the imperial monarchy (Janowski 2004). This sense of dependency and hierarchy within the monarchy stands in direct opposition to the ideas of American 'frontierism,' where progress and prosperity were perceived in part to be within one's control. Since the collapse of the Austro-Hungarian Monarchy, Austria has experienced multiple regime changes and seen its borders decimated. A Viennese literary scholar who had experienced the desolation of

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[22] In interviews among women with breast cancer, only three women (out of 60) in their 50s mentioned their faith in the Catholic Church. One woman said that she believes in the power of prayer, and the other mentioned that the Church serves as a main source of support for her and that she would not fear death because she knows she would "feel protected by God."

post-World War II Austria explained to me "Austria will never be the first violinist in the global orchestra again. We are just a small country, and we don't think we'll ever rise to prominence again." Given Austria's complicated relationship with its past, it is understandable that Austrians and the Austrian government would not have the audacity to declare "war on cancer," as Nixon did, or to presume that it will be the context in which a cure for cancer is found.

Despite growing religious diversity in Austria, the national identity and bureaucratic structures are steeped in a conservative-Catholic tradition (Thaler 2001). An American scholar and cultural ambassador who has been living in Vienna for almost four decades explained it to me as "the legacy of a Catholic *sensibility*, rather than an actual belief or practice." He continued,

> "In the Bible, in the Book of Ecclesiastes, we learn that 'time and chance befall us all.' It is not about the institution or organizing of the church, but there is a legacy of the sense is that we are not fully in control or self-made, the latter of which is diametrically opposed to the American ideal of working hard in order to fulfill or realize one's dreams. Stripping away the theological accoutrements of Catholicism, you simply have a sentiment that manifests itself with a sense of resignation."

Thus, the overarching sense is that bad fortune can strike at anytime, so one should enjoy a trouble-free life as long as one has the luxury. Even the Austrian idea of *Gemütlichkeit*,[23] which Johnson describes as "the casual, roundabout way of doing things or the ability not to take life too seriously…is one criterion for distinguishing southern German Catholics, like Bavarians or Austrians, from northern German Protestants." He

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[23] *Gemütlichkeit* lacks a clear English translation. In Austria, it is used in a variety of situations. For instance, one can describe a cozy, comfortable space as *gemütlich*. A content, relaxed mood among people can also be described as *gemütlich*. Additionally, it can be used to talk about a state of doing something with leisure rather than having to hurry. Cultural sociologist Lutz Musner (2009) offers an archaeology of *Gemütlichkeit*: Put briefly, in writing about the habitus of Vienna he mentions the social functions of *Gemütlichkeit* as a form of social compensation for the problems of everyday life, social dislocations in the modern and rapid pace of life.

continues, "the Protestant work ethic was based on postponed gratification; the Catholic ethic of *Gemütlichkeit* obviously was not" (1996:121). In fact, *Gemütlichkeit* is often used to differentiate Austrians from the northern German emphasis on assertiveness, efficiency, and diligence (Wodak et al. 2009).

Because misfortune can occur without notice, despite one's virtues and good intentions, one should relish pleasant company and the material comforts of life. Particularly among the older generation (the generation most affected by cancer), there is a *habitus* of a feigned disillusion in regard to misfortune such as cancer. Historian William M. Johnston (1972) recapitulates the notion of *therapeutic nihilism*, which first emerged in the late 19th century in the Medical Faculty of Vienna, in which the role of the physician was simply to assist the patient as nature and fate inevitably took control. The sense was, and to a large extent still is, that the doctor is the only one who holds power over the prognosis of the patient, not the patient. The legacy of this almost disturbing notion is one that emphasizes a staunch obedience to everything a doctor prescribes and advises and leaving the rest to fate. In other words, the patient does not need to will oneself to better health. If treatment does not work at that point, fate has taken over. Furthermore, there is a propensity to not seek out psychological assistance and to remain stoic when facing mental health problems, which was explained to me from a 50-something year old Viennese man as, "After Jesus fell for the third time, he didn't ask to see his therapist."

While it may seem tangential, it is critical to describe this in regard to construction of cancer in order to understand why the forthrightness and even cheerfulness with which Americans treat cancer awareness campaigns would be a key point of discordance in Austria. Thus, the previously mentioned American ideas of personal responsibility to recover from cancer, speaking openly, and testifying to the positive changes cancer has made on one's life (i.e. the sense of being a 'hero-survivor') are foreign in the Austrian context. In other words, to turn one's misfortune into a heroic posture comes across as nearly absurd. For that same reason, I was not surprised that I never once encountered any advocacy for cancer in Austria associated with the audacious notion of "finding a cure." Moreover, the idea of cancer as "fate" does not invite a "fight," which may explain why I heard the word "fight" in only one interview out of the sixty women I interviewed.

War, hero, and survivor metaphors become even more problematic when considering Austria's troubled history. The German terms for hero and survivor, *Held* and *Überlebender*, are almost exclusively reserved for concretely discussing war. War monuments and memorials in Austrian villages remember and honor "the fallen heroes" (German: *die gefallenen Helden*) of World War I and II, two wars that utterly shattered the nation. The term "survivor" is strongly associated with being a Holocaust survivor or a survivor of a Russian prisoner-of-war camp. Despite some resistance to the Anschluss of the Third Reich in March 1938 and the problematic notion that Austria was Hitler's first victim, Austria's reputation is still tarnished by its overall complacency as the Nazis carried out the atrocities of the Holocaust and the fact that Nazism existed in Austria prior to the Anschluss (Karner 2011; Pauley 1992).[24] The irony of course is that for as much as Americans verge on romanticizing and celebrating war with the use of war

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[24] Interestingly, the Nazis had actually made cancer control a top priority and the Nazi body politic prioritized cancer control, including a sophisticated tobacco-related cancer epidemiology and a subsequent anti-tobacco campaign (Proctor 1999), the latter of which is regarded today with contempt by most Austrians, many of whom see smoking as a necessary pleasure in life and worth the health risks.

metaphors, they never faced that level of destruction on their own soil. Austrians are not and cannot be proud of war. Instead, they rally around their post-World War II mandated neutrality, which is a key defining factor of the Austrian national identity (Reinprecht & Latcheva 2003). Therefore, the use of war metaphors and the term "survivor," so widely used in the United States, comes across as uncomfortable and inappropriate.

Along with the sense that people are subjected to fate, death is understood as a manifestation of life, rather than the end of life. The Viennese, more than other Austrians, have a well-known fascination with the aesthetics of death, exemplified by the folk song "*a schene Leich'* " (*Wienerisch*: an attractive corpse) (Holmes & Silverman 2009: 1; Schmölzer 1980).[25] Austrian Actor Josef Hader attributes the Viennese preoccupation with death as the blend of "yiddish humor, black humor, a typical Viennese character trait, and a means of turning the uncomfortable sense of death into something more palatable" (Glass 2012). Hence, the morbidity of death is romanticized and turned into the subject of jokes. In Alpine villages, I heard on numerous occasions from the older generation (and men in particular) that they would rather die than endure a regimen of chemotherapy; in other words, one's physical and mental weakness during chemotherapy is more damning than death, as death is seen as a form of salvation from suffering. This is a stark difference to the American anxiety and avoidance of death, as well as the cultural norm of discouraging the articulation of fears surrounding our own mortality (Comaroff & Maguire 1981; Stearns 2006).

Constructions of cancer in transition

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[25] Cabaret artist Georg Kreisler wrote a song, "Der Tod, das muß ein Wiener sein" (*English*: Death must be Viennese/Death must be a Viennese man) in 1969. The song is still widely known today and has been adapted from other artists, including the Austropop genre's Wolfgang Ambros (Musner 2009).

In order to elicit how Austrian women with breast cancer conceptualize cancer, I asked them to describe cancer in other words. While all women I interviewed reflected some of the dominant metaphors of cancer in Austria, those who felt that they had good prognoses would often add that their case was not as severe or drastic as the Austrian metaphors of cancer might lead one to believe. Anita (64) reflected the sense that cancer invokes a lack of control in stating that it is “the plague of our time.” In other words, she meant that cancer is an inevitable part of life in the modern, postindustrial age over which we have no control. The lack of control is also reflected in Gabrielle’s (56) description of cancer, “I’ve got to be honest with you. I wasn’t afraid of cancer. Fate is fate, and we’ve just got to live with that. You can die of a lot of different diseases.” Gabrielle, a single mother, was diagnosed when her twins were 13 years old. I found her reaction of resignation particularly striking. She explained that while she would have been afraid to leave her children alone, she could not control the situation. Lisa (56) parsed apart different forms of cancer in stating, “Well, how I would describe cancer depends on the type. If I keep on smoking like I do, then it’s pretty obvious why I would get lung cancer. But otherwise, cancer is just misfortune, a bad fate.”

For Manuela (42), who could barely speak of her breast cancer to me and spoke of her illness only with her husband, cancer meant simply all that she had repressed in her life. Sabine (53) channeled the pressure of modern life in describing her cancer in relation to her daily stress of caring for ailing family members alongside dealing with an anxiety-ridden work environment and subsequent burnout. “Cancer is a massive outcry of the body,” she explained “I absolutely believe that all of the stress and never having time for myself played a role in my cancer.” This theme will be discussed in relation to women's explanatory models for their breast caner, but suffice it to say that cancer for many respondents reflects a long history of stress and challenges. In addition, it is not readily interpreted as a new challenge or journey, as the metaphor goes in the United States; in fact, I only once heard that "cancer is a learning process and lifelong challenge" (Julia, 28). For others, "cancer is the unknown," or it is "an evil disease." Kathrin (54) felt much more at ease and felt as though she was back on a path to good health after her "evil tumor" was removed.

I then asked women generally what they had heard about cancer and if people talk about cancer in society. Women noted that there was more attention given to cancer in the media than in the past, but this had not yet translated to open discussions regarding cancer within the broader society. The responses were split between a gradual lifting of the stigma and the sense that cancer is losing its association with fear and dread, and the belief that cancer is still a taboo topic that is not to be discussed publicly. Anita (64) noted, "Cancer is only discussed when it becomes really acute, otherwise it's like 'ugh, being sick, let's just stop talking about it'." She continued expressing that discussing cancer among friends is risky, since many can become rather fearful and do not know how to react. Reflecting the resignation and stoicism dealing with hardship, Sophie (55) said, "I don't know what there would be to even talk about." Susanne (28), a well-traveled, educated young professional before she lost her life to breast cancer said, "Austrians don't really like to talk about negative things or to talk about fate. Illnesses are still a taboo topic in Austria." Christine (53) added

> "People just kind of think cancer doesn't happen to people in society. Our society is oriented towards 'fun,' so people only want to hear good news, and not talk about diseases, and definitely not diseases like cancer. Cancer kills a lot of people, people are afraid of dying. I never went on sick leave. I just wanted to

> have my normal everyday life. Well, I mean, I didn't want to look or act like I was sick."

As expected, the idea of the testifying one's cancer, which is linked with the breast cancer awareness campaign in the United States, is not overtly encouraged. Instead, women practiced more discretion and privacy in regard to their illness, often only sharing their illness experience with a small, tightknit group. This is however difficult for women in the rural areas, who may have to practice the art of discretion while being fully aware that they cannot hide their illness and are the topic of gossip among the villagers and townspeople. Still, many others expressed that although they may not outwardly proclaim that they have cancer, they certainly would not try to hide the disease and are always open to talking about breast cancer with interested parties. Nevertheless, speaking about cancer is still considered to be atypical and it is not presumed that one would automatically be open in regard to cancer.

The Austrian press reveals the same ambiguity in regard to openness and hopefulness of dealing with cancer. A survey of all articles from 1995 to 2013 in the popular weekly news magazine, *News*, revealed an interesting shift in discourses of cancer. Jäger & Klech (in review) note that earlier articles contained portrayals of cancer as an enemy, parasite, and a cancer diagnosis as fate and desperation. In 2002, *News* first mentions the association between the color pink and breast cancer (*News,* September 26, 2002). The title reads, "Breast Cancer Prevention: Pink Lights as a Reminder" (German: *Brustkresb-Vorsorge: Rosa Licht als Mahnung*). The prefix *mahn* denotes a sense of urgency or worry. Thus, the use of the word *Mahnung* signifies a strong reminder to avoid something negative, which is more threatening than its more neutral variant

Erinnerung. In contrast to this more threatening tone, more recent articles refer to the campaign with Pink Ribbon Austria's motto "Because we love life" (German: *Aus Liebe zum Leben*). This transformation is softer, friendlier, and influences women to take up mammographic screening not out of a threat but 'out of love for their lives.'

The discourse used in recent years has diverged from the drama and panic of the earlier articles. The articles juxtapose fate and hope, and sell cancer as a manageable chronic disease. Nevertheless, the articles still emphasize the fact that cancer is a stigmatized condition in Austria. Articles after 2011 have also begun to include statements from important figures in the medical, pharmaceutical, and media industries. For instance, medical journalist for the Austrian Broadcasting Corporation, Kurt Langbein, wrote of his own experience with prostate cancer (2012), which the press referred to as a "stroke of fate" (German: *Schicksalsschlag*). He stated,

> "The disease is still a taboo topic. A cancer diagnosis is in general something eerie. Then on top of it, the disease changes your circle of friends too. Some good friends downright turned away from me because of their own fear…As soon as you can really look at cancer and say to yourself, "I want to live, I want to beat this," but at the same time you're prepared to accept death, you'll be doing better." (*News*, May 23, 2012)

The themes of accepting death and dealing with stigmatization are present in Langbein's description. However, there is a notion of hope in being able to restructure and accept one's life following a diagnosis. I postulate that part of the 'hope' is related to a growing emphasis on a steadfast belief in medicine, despite nominal advancements (see chapter four). However, another interpretation is simply that the feigned pessimism and stereotype of resignation is lightening up in younger generations. Hope and positive thinking may not cure someone of cancer, but they may make them more willing to adhere to a treatment plan and allow them to live longer as a result. Still, it is important to keep in mind that inner drive to want to survive cancer while cautiously keeping death within sight, is largely internalized. It signifies a personal, private transformation. As was the case with politician Barbara Prammer, the decision to be forthright about *having* cancer was already an amazing feat, and her discretion in regard to the details of her diagnosis was respected. Indifference is easier than facing the truth, and this attitude functions both within public life as well as on personal horizons in regard to cancer.

Despite the tenacity of the resignation, a feigned defeatism, and distaste for pride or heroism (or even forthrightness) in regard to illness, more prominent Austrians with cancer like politician Barbara Prammer are breaking the silence shrouding their disease. Journalist and former chain smoker Kurt Kuch (1972-2015) started an anti-smoking campaign in Austria after his lung cancer diagnosis. Minister of Health Sabine Oberhauser began to appear in the media without a wig following her chemotherapy-induced hair loss. Hence, these ways of conceptualizing and reacting to cancer are fluid and by no means stand in direct contrast to constructions of cancer in the United States. Although constructions of cancer are always in a state of transition, comparing Austria and the United States provides an interesting vantage point from to understand the discordance of importing the American-style breast cancer awareness campaign into Austria.

The Interplay of Social Representations of Cancer and the Illness Experience

This broad overview sought to show some central points in how Austrians have traditionally conceptualized and reacted to cancer. Some of these points, particularly the emphasis on fate and the rejection of the ‘hero-survivor’ label, differ starkly with the dominant American construction of cancer. This is an important point to make, considering that much of the breast cancer awareness campaign is rooted in the underlying assumption that breast cancer sets women on a new ‘journey’ in life and reconfigures the identity as a ‘survivor.’ I began by making the important point that cancer is inherently both a biological and a sociocultural phenomenon and that cancer is an effective lens with which to understand how cultures interpret hardship, a loss of control, and uncertainty (McMullin & Weiner 2009). This previous section drew upon anthropological insights into cancer to build an understanding as to why cancer invokes and imparts and excess of meaning, which is largely based on the inability to grasp the causes of cancer or to find a cure for it. I then described how the ambiguity and fear surrounding cancer is handled within the American and Austrian contexts. This analysis is limited by generalizations, but nevertheless provides an understanding of the cultural aspects of cancer and the social implications of having the disease. The decision to examine these two cultures was not arbitrary, but rather sets the stage for understanding the points of discordance within the global flow of the American-founded breast cancer awareness campaign in Austria.

This sets the stage for subsequent chapters, which aim to understand how health and wellbeing are increasingly influenced by dynamic interactions between local and global influences (Baer et al. 2003; Dilger & Hadolt 2010; MJD Good 1995; Janes & Corbett 2009). It is essential to examine what is at stake in the new formations of global assemblages that affect daily life, local institutions, and social identities in unpredictable ways, and to unpack what is concealed in the ostensibly benign concept of global connections (Appadurai 1991, 2001; Gille & O Riain 2002; Strathern 2002; Tsing 2000).

On a broader scale, the work presented here should also serve as a caution in anthropological work to avoid homogenizing constructions of illness within the ‘West’ and ignoring the role of historical and religious underpinnings when examining the ethos surrounding a highly charged illness such as a cancer.

The underlying discordances in construction of cancer between Austria and the United States are a good starting point for grasping the local interpretations of the breast cancer awarenss campaign. In the following descriptions of the breast cancer awareness campaign in Austria, these novel constructions of cancer will shed light on the ways with which women come to terms with their illness and find personal meaning in the experience of having breast cancer.

CHAPTER THREE: AN INDISCRIMINATE DISEASE, AN EXCLUSIVE CAMPAIGN

Two Shades of Pink

The invitation alone for the *Pink Ribbon Austria* kick-off gala made it clear that the event was to be a swanky if not flamboyant affair. That the invitation fell in my hands came as a surprise, as such events are often reserved for Austria's *prominenti* or "*Promis*" (distinguished people) and well-known medical doctors, not an anthropologist and, crudely put, a nobody in Vienna's social scene. Nevertheless, my affiliation with a European-wide breast cancer advocacy organization had apparently made me part of the so-called "Pink Ribbon Family," and worthy of joining in.

The large invitation featured photographs of Vienna's famous Ferris wheel, the center of the historic *Prater* city amusement park, which was to be illuminated in pink to commemorate the start of the 2014 breast cancer awareness month. The event organizer, Pink Ribbon Austria, which is affiliated with the international Estee Lauder Pink Ribbon Campaign and the Austrian Cancer Society, described the Ferris wheel as more than an iconic trademark of Vienna. Instead, they recounted a shocking incident that occurred in 1898 when an impoverished artist Marie Kindl dangled herself on a rope outside of a Ferris wheel car to draw attention to the dire situation of unemployment and extreme poverty in Vienna. Pink Ribbon Austria likened its mission of bringing awareness of breast cancer to Kindl's desperate plea to free the masses from abject poverty in fin-de-siècle Vienna.

But the cool, club-like atmosphere of the event seemed hardly full of despair, at least not in the sense of desperation in Marie Kindl's bold act. The gala took place in the patio of a historic upscale restaurant directly facing the Ferris wheel. The patio was dotted with pink cardboard cutouts of a generic female form (like that on the door to a women's restroom), anonymously symbolizing Austrian women with breast cancer. Alongside the cutouts stood 18-year old men serving their mandatory duty in the Austrian army who were there to help set up and the take down the event. Young, attractive blonde women guarded the guest list at the foot of the hot pink carpet as invitees decked out in top fashion pinned pink ribbons on themselves and leisurely joined the party. Professional photographers gave guests the once-over, assessing whether or not they fit the label of being a *Promi*, or VIP. The guests included Estee Lauder business executives, sponsors of Pink Ribbon Austria (most above the €10,000 mark), prominent oncologists, top-tier politicians, and the so-called 'charity ladies' (said in English). While I looked the part, sipping sparkling wine and showing the same tepid glances as the others guests, I was an outsider in a chic world of Austrian cultural privilege.

These types of events, whether for charity or not, are commonplace in the glamorous, absurd, Panopticon-like Viennese high society. The *Promis* are the decadent, if not indecent, Austrian VIPs. They are entertainers, musicians, dancers, athletes, and occasionally politicians with one thing in common: an affinity for the limelight. More personalities than people, they are as much mocked as they are idolized. The codes of behavior verge on vulgar to those of the dignified upper class, who eschew the theatrics of the nouveau riche. If the pink ribbons and select oncologists were absent from the gala, it would be to a certain degree indistinguishable from any other *Promi* event. In other words, the Pink Ribbon Austria gala had a firm footing on the *Promi* stage.

The evening moved along as hors d'oeuvres and wine were served. At regular intervals, event organizers and important medical practitioners from the Austrian Cancer Society spoke on behalf of the accomplishments of Pink Ribbon Austria, while describing the need for more support for breast cancer care and awareness in Austria. "Only half of Austrian women get mammograms…", "Breast cancer is still stigmatizing….", "10% of Austrians live on or below the poverty line…just think what it is like to get cancer…" they announced, but I could barely hear over the uninterrupted conversations and glass clinking. I found myself distracted by an older, famous businessman who locked lips with his very young girlfriend throughout the speeches. Whispers settled as a former Miss Austria took the stage to play the techno versions of Johann Strauss classics on an electric violin. Shortly thereafter, event hosts illuminated the iconic Ferris wheel in pink spotlights. Guests then exited the party as nonchalantly as they came in to take a private ride in the Ferris wheel and head off somewhere else.[26]

As an American, I have attended numerous cancer advocacy and fundraising-related parties from black tie galas to the 'World's Largest Disco.' What was so striking about the event was not the party atmosphere. Instead, what caught my attention at this

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[26] As an American, I have attended numerous cancer advocacy and fundraising-related parties from black tie galas to the 'World's Largest Disco.' Instead, the major difference at this breast cancer advocacy event was the stark absence of breast cancer. There were no personal stories, no presence of volunteers, and no participation (or access) for commoners. In the United States, volunteers work tirelessly to plan events, mostly in the names of friends and family members they have lost to cancer. I do not mean to suggest that the attendees are unconcerned with breast cancer, as the event leaders had mentioned the issues of poverty associated with a breast cancer diagnosis, but the atmosphere made it impossible to glean to what degree most of the guests are directly involved in cancer advocacy. Sporting a pink ribbon at high profile events is one form of raising awareness, but as many Austrians expressed, it appeared to be more like any another *Promi-world* party.

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It happened to be the second time that week that a young blonde woman pinned a pink ribbon to my lapel. The contrast in the events was jarring, however, for instead of checking my name off on a VIP list, the young woman at the second event asked me to sign a guestbook for Susanne’s funeral. Susanne was an intelligent, worldly woman in her 20s who passed away a year after being diagnosed with triple negative breast cancer, a highly aggressive form of breast cancer that affects younger women. No modified personal behaviors, no genetic test revealing a mutation, and no asymptomatic mammogram could have saved Susanne’s life. She went to her doctor three times complaining of swollen lymph nodes in her underarm (a symptom of breast cancer) before she was sent to receive a diagnostic mammogram. Her case is one that shows the tragedy of cancer as well as its persistent ambiguity and elusiveness. The small church was overflowing with international friends and family shocked by her death. As I stood outside with Susanne's work colleagues, confetti thrown at the wedding that took place just days before the funeral stuck to my shoes. I was reeling at the thought that I was at Susanne's funeral instead of her wedding. In that moment, I wanted to cling to anything that would connect me to others in my grief over her death. Wearing the pink ribbon represented the sense of solidarity, hope that other women will not meet a similar fate, and shared grief. It meant that neither she, nor the disease that took her life, would be forgotten.

The pink ribbon is a meaningful symbol that has the power to unite people in showing their struggles with breast cancer. Campaigns like Pink Ribbon Austria use the symbol of the pink ribbon, but at times lose sight of the heart of the matter: there is a major burden of breast cancer-related morbidity and mortality around the world. The context in which a woman is diagnosed either exacerbates or mitigates adverse events from breast cancer. On a global scale, Austria offers excellent diagnostic and therapeutic care for breast cancer to almost the entirety of its population. This calls the desperate plea made by Pink Ribbon Austria to improve the state of cancer care in Austria into question. I then situate the breast cancer awareness campaign within a particular style of health-related advocacy events and charitable organizations in Austria. This is followed by a review of ethnographic material gathered at campaign events and in interviews with key personnel from September 2012-November 2013, as well as media reports, printed materials, campaign rhetoric, and marketing and products sold. At the center of the analysis are the reactions of women with breast cancer, who are for the first time encountering novel public representations of breast cancer and as a result are questioning their own stance on being forthright about having the disease. In addition, this chapter is concerned with exploring the practice of philanthropy and awareness campaigns through a political economic lens to critically evaluate the visibility and voices of women with breast cancer within the campaign. Furthermore, I look at how such novel sociocultural representations of breast cancer are received by those going through the illness.

The Infrastructure of Cancer Care in Austria

On the global scale, the infrastructure of breast cancer care in Austria is so exceptional that it seems ludicrous to liken the cause for awareness to the direness of the masses living in abject poverty in fin-de-siècle Vienna. With cancer remaining a heinous, unspeakable misfortune in so many parts of the developing world, it seems to be an injustice to call Austria's situation dire or even lacking. Oncology is only now being implemented in many parts of the world, particularly those areas where the HIV/AIDS epidemic overshadowed the cancer burden (Livingston 2012). In stark contrast, organized care for cancer within the Austro-Hungarian Empire began in 1910 in the form of a task force, which currently exists as the Austrian Cancer Society (Gamper 2010). Anthropologists have used cancer as a lens through which to grasp global and local political economic injustices and inequalities (Balshem 1993; Chavez et al. 2001; McMullin & Weiner 2009). For instance, Livingston (2012) describes the wretched conditions of the oncology ward in Botswana where over half of the women with breast cancer get to the clinic after their tumors have burst through their breasts. Similarly, Gregg (2003) portrayed the dismal conditions of the cancer ward for women with cervical cancer in a Brazilian *favela*. Around the world, patients die waiting for a constantly malfunctioning radiation machine and vital chemotherapy drugs that never come. The few oncologists available are mostly palliative practitioners, trying to manage pain and infection of purulent tumors protruding out of the skin. In short, many in the West have no comprehension of this level of misery, suffering, and struggle for even basic medical care. The differences in cancer care between Austria and developing countries are appalling. Needless to say, true advocacy and awareness for cancer is sorely misplaced in this world.

Instead of dire settings where people are just coming to understand what cancer is, people in Austria are learning how to come out of the "architecture of the closet" (Klawiter 2004: 847) and speak of it. Fortunately they can do so in a highly sophisticated healthcare system, which once ranked ninth best in overall performance from the World Health Organization (World Health Organization 2000).[27] Theoretically, all Austrians and those legally registered in Austria are fully covered by the national health insurance.[28] While Austrians have the advantage of a top-notch healthcare system, it has been suggested that the system is hindered by a lack of preventative health measures

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[27] Naturally a ranking says little about the intricacies, limitations, and political economy inherent to healthcare systems. To be ranked 9th in the world according to the WHO's appraisal of efficiency, efficacy, and equity within a system demonstrates that the overall system is in a privileged position on a global scale.

[28] One must be a tax-paying resident, married to a tax-paying resident, in retirement after paying taxes, or a student. Non-taxed residents of Austria can purchase their own health insurance for a reasonable charge. Conversations with *Statistik Austria* suggest that approximately 100,000 people in Austria are without legitimate coverage. The reasons behind various gaps in coverage include: those working on the black market, students in-between graduating and receiving employment, after a divorce when one spouse was not employed, not being able to pay for self-insurance, and not being legally registered in Austria. Catholic hospitals accept patients regardless of their insurance status.

taken up by Austrian society, therefore exacerbating the significant and costly burden of certain forms of cancer more directly tied to personal behaviors (Jäger 2011).[29]

After much debate and deliberation over coverage of costs, in January 2014 the Austrian Ministry of Health (MOH) together with the Austrian Cancer Society enacted a universal breast cancer screening program.[30] The program was structured so that women between 45-69 received an invitation to attend mammographic screening by a program-certified radiologist every 2 years. Women between 40-44 and 70-74 could opt in at their discretion. However, participation from eligible women between January and June 2014 was dismally low (see chapter four). Facing political pressure, the MOH amended the program, and as of Summer 2014, an invitation to screening is no longer required and women over 75 can continue to attend mammograms. This linchpin of the 2013-2014 Pink Ribbon Austria campaign failed only a few months after its enactment.

The success of screening is also hindered by poor attendance among women from immigrant backgrounds, which differs from that of native Austrians (Wimmer-Puchinger, Wolf, & Engleder 2006). For instance, only 30% of women from former Yugoslavian nations reported having attended a mammographic screening, in contrast to 78% of native

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[29] For instance, smoking rates among women continue to increase, whereas smoking rates for men decreased throughout the 1970s and have since leveled off (OECD Reports 2014). Considering that tobacco-free legislation in Austria is virtually non-existent and smoking is not a social taboo, tobacco use is likely to remain high (*ibid*). At over 13.5 liters per capita per year, consumption of alcohol is fairly high and drinking is considered a cultural norm (*ibid.*). Cultural attitudes towards smoking and drinking remain lax and open. The prevalence of obesity is also on the rise with over 40% of adult women and over 50% of adult men classified as overweight or obese. As is the case with other high-income nations, those in lower socioeconomic groups have a higher risk of being of overweight and obese (Statistik Austria 2014).

[30] One major issue with screening prior to the implementation of the program was the fact that the Ministry of Health only collected data on raw numbers of mammograms carried out, so they had no way of knowing the exact demographics of women attending, nor were they able to glean if the same women were attending within a given time span.

Austrians (*ibid.*).[31] Aside from the issues and limitations of breast cancer screening, these statistics point to a broader issue of barriers to healthcare among immigrant populations in Austria.

Those insured in Austria have the right to spend a few weeks in a health resort, or *Kur,*[32] for a wide variety of conditions including cancer. Cancer patients requiring more medical care and a stricter regimen may attend an oncologic rehabilitation clinic,[33] where those with cancer are placed in more controlled, hospital-like setting. Both *Kur* and Rehabilitation are intermediate steps between completing treatment for cancer and returning to a life after cancer, and both offer those with health issues the opportunity to enjoy exercise, fresh air, and a fixed daily regiment of rest and therapeutic sessions. The difference with rehabilitation clinics is that attendees are treated as patients, are required to follow strict schedules, and are generally limited in their daily activity choices.

In addition, those with cancer have free access to psychological help with a therapist or psycho-oncologist, and in many cases, a psychologist is sent to a woman in her hospital room directly following a breast operation. Health insurance covers the cost of breast prostheses and women have the right to new prostheses every two years and a new brazier every six months. Most Austrians even have a right to daily transportation to the nearest treatment center, which is required by many elderly people living in Alpine

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[31] Given the difficulty of primary prevention strategies, the Ministry of Health in conjunction with the Austrian Cancer Society has focused its efforts in cancer control on secondary cancer prevention (i.e. early detection).

[32] A *Kur* is a form of health spa/resort where people with almost any type of health issue can go for rehabilitation, rest and recovery for a few weeks. They generally combine a form of exercise, fresh air, healthy eating, and abundant rest.

[33] Cancer rehabilitation (not *Kur*) has been criticized by anthropologists for being part of a neoliberal paradigm of health through which those living with cancer are pushed to return to a normal life (i.e. the workforce) as soon as possible (see Hansen & Tjørnhøj-Thomsen 2008). Austrians with whom I spoke regarding cancer rehabilitation found it to be a positive, helpful experience.

villages who have to travel an hour daily to and from the nearest radiation clinic for six weeks, or those in the city who may find taking public transportation uncomfortable while undergoing chemotherapy.

Even more state-of-the-art are the options available for carriers of the BRCA I or II genetic mutations, which were recently publicized by Angelina Jolie's decision to have a prophylactic mastectomy after discovering that she was a carrier. When a woman fulfills particular criteria for breast cancer cases in her family,[34] she is eligible to have the test done at no cost. If she is discovered to be a carrier, she is offered psychological assistance to help guide her decision, and can ultimately choose to either attend mammographic screening earlier and more frequently, or to have a prophylactic mastectomy and subsequent breast reconstruction.

Despite the warranted acclaim for the system of cancer care in Austria, there are areas in which it could be drastically improved. To begin, although there are laws and policies in place to help those with cancer from losing their jobs, the actual implementation and practice of these laws and policies is hardly ideal. For instance, employers in Austria cannot legally dismiss an employee on the basis of having cancer and employees are not required to declare their diagnosis to their employer. But with too many loopholes and a narrow window of time to report an unfair dismissal, employers are often able to get around the rule by finding another reason to dismiss an employee. A recent study from a head nurse at Vienna's largest breast surgery unit revealed that

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[34] In order to be eligible for a free genetic screening for the BRCA 1 & 2 genetic mutations, an interested party has to fulfill any one of the following criteria on at least one side of the family (maternal or paternal): 2 cases of breast cancer before the age of 50, 3 cases of breast cancer before the age of 60, 1 case of breast cancer before the age of 35, 1 case of breast cancer before the age of 50 and 1 case of ovarian cancer at any age, 2 cases of ovarian cancer at any age, and lastly, 1 case of breast cancer in a male and 1 case in a female at any age.

employers dismissed 17.4% (n=63) women diagnosed with breast cancer (Frank 2005). Those who decide to continue working full-time or are self-employed throughout chemotherapy and radiation treatments must also cope with negative side effects and the loss of time from trips to the hospital. The women who took this route informed me that working part time would have meant the same workload and half the salary, so they either promptly returned to working full time or went on sick leave. Thus, despite a law in place, these safety nets for those with cancer lack teeth.

There are also significant differences in the quality of cancer care within the Austrian healthcare system due to regional differences in care offered and in the type of insurance coverage. Most of top oncologists and researchers aspire to be university professors, meaning that they are associated with one of Austria's four teaching hospitals, all of which are in larger urban areas.[35] Outside of these teaching hospitals, there are a host of additional hospital facilities in suburban areas as well as in mid-size and smaller municipalities. Austrians living in smaller municipalities are in general less mobile and less apt to driving considerable distances to the nearest teaching hospital to receive cancer treatment. In addition, trust in a local doctor also plays a role in where a patient decides to be treated. While trust is certainly an important factor in treatment, conversations with public health and medical professionals as well as patients reveal significant differences in treatment between urban, suburban, and rural settings. Medical practitioners outside of urban areas are accused of not being as up-to-date or as experienced (simply based on the lower number of cases they see) as their urban

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[35] Although a comprehensive cancer hospital in Vienna was once in the works under the last emperor Franz Josef, plans were cut as World War I broke out and the topic has since then never been seriously reconsidered (Gamper 2010).

counterparts.[36] Multiple medical professions from across Austria also alerted me to the fact that emergency and intensive care situations are also best handled in teaching hospitals.

There is wide variation in care and expertise offered between breast care centers. To overcome this issue and improve quality control, the independent Austrian Certification Commission (German: *Österreichische Zertifizierungskommission*) enacted a program to perform a quality assessment of all breast health centers in Austria (see Neunteufel 2015). As of January 2015, only 20 centers have been certified under stricter guidelines. The Austrian Certification Commission claims that only half of those with breast cancer are treated in quality-assured settings. Furthermore, the use of the term "breast health center" is often misunderstood to imply that it is certified, which is not always the case. The goal is to have all centers certified by 2016, but with some provinces completely lacking certified breast health centers, this goal may be unattainable. Thus, breast cancer care in Austria remains varied and unequal, and there are very concrete areas in which awareness of the problem and subsequent advocacy can stimulate political action and positive change.

Aside from regional differences, one hears often about Austria's two-tiered health system (German: *Zweiklassengesundheitssystem* or *Zweiklassenmedizin*), or even the society in general (*Zweiklassengesellschaft*), which refers to the ability to enroll in private health insurance for an additional cost. Although there is a law stipulating that

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[36] For instance, one non-teaching hospital doctor insisted on performing a lumpectomy for a suspicious tumor in a woman's breast instead of a biopsy, reporting that a biopsy would have come with the risk of puncturing her lung. An urban doctor who saw the report insisted that any oncologist with more experience could have performed a biopsy without any problem. In the end, the woman chose to have the operation in her home hospital instead of driving the distance to the nearest teaching hospital. Her tumor was discovered to be benign after all, meaning that she could have avoided an operation if a proper biopsy had been performed.

treatment must be the same for all policy holders, those with private health insurance have shorter wait times for therapy and more time with medical practitioners.[37] There is no doubt that the option for private insurance brings a major financial boost to the health and economic systems, but the issue lies in overall transparency in regard to wait times for those with and without private insurance. In addition, doctors' fees for treating those with private insurance are higher, meaning that medical practitioners are willing to take more time to speak with patients and provide more in-depth explanations and answer a patient's questions. Additionally, the 'Cadillac model' of private health insurnace allows for more comfortable stays in the hospital and often a private room. While a private room will not influence the treatment outcome, having more time with a doctor and understanding more about the complexities of cancer and its treatment does confer an advantage.

As in many other countries, health literacy in Austria is also lacking. Health literacy denotes one's ability to comprehend and utilize healthcare-related information. Higher health literacy enables individuals to make informed decisions about their healthcare, which can improve the success of medical treatment and reduce error on the part of the patient, thereby improving success of medical treatment and reducing error. In Austria, health literacy is relatively low and ranks considerably behind other Western European nations (Kickbusch et al. 2011). In fact, 55% of Austrians have inadequate or problematic health literacy (*ibid.*). Considering the complex nature of cancer treatment, particularly chemotherapy regimens and side effect management, and the duration of

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[37] Patients can also pay out-of-pocket and apply for partial reimbursements from the governmental healthcare system. In my case, I was in need of an appointment with a dermatologist and was told the next available appointment would be in three months. I then called a private doctor who scheduled an appointment for the same day, albeit for the hefty charge of around $350.

breast cancer treatment (often up to five years or more), enacting policies to improve health literacy could potentially make a positive impact on overall cancer care.

Lastly, the persistent stigmatization of breast cancer, although better than the past, remains an unnecessary source of suffering for those confronted with the disease. In a related sense, women spoke about the aversion to being forthcoming with breast cancer. Ingrid (51), a school teacher, explained:

> "Somehow cancer still taboo. I mean, they're doing this whole Pink Ribbon thing and they want to make breast cancer a hot topic, but for normal people it's not on their radar. It's the same thing with other 'intimate' illnesses. People talk about dental problems or a broken foot, but the kinds of things that are this personal, people just don't want to talk about…The younger generation, my son's generation, they're more open with it. But the older generations and men, no way. This campaign can say what it wants, but it's not changing anybody. (I asked: Do you think the campaign isn't useful?) Well, no, not that. Maybe it will grow and people will start to be more open. And talk about it. That's going to take a long time though."

Culture changes slowly, and Ingrid is likely right in her projection that the older generations will still need a significant amount of time before they are ready to open up about breast cancer. The breast cancer awareness campaign is certainly creating more attention for breast cancer on the Viennese cultural landscape, but the degree to which it allows women to speak truth to their own illness experiences is questionable. Thus, the campaign may start to make people feel more comfortable with the term breast cancer, but it may limit the ways in which women with breast cancer are able to share their own realities of living with it.

From a public health and patient advocacy perspective, there are aspects of the healthcare system for which advocacy and awareness for breast cancer could make concrete contributions and better the social lives of those with the disease in Austria. In the following section, I will compare these noted issues pertaining to cancer care and quality of life among those with cancer and the items on the agenda of those promoting the breast cancer awareness campaign in Austria. This is followed by an evaluation of how the various groups and actors involved are able to achieve their mission. But first, this chapter will set the stage to situate the breast cancer awareness campaign within an Austrian style of charity campaigns in order to understand what is distinctive about this particular newcomer on the Austrian cultural landscape.

Charity Campaigns in Austria

Before describing the style of charity campaigns within Austria, it is critical to underscore the difference between a charity campaign and the grassroots mobilization inherent to a social movement. Whereas grassroots participation implies “change from below,” a charity campaign can be promoted or driven from those in positions of power through a top-down approach. This can remove or limit the participation and voice of the community or group a charity seeks to support. It can also enhance the private interests of those running the charity.

This anthropological study does not belong in the anthropology of social movements (see Edelman 2001), except to reveal that this example of the current implementation of pink ribbons and breast cancer awareness in Austria is *not* tied to grassroots, collective social action, a social identity, and direct participation from those with breast cancer.

To understand the practice of charity in Austria, I must first briefly describe the milieu of the Austrian welfare system. Leichsenring (2001) outlines how this system is shaped by the strong influence of the Catholic Church and its tradition of charity, the emphasis on consumer cooperatives, a corporatist leaning of state regulation, and lastly, the separation of society along political and religious lines, each with their own interest-driven welfare organizations. As a result, charity can be underrepresented or considered unnecessary in a wealthy nation such as Austria with a strong welfare system. As is the case in other European nations, "charity work in general, and especially in areas which are already the responsibility of public authorities, is generally disliked" (Bengtsson & Hulgård 2001:66). In other words, where charity work is practiced, it is done generally through financial means and not hands-on work. The general expectation is that the government will care for those who cannot care for themselves.

Charity campaigns base their success on fundraising and less on the direct engagement of Austrians, who are more or less ambivalent in regard to health-related issues (Felt et al. 2008). On the one hand, the lack of hands-on charity work can in part be attributed to Austrian, or at least Viennese, cultural norm of indifference, apathy, or at worse a lack of compassion. I often heard that Austrians are mostly concerned with themselves and their families, which may appear to be more of a fact of life in the 21st century West rather than a particular Austrian cultural attitude. From my conversations with Austrians, it is clear that more people are more willing to donate money to a cause than give their time to advocate for a certain issue. This means that various charitable organizations receive adequate donations and are able to fulfill their particular mission; however, this form of charity (giving money from a distance) means that most Austrians are not directly confronted with the particular issues at hand and are not as personally affected.

Many of these charities are driven by another Austrian (and particularly Viennese) tradition of the *Promi* charity fundraisers (German: *Wohltätigkeitsveranstaltungen*). So, when charity fundraisers are placed on *Promi* turf, the public is even further distanced from the particular issues at hand. As mentioned, *Promis* are an Austrian institution that is firmly rooted in the rise of democracy, mobility between social classes, and the media boom of the 20th and 21st centuries (Eberl 2013). As is the case around the globe, these celebrities pique the interest of the petite bourgeoisie and the working class (Kurzman et al. 2007), often bearing the title of in the media and common parlance of 'charity lady.' In Vienna, fundraisers sponsored by the elite have been a cultural mainstay since the time of the monarchy. In fact, in 1912 Countess Pauline von Metternich organized a soiree to benefit the then Austrian Cancer Society in Vienna (Gamper 2010). The difference from the present is that the countess was part of nobility, and never would have been classified as a *Promi*.

Post-war Austria has been saturated with longstanding Austrian charity organizations. One example is *Licht ins Dunkel* (English: Light into the Darkness), which provides funds primarily for the disabled and has held an annual Christmas telethon since 1978. While the funds are raised for a good cause, the event has been criticized for its effect of making the disabled appear helpless instead of as people capable of living happy and healthy lives despite (or because of) their disability. Another popular charity is AIDS Life, which since 1992 has hosted the world-famous Life Ball and attracted far-ranging international celebrities. Although the Life Ball raises millions of Euros for organizations supporting those with HIV/AIDS, it has been criticized for straying away from its initial provocative stance of raising public awareness for

HIV/AIDS. For instance, as of late, members of Austria's far right conservative party have been in attendance, meaning that the event is becoming a more mainstream *Promi* party at which to see and be seen. Founder Gery Keszler sees this as a necessary means to an end for raising awareness and funding, as well as rallying support for those living HIV/AIDS.[38] While the event is widely successful, it is unquestionable that the hard truth of HIV/AIDS around the world is overshadowed by the Life Ball's haute couture fashion shows, theatrical spectacles with half-nude models and red carpet interviews. It is indeed a celebration of life, but it does not speak to or for the multitudes of people affected by HIV/AIDS. In addition, its once shocking and provocative messages have over the last twenty years slipped back into the world of *Promi*-driven charity to the point that one can question the degree to which the tolerance and humanity sought after has been replaced by a normalized party atmosphere.[39]

Although the *Licht ins Dunkel* telethon and the Life Ball are poles apart, what they share in common is a lack of personal testimonials from the communities of sufferers they aim to help. *Licht ins Dunkel* is critiqued for having the effect of *othering* those with disabilities by allowing celebrities to speak on their behalf and present them as

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[38] At the 2013 Life Ball, US Olympic Diver Greg Louganis was interviewed on the red carpet and tried to send a message of the how challenging it can be to come out not only as homosexual but also HIV positive. The sobering moment was interrupted by former pornography star and entertainer Carmen Electra, who contorted her body in sexually suggestive positions in front of the camera and repeated that she "only likes to date bad boys." In my opinion, the dissonance between Louganis' plea to empower people to get tested for HIV and for those with HIV to go public with their diagnosis getting interrupted by the flippant asininity of making sexual poses and reinforcing the trope of the playful, sexualized girl exemplified the critiques levied against the Life Ball. In many ways, this shift mirrors what Paul Farmer (1999) describes as the current invisibility of the HIV/AIDS epidemic after the population most affected from the disease shifted from white men in the US to poor women around the world.

[39] The 2014 Life Ball advertisements from photographer David LaChapelle were still incredibly provocative. They featured a surrealist interpretation of Garden of Eden with Adam and Eve, except that Eve is voluptuous transgender model Carmen Carrera who in one photograph has a vagina and in the other a penis (both with all pubic hair removed to enhance the explicitness). The text read, "I am Adam. I am Eve. I am me." The emphasis was on beauty removed from the constraints of gender and heternormativity. Posters featuring this image were seen all over Vienna, and while some felt uncomfortable about the image, I heard far more conversations about what a fabulous party Life Ball must be.

people in dire need of help, whereas the Life Ball allows traditionally culturally-conservative Austrians to take part in a ritual of inversion where they can experience a lavish, provocative, fantasy-filled playground for an evening while hardly addressing the root causes of HIV/AIDS. Thus, while these organizations are highly successful at fundraising, they have done little to actually get Austrians to care about the communities of suffering they aim to help.[40] Stripping away the voices and agency of those in need, this form of passive activism warps into a form of patronization (i.e. this form of activism speaks *for* those in need, defining their challenges and issues, rather than listening to their own interpretation).

The following section situates the implementation of the breast cancer awareness campaign in Austria within this paradigm of passive activism despite the desire of women with breast cancer to actively take part in the campaign. In many respects, the organizations that function under the auspices of the campaign (e.g. Pink Ribbon Austria) mirror the standard practice of 'hands-off' charity in Vienna. Moreover, this section evaluates the extent to which the awareness campaign addresses the aforementioned areas in need of improvement in regard to breast cancer care, as well as how the campaign's methods and ethos fit into the generally reserved attitude Austrians have towards cancer (see chapter two).

The Enactment of the Breast Cancer Awareness Campaign in Austria

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[40] It is important to note that in Vienna, disabilities, abnormalities, and other forms of identity, which do not readily fit to the Viennese cultural mainstream, are hardly seen. For instance, among Vienna's approximately two million inhabitants and superior disability access to public transportation, one rarely sees people with physical and mental handicaps.

Before the pink ribbon kitsch of teddy bears, cookies, sneakers, yogurts, and even handguns, breast cancer awareness in the United States for many women meant taking concrete, even confrontational action. For instance, the women marching on Capitol Hill were fed up with sequestering their illness, not having a say in their course of treatment and wanted to "gaze back" at physicians and at a society that constructed the closet in which women hid their illness (Klawiter 2008). As described in the introduction, from the start of the Women's Health Movement and throughout the 1990s, political groups, grassroots campaigns, and multiple corporations working in conjunction with non-profits thrust breast cancer into the American public eye (Kasper & Ferguson 2002; Sherwin 2006). The United States became the lifeline of breast cancer awareness, acting as a place where many women could speak openly and take control of the personal impact of the disease (Kaufert 1998). But throughout the 1990s and 2000s, corporate involvement in breast cancer awareness in the U.S. intensified, thus deconstructing the once grassroots movement of breast cancer awareness (King 2006; Sulik 2012). The main corporations at hand in this shift towards bringing breast cancer awareness into American supermarkets and National Football League stadiums were Avon, the numerous corporate sponsors of Susan G. Komen For the Cure, and Estee Lauder, which is the focus of this section.

While the pink ribbons have become a ubiquitous part of the American cultural landscape, they have only since 2002 gained a marginal presence in Austria. But with approximately 5,000 new cases diagnosed annually (Zielonke et al. 2014), breast cancer is the most commonly diagnosed cancer among women in Austria and is a significant threat to women's health. Additionally, each year approximately 1,500 women will lose their lives to the disease (*ibid.*). Thus, it is curious that the presence of pink ribbon is at best on par with that of the red ribbon, despite a far lower prevalence of AIDS among Austrians in comparison to breast cancer.[41] The tour de force Life Ball to "fight AIDS and celebrate life" as an annual cultural event garners both the fascination and generous donations within Austria as well as internationally, despite the fact that the majority of Austrians would not consider themselves at risk for HIV/AIDS (either because they practice safer sex, are in a monogamous relationship, or do not use intravenous drugs, for instance). Alternatively, breast cancer as an indiscriminate disease presents a real health threat to virtually all Austrian women. In other words, breast cancer is a more mainstream health issue that hits home for thousands of Austrians across geographic regions and socioeconomic strata. In contrast, breast cancer has a much greater presence on the cultural map than HIV/AIDS or any other form of cancer in the United States (Bell 2014; Ehrenreich 2001), whereas in Austria that cultural presence is minimal. In that sense, it seems incongruous that mobilization for a breast cancer awareness campaign would only since 2002 (and effectively only since 2010) gain a presence in Vienna. The Viennese explained this to me in terms of HIV/AIDS still being considered as a foreign problem, one that is simply 'out there,' and therefore not as frightening or unsettling as cancer, a real threat to Austrians.

I reiterated the initial grassroots initiatives of the breast cancer awareness movement in the United States at the start of this section to emphasize that this same kind of collective action was virtually absent in bringing breast cancer awareness to Austria. Likewise, I describe the popularity of the Life Ball to demonstrate the discordance of

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[41] In 2011, 19 women in Austria were diagnosed with AIDS and 8 lost their lives to the disease (Austrian Ministry of Health 2012). The Federal Ministry of Health in Austria estimates that 864 women in Austria were diagnosed with AIDS and 390 died of the disease between 1984 and 2012 (*ibid.*).

popularizing a disease that is not a major threat to Austrians, while breast cancer has been largely ignored. When the pink ribbons began cropping up in Vienna, they appeared not as a result of the same kind of rallying camaraderie that made them popular in the United States over a decade prior. Instead, one administrator from the Austrian Cancer Society who admired the American attitudes toward breast cancer during her frequent trips to upscale towns in the U.S. is primarily responsible for bringing the pink ribbon to Austria. She recounted a story of traveling with a friend, who at the time had breast cancer and experienced chemotherapy-induced hair loss. As they settled in at their vacation destination, her friend felt encouraged enough to remove her wig in public, something she never would have done in Austria. She explained:

> "Other women started coming up to her in restaurant bars and treating her to a drink, telling her things like 'Wishing you lots of luck! You'll get through this!' and I thought it was really great. That's missing in Austria and that's what I want here. I want women to be forthcoming with their breast cancer and instead of people giving them pity, I want them to be encouraged from others."

Thus, one of her stated goals in bringing the pink ribbon into Austria is to make breast cancer a source of camaraderie and togetherness among Austrian women. But unlike the emergence of breast cancer awareness in the United States (her point of reference), the deployment of pink ribbons within Austria included minimal participation on the part of women with breast cancer and began as a top-down campaign, rather than a grassroots movement. Instead of sponsoring a burgeoning patient-led movement or even working together with patient groups (as was more or less the case in the US), the initiators behind the pink ribbon in Austria self-selected the aspects they deemed would fit best to the Austrian context and to their own aims. Part of this was linking up with the

Estee Lauder Companies Breast Cancer Awareness Campaign,[42] which was instrumental in founding Pink Ribbon Austria.

Based on an in-depth interview with the staff member of Pink Ribbon Austria and multiple conversations with additional staff and sponsors, the aims of the organization are to raise awareness for breast cancer prevention and early detection through the distribution of information, to provide financial assistance for those with breast cancer, and ultimately to destigmatize breast cancer. To be clear, Pink Ribbon Austria has the most widespread presence of pink ribbons and is the largest organization within Austria's breast cancer awareness campaign. There are however multiple organizations that utilize the pink ribbon or some variation of it. For instance, the Private Charity for Breast Health (German: *Privatstiftung für Brustgesundheit*) sports a variation of a pink ribbon (simply shaped differently), as does the charity group Knowledge Leads to Health (German: *Wissen macht Gesund*), which features a darker-shaded pink ribbon that is not tied into a loop. The manager of the Austrian Cancer Society made it clear to me that their organization wants to remain the only to feature the so-called authentic pink ribbon.

One tenet of Pink Ribbon Austria's campaign is to conform to the cosmopolitan, sexy, and globalized image espoused by the Estee Lauder corporate office. For instance, annual campaign images are in line with what Estee Lauder corporate offices develop and send out. In the past, they have featured model and actress Elizabeth Hurley, a longtime Estee Lauder Breast Cancer Awareness Campaign spokeswoman. This shows the

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[42] Estee Lauder is a global leader in the cosmetics industry. Avon Cosmetics also has a pink ribbon campaign, but the two do not operate in conjunction. Likewise, Estee Lauder's campaign is not connected with the Susan G. Komen For the Cure campaign. The late Evelyn Lauder, daughter-in-law to its founder, was a classic New York socialite and face of the cosmetics company. She adapted the one *peach*-colored ribbon campaign into the pink ribbon campaign in 1992 in Manhattan. Coincidentally, Lauder was born in Vienna in 1936, but fled Nazi-occupied Austria shortly thereafter.

campaign's and company's roots in aesthetic beauty ideals. In Austria, the campaign uses the name and term 'pink ribbon,' instead of its German equivalent *rosa Schleife*, presumably to uphold their international image. However, Austrians who are not proficient in English (many of whom include middle-aged and senior women and men) cannot readily recognize or use the term. In fact, I often heard people make the automatic assumption that the pink ribbon must be part of (and not an analog to) the red ribbon, made popular through Life Ball. Some posters used by the campaign also feature bolded words in English such as "Courage" or "Together" (figure 3.1). In casual conversations, younger Austrian women explained that the use of English made the campaign appear trendy and geared for a younger audience. It is important to note that these posters are also found on some of Vienna's most upscale touristy districts, meaning that they are there to appeal to an international crowd, and not necessarily to the average Austrian/Viennese woman.

Key figures and contributors to the campaign are categorized into various roles in the "pink ribbon family" (family is also said in English). Even other breast cancer awareness campaign organizations are invited to come under its umbrella and be "part of the family," provided they fit into the aims of Pink Ribbon Austria. The members of the family include pink ribbon *Botschafter* (English: ambassadors) and *Partners* (an indirect term for sponsors). *Botschafter* are *Promis* who have vowed to support the cause and informally agreed to wear the pink ribbon at all public events. While their purpose is to "spread the word" as a Pink Ribbon representative said on national television (in English), I have yet to see a *Botschafter* wear a pink ribbon at any public events and media interviews outside of pink ribbon events. It is also important to note that the

Botschafter do not have breast cancer (or at least are not public about it), with the exception of Olivia Newton-John's one-time appearance in Vienna. So, while celebrities with breast cancer on the Austrian media radar like singers Anastacia, Kylie Minogue or Dutch model Sylvia van der Vaart (whose husband is rumored to have left her following her chemotherapy) may be seen wearing the pink ribbon, none are explicitly tied to Pink Ribbon Austria, nor are any of them Austrian. Thus, there are to date no celebrities tied to the campaign in Austria who can speak personally about the experience of having breast cancer.

The idea of a "pink ribbon family" also reflects how corporate interests are cloaked within the idea of community, family, and personalization (see Rose 1999). Samantha King (2006) outlines how this metaphor of community or family is intelligible to American consumers. This has in turned made breast cancer-related cause marketing an effective corporate tool as well as a way for American consumers to believe that by purchasing certain products to working for a particular cause are meaningful and effective actions.

However, that idea of family and community in Austria, especially when uttered in English (as in "the pink ribbon family"), was as unconvincing to Austrians as it was the anthropologist. By failing to convince average Austrian women that they are part of the campaign (as the average American woman, man and child are made to feel included in the 'fight against cancer'), the campaign was already on shaky ground.

Figure 3.1: This is the 2012 Pink Ribbon Austria campaign poster. The word courage is featured on this Estee Lauder Breast Cancer Awareness Campaign poster in Vienna's inner city. The text in German underneath reads: We believe in a world without breast cancer and we will be there until we reach that goal.

Fundraising & Events

Breast cancer awareness campaign coordinators reiterated to me the importance of transparency in fundraising to the point of it becoming peculiar. In all fairness, Austrian companies, particularly banks, are notorious for corruption and nepotism, lightly referred to as *Freunderlwirtschaft* (English: cronyism, or an economic system among buddies. *Freunderl* is the diminutive of friend.). Thus, such a declaration of transparency may very well be necessary for upholding legitimacy. One way the organization claims to uphold transparency is by publishing the total of their annual donations online (pinkribbon.at), followed by a breakdown of how they allocated the funds raised. For instance, out of the €567,859 raised in 2013, €169,300 was spent on printed and online information for the newly enacted (and promptly dismantled) mammographic screening program, €2,636 on breast cancer research, and €395,923 for financial assistance for women with breast cancer, which was exclusively financed by pink ribbon products. The public is privy to how some of the funds were spent, but there is no mention of salaries, regular operating costs (including the prime real estate office in Vienna), or who footed the bill for the events. In this case, one could easily call into question what is exactly meant by transparency. Pink Ribbon Austria raised €505,898 in 2014, out of which €353,953 were devoted to immediate financial assistance for women with breast cancer.

I can only speculate, but it seems that those with breast cancer would likely benefit more if operating costs were lower or if funds were not wasted on marketing for a poorly planned screening program. Suffice it to say that this muddied transparency is on the radar of potentially important donors, including one prominent doctor who remarked, "Pink Ribbon raises money for these events and spends it on more events. What are they really raising money for? Pink balloons?" If there are rules to good philanthropy,[43] it is dubious that these practices are following them.

The doctor's dismay likely stems from the types of publicity events carried out by organizations such as Pink Ribbon Austria, which are temporarily turning cultural landmarks and cityscapes pink as a form of raising awareness.[44] Specifically, he was referring to the release of 5,000 pink balloons into the evening sky to commemorate the 5,000 Austrian women diagnosed annually with breast cancer. In addition, each year, a

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[43] It turns out there are set guidelines to good philanthropy. The US has an organization called "Charity Navigator," which serves as a watchdog for donors. I have heard there is a similar organization in Austria, but I could not find any more information on it.

[44] These events are not to be confused with the breast cancer informational events, which will be discussed in the following chapter.

pink ribbon is hung on the façade of the Austrian Parliament Building (figure 3.2) in Vienna to commemorate the start of Breast Cancer Awareness Month. Likewise, cultural landmarks such as imperial palaces or the Viennese Ferris wheel described at the start of the chapter are illuminated in pink as part of a trend started by the Estee Lauder Pink Ribbon movement. These events are passive, diffusing their way into the media and the Viennese cityscape subtly and without any real civic engagement. While it is easy to be critical of the substantial financial costs (and environmental costs of the popped balloons) of these events, they do lead to widespread media presence. In this sense, raising awareness is equated with increased media presence. There is obviously a difference between recognizing a symbol and knowing truly what it is for. Hence, it is doubtful that the release of 5,000 balloons can really serve as a representation for the women with breast cancer in Austria.

The second type of events sponsored by organizations like Pink Ribbon Austria consists of charity fundraisers that are decidedly exclusive and largely out of reach for the average Austrian woman and her family members. Take for instance the Pink Ribbon Golf Series, now in its fifth year, taking place over the course of four months at a host of country clubs around Austria. Golf equipment, dress, and greens fees are expensive, besides the fact that one would need access to a country club where the tournament is taking place in order to take part. Rural Austrians near Alpine tourism regions lamented the new golf trend brought on by tourists in the region for its significant reduction of wildlife space. “I think we all know who’s really paying for this view,” a farmer said to me shaking his head as we drove past a golf course in his hometown. Additional exclusive events include the annual kick-off gala (described at the start of the chapter), displays at art and furniture galleries, cocktail parties at swanky bars, fashion shows and casino nights. No actual donations were collected at the gala I attended; however, other such events are considered fundraising events for the organization.[45]

The third type of events is open to the public and is intended to bridge an upbeat, lively atmosphere with interludes of information on breast cancer screening, prevention, and a blog from an attractive and energetic woman with breast cancer in her 40s called "Susie has cancer" (German: *Susie hat Krebs*). The events are entitled "Pink Ribbon Tour Stops," where the Pink Ribbon bus and sporty Mercedes Benz drive across Austria to regional cities and upscale towns and set up a mammoth-sized inflatable pink ribbon in town squares and shopping centers. Because of the fact that most events are held in urban and suburban areas, many women living in rural areas would not logistically be able to attend. The cultural divide also plays a role. Representatives from Pink Ribbon Austria lamented the fact that they could not do more in rural regions, but they explained that by nature of being Viennese, it is difficult to gain acceptance among rural women.[46]

These events are intended to raise public awareness for breast cancer and mammography. I attended a "Tour Stop" set up at a shopping center of Vienna. The set-up included a small stage with audio equipment in front of the inflatable pink ribbon, a long custom-made pink ribbon carpet, and a table displaying small prizes for a raffle drawing. Two separate sets of chairs were arranged in front of the stage for the six invited guests, or Pink Ribbon *Botschafter*, and the audience. Coincidentally, there were more invited guests than there were people in the audience. Those who stayed were

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[45] Expensive, private galas for breast cancer fundraising are of course not limited to the Austrian context. For instance, one of the first Susan G. Komen For the Cure fundraising events in the United States was an exclusive polo tournament.

[46] The representatives are not far off, as there is a sense of aversion to the Viennese from those from rural regions.

senior citizens who appeared relatively unfazed. Onlookers in the shopping center passed by curiously, but rarely stopped to get more than a brief glimpse at the event.

Two female moderators took the stage decked out in pink attire. Together they introduced the guests, including the head of the Viennese office of the Austrian Cancer Society, who pressed the need for psychological help for patients, a radiologist who promoted the newly-enacted universal screening program, a general practitioner who described the necessity for boys and girls to obtain the HPV vaccine, a 40-year old woman with breast cancer who promoted her blog, a pharmaceutical professional and breast cancer advocate who pushed for better certification of breast health centers and lastly a director of a dance school, who led her dance troop through an American-style country line dance as the entertainment throughout the show[47] (photo 3.3). The short speeches all would have been more worthwhile if the audio equipment had actually functioned properly, which also may have been the reason why the event did not attract more attention. Despite the technical difficulties, the moderators did their best to announce that self-proclaimed breast cancer 'survivor' Olivia Newton-John made a new album with a new rendition of her 1980s hit "Physical," before photographing the guests for press releases. Representatives reported that attendance was better at other "tour stops," but that they were overall pleased with the event.

The "Tour Stops" are the only events where actual woman who have had breast cancer are present. Other than these events, women with breast cancer, or even stories of women with breast cancer, are largely removed or concealed from these events. For instance, there were no women outwardly with breast cancer at the kick-off gala, and

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[47] The wife of a famous Austrian downhill skier-turned-game show host Armin Assinger had intended to appear, but canceled at the last minute in the wake of her husband's cheating scandal. This is typical *Promi* gossip.

ostensibly none at the release of the pink balloons. It is essentially a means of paradoxically opening up a discourse on breast cancer while simultaneously not really attending to the real issues at hand.

Figure 3.2: The pink ribbon on front of the Parliament Building in Vienna. The pink ribbon hangs in front of the building for approximately a week to commemorate the start of breast cancer awareness month in October.

Figure 3.3: Country line dancers at the Pink Ribbon Tour Stop in a Viennese shopping center.

Informational Materials

Aside from hosting events, Pink Ribbon Austria produces posters, brochures, and magazine and television advertisements. Posters are displayed on street corners, at bus and streetcar stops, and in front of cosmetic shops. Magazine advertisements are exactly the same as the posters and are featured mainly in women's magazines. Likewise, the same main image is used on the cover of the annual brochure distributed from Pink Ribbon Austria about "women and cancer." The images of the campaign are chosen by Estee Lauder International and distributed throughout campaigns acting under the auspices of Lauder's Breast Cancer Awareness Campaign. Figure 3.4 depicts the campaign image from 2011.[48] In the image from 2011, we see four pencil thin supermodels, ostensibly naked except for the pink ribbon around their wrist, with bright

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[48] The 2012 image is featured in figure 3.1, and the images from 2013 and 2014 are discussed in chapter four and the conclusion, respectively

pink pursed lips and glossed bodies huddled close and touching each other. For the sake of comparison, I have included this lingerie advertisement off of a busy street in Vienna (figure 3.5). The 2012 campaign image features a young, nude supermodel with her hands wrapped around her body and pressing her breasts together.

If the pink ribbons were removed from any of the images, they would easily be interchangeable with any haute couture or cosmetic advertisement, which are notorious for the objectification and sexualization of the female body (Lindner 2004). The young women's faces are mostly hidden from the images, with the exception of the voluptuous pink lips, heightening the emphasis on the coquettishly postured, perfect(ly airbrushed) bodies. These images represent not only the traditional trope of female beauty, but also the sexual attraction of the heterosexual male gaze, grabbing attention by arousing. Coincidentally, while in the company of adult male athletes in a café, I opened up a magazine to the advertisement of the young models and asked them what they thought of the advertisement. "Oh yeah, that's hot!," "Pretty sexy," "Yeah, that does it for me!" they said making clear that they found the image appealing. "Anyone know what the pink ribbon is for?" I asked followed by a short pause. "Oh wait, yeah, isn't that for breast cancer?" one asked, as I nodded affirmatively. "Well that's unsettling. I mean, it's such a hard topic," he said. "Those poor women with breast cancer. This isn't what breast cancer looks like." The fact that the images are erotic and provocative initially made them eye-catching, acceptable, and sexy; however, once the real meaning behind the images is revealed, the photographs became inappropriate.

The sexualization of breast cancer within the campaign makes using the term breast cancer more socially acceptable, softer, and lighter. This may help some women get over their initial embarrassment and seek screening, although the failure of the universal mammographic screening program may suggest otherwise. The main issue is that breast cancer is under no circumstances sexually arousing or aesthetically appealing. Breast cancer and its treatment attack breasts and hair, key signifiers of female identity. While I believe it is unintentional on the part of Pink Ribbon Austria*,* there is a sense of cruelty in emphasizing a standard of beauty that no healthy woman can attain, let alone a woman with breast cancer who has potentially lost her hair, had her breasts deformed or removed, and her skin burned from radiation. While it may initially break the silence surrounding breast cancer, it trivializes and sexualizes a disease that can at the very least change a woman's relationship to her body permanently and most drastically, can take her life. One of the aims of the breast cancer awareness campaign as described by a top representative is to promote a sense of solidarity with women with breast cancer, but virtually no woman, especially those with breast cancer, can personally relate to the women featured in the images. Instead, she may feel confronted with a narrow form of beauty and bodily normalization particularly at the point where she must come to terms her post-breast cancer body. Such images are particular insulting to women facing end-of-life issues, especially when many have nothing but two half-circle scars where their breasts used to be. If the organizations of the breast cancer awareness campaign want to simultaneously attract young women by making breast cancer early detection sexy, they cannot do it under the same motto of wanting to build solidarity with women with breast cancer. Female sexualization in fashion and cosmetic marketing is ubiquitous in Vienna, thus making the sexy *Pink Ribbon Austria* advertisements appear normal. However, what breast cancer does to the body is anything but normal. In fact, Barbara Ehrenreich, social critic who was diagnosed with breast cancer, resents the normalization of breast cancer through these marketing tools. Ehrenreich said passionately, "I wish that they could also hear from all the women who have been through breast cancer and resent the effort to make it pretty, and feminine, and normal. It's not normal. It's horrible. It has to be stopped" (Pool 2011). In addition, a public health standpoint would take issue with the fact that younger women are representing awareness for breast cancer, including awareness for mammograms, which is beneficial to women beginning at age 50.

Figure 3.4: 2011 Estee Lauder Breast Cancer Awareness Campaign image, also used in Austria in poster form and on brochures.

Figure 3.5: Permanent advertisement for the Austrian lingerie company, Palmers, at the corner of the Mariahilferstrasse, a popular shopping street. This image is used as a comparison to the 2011 campaign image, which also features nude women in an erotic setting. The difference is that the pink ribbon images are part of a campaign intending to create solidarity with women with breast cancer and raise awareness for breast cancer, and the other a marketing tool for selling lingerie.

Products

A financial cornerstone of the campaign is the distribution and sale of pink ribbon products, manufactured and sold by pink ribbon partners. In order to hold the title of partner, a company must raise a minimum of €10,000 per year. The products are diverse in function and cost, ranging from pink Swarovski jewelry for €160 to a coffee mug for €3. Examples of additional products include pretzels, calendars, sparkling rosé wine, leather handbags, bathrobes, tape dispensers, Post-it® notes, barely-there lingerie (under the name "dark innocence") and a toaster. Some displays either feature just the product, or the product together with an explanation and a set of the brochure "Women and Cancer." For instance, the pink ribbon shoes from 2012-2013 at the upscale shoe store, Salamander, were displayed next to the brochures and a short description of how the shoes support pink ribbon (figures 3.6 and 3.7). The description ends with an incomplete sentence (with the word "and"):

> Do something good with shoes…you can do that [something good with shoes] again this year, as SALAMANDER is supporting the Austrian Cancer Society for the sixth year. These beautiful pumps and ballerina shoes came out of our exclusive cooperation with Högl [an high-end Austrian shoe manufacturer]. These shoes are perfect for the office and for clubbing. The pink ribbon makes them a real statement piece. The large part of the proceeds goes directly to the Austrian breast cancer initiative. [Symbol of the Pink Ribbon] For 21 years now, the pink ribbon has been distributed in October under the motto "because we love life." This is a sign of solidarity with women sick with breast cancer and[49]

Figures 3.6 and 3.7 An example of an expensive pink ribbon product on display next to a brief explanation of the meaning of the purpose behind the shoes and the breast cancer awareness brochure from *Pink Ribbon Austria*, "Because we love life." The adjacent image shoes the same shoes two months later on a crowded sales rack without any explanation for their purpose.

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[49] The text in German is: Mit Schuhen Gutes tun…das können Sie auch heuer wieder, den SALAMANDER unterstützt bereits zum 6. Mal die österreichische Krebshilfe. Aus der exklusiven Kooperation mit HÖGL entstanden diesmal wunderschöne Pumps und Ballerinen, die sowohl für's Büro als auch für's Clubbing geeignet sind. Die Pink Ribbon-Schleife macht sie zu einem richtigen Statement-Piece. Der Großteil des Erlöses geht direkt an die österreichische Brustkrebsinitiative. [Pink Ribbon] Seit nunmehr 21 Jahren wird speziell im Monat Oktober unter dem Motto „Aus Liebe zum Leben" die rosa Schleife verteilt. Diese ist ein Zeichnen der Solidarität mit an Brustkrebs erkrankten Frauen und...

I observed the display in the store on a busy Saturday afternoon for two half-hour stints, Between 2011 and 2013, pink ribbon partners have changed, dropped out, or joined the cause, with the exception of Estee Lauder company cosmetics, which have not surprisingly held the largest market share of pink ribbon products. This is because Estee Lauder was the original "pink ribbon partner" and the impetus for bringing the breast cancer awareness campaign into Austria.

Throughout October 2012 and 2013, I scanned the shopping areas of the city for pink ribbon products, inquiring in dozens of stores about how the donations are allocated, how products were selling, and what the clerks perceived as the purpose behind the products. Store clerks were unclear over where the funds were allocated and how much of the proceeds were to be donated. Some asserted that 100% of the *cost*, rather than a portion of the amount earned beyond the manufacturing costs would go to pink ribbon, while others were under the impression that only 10% of the proceeds are donated. In addition, there was confusion over what the donations were used for, with some saleswomen claiming that all the proceeds go to breast cancer research, others to patients, and others did not know. In its brochure, "Because we love life: What women should know about cancer prevention and early detection,"[50] Pink Ribbon Austria is also elusive as to how much of the proceeds from pink ribbon products are donated to the organization, but a private conversation with a head representative revealed that a company must commit to contributing at least 15% of the sale of a product. These companies can determine the types of products they choose to market. They also have control over what specifically is mentioned about the pink ribbon or breast cancer. For

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[50] The former title of the brochure was simply "Women and Cancer: Prevention and Early Detection."

instance, the pretzels sold for *Pink Ribbon Austria* simply state “Think Pink!” on them without any explanation that some proceeds of the sale go towards the Cancer Society or to helping women with breast cancer. Another example is a pink ribbon handbag bearing a large photograph of a bulldog’s scrunched face with a pink bow on its head which retailed for €149.90. One could easily overlook the small pink ribbon above the dog’s head. Thus, to anyone unfamiliar with what the pink ribbon symbolizes, these products do little to bring the organization into the public’s consciousness.

Products sporting a pink ribbon are also found at “Women’s Shopping Days,” where Austrian home goods stores set up stands inside the shops to sell various products they feel appeal to women, including cosmetics, candles, ceramics and soaps. At a Women’s Shopping Day in Vienna, a home goods store devoted one stand to the sale of pink ribbon products. A representative from the Cancer Society explained to me that the coffee mugs and reusable shopping bags were selling well, but the other (more expensive) products, such as a bathrobe for €59.90 were not. I observed the stands for an hour, but did not see purchases from the Pink Ribbon kiosk. Two floors up in a secluded corner of the store, store clerks offered astrology readings in exchange for donations to Pink Ribbon. One clerk told me she believed that women wanted to have readings done to try and divine their futures, rather than to donate to the cause. Interestingly, the astrologists were store clerks. In addition, the clerk mentioned that very few women had actually wandered to that section of the store and had an astrology reading performed.

In the nearby upscale shopping districts of Vienna, pink ribbons could be found in shoe stores, cosmetic shops, and at Austria’s own Swarovski crystal shops. The products, like the “For love of life” brochure, appeal to a younger, trendy, ultra-feminine (or even ‘girly’) women with enough disposable income to buy expensive accessories. For instance, Swarovski sold an oversized baby pink gem ring and a handbag company produced another shopper-size leather handbag with a “pink ribbon pin-up” girl done up in 1940s-style sailor dress. Needless to say, this is a narrow view of women’s consumer interests. However, I heard a Pink Ribbon representative and two sales clerks in cosmetic stores selling pink ribbon products proclaim, “I don’t know any woman who doesn’t love pink!”

Coincidentally, a head representative from Pink Ribbon Austria explained to me that a main barrier to expanding the impact of the pink ribbon in Austria is not being able to reach women from immigrant backgrounds, who according to her are less likely to attend mammographic screening and seek early medical attention due to the fact that there are few female doctors in oncology but also that it’s about “mentality and religion.” Thus, the same issue with product exclusivity applies and the products remain outside of the general public’s awareness, and do not attract the attention of the women the organization is ostensibly trying to persuade to attend mammograms.

With the exception of pretzels and laundry detergent, the products are luxury items and are prohibitively expensive for many. On October 14, 2014, the Pink Ribbon Austria hosted another “Pink Ribbon Shopping Day!,” except this time the boutiques and shops, among them Giorgio Armani and Meinl am Graben (Austria’s most exclusive grocery and wine shop) had become more exclusive than ever before. Pink Ribbon Austria does not see this as an issue, as a staff member explained,

> “Well you see, this is a charity organization. It’s not about making sure that lots of women have the products. Women who can’t afford the products can wear a pink ribbon. That only costs a couple of euro. It’s about making a good sale too and making sure that the partners get something out of it…Women who can afford the products should make a

> contribution on behalf of the women with the disease [breast cancer] who can't afford it…Women who can help other women with their donation can buy the products and as a thank you, they get a product in return."

In the staff member's view, the wealthy are invited to take part in buying the products, and the less affluent can only do a symbolic gesture such as wearing a pink ribbon or choosing pink ribbon pretzels over another brand. The pink ribbon products are therefore another source of exclusivity within the campaign due to their inaccessibility to women from more rural regions of Austria, their lack of appeal to all women, and their prohibitive cost.

More than simply being exclusive, these products are part of the troublesome notion that buying products such as shoes or bathrobes is can actually contribute to the fight against breast cancer, when in fact this act contributes little. By believing that one has actually made a difference by buying a pink ribbon handbag, one is less apt to take a political or activist stance to push for better care for those with cancer or a more effective and efficient form of mammographic screening. In other words, privatizing and commercializing breast cancer depoliticizes the structural barriers and issues mentioned in this chapter.

In addition, selling products in the name of helping those with breast cancer without ever really mentioning breast cancer does little to contribute to changing the public's mindset of keeping quiet about the disease and shutting it out. As Mara Einstein points out in her work on cause marketing and consumerism,

> "bringing philanthropy into a consumer mindset has a downside both for individuals and for society at large: it depoliticizes issues by putting a pleasant face on complex problems…charity becomes mediated and depersonalized, inuring us to human suffering.'' (2012:xiv).

Indeed, a pin-up girl pink ribbon handbag seemed to be a far cry away from the suffering I witnessed of the women in the study who were losing their lives to breast cancer. Like much else within the neoliberal paradigm, buying cause-marketing-related products is seen as a logical and effective means or doing good and promoting health, when it actually has the effect of masking the limitations of scientific and medical development as well as structural and political issues surrounding women's health.

Nevertheless, the pink ribbon does represent a means of showing that someone's life has been impacted by breast cancer. Only one woman in the sample (N=54) undergoing treatment for breast cancer had purchased a pink ribbon product. Sigrid (56) is a German woman who has lived in Austria for thirty years. She told me she carries her pink ribbon keychain as a way of opening up about breast cancer to those who inquire about it. She noted that she is often asked about what it means, to which she explained "I just tell people short and sweet in two or three sentences that breast cancer can affect every woman. But you know, I *love* the color pink, so that could also be a reason why I like to use my keychain." When I asked Sigrid if she would attend any events, she began laughing hysterically and said she would never be let in. "Never say never though!" she added.

In addition to allowing some women to initiate discussion about breast cancer, donations from the products are specifically earmarked to provide immediate financial assistance for women with breast cancer. Even if a product sells poorly, the sponsoring company is still expected to donate at least €10,000 to Pink Ribbon Austria. This initiative is important considering that it is not uncommon for women to face changes in their current work status or to lose their jobs altogether following their diagnoses (Frank

2005). However, while Pink Ribbon is far flashier and has a greater media presence than the Austrian Cancer Society, all donations to women with breast cancer are carried out by the Austrian Cancer Society which provides the immediate financial assistance for those with breast cancer. It should also be noted that financial assistance for illness-related is available for all people with cancer who are facing poverty as a result of their illness. The Austrian Cancer Society notes that people can lose their jobs due to no fault of their own and cannot cover the additional costs of the illness, including a wig, transportation costs, or prescriptions.[51] Hence, *only* illness-related are covered and all alternative medicine claims are denied. Patients must have a personal meeting with a representative of the Austrian Cancer Society and provide all necessary documents to prove their financial need. Finding one's way around from the Pink Ribbon website to the necessary information is not straightforward and requires savvy Internet skills or the knowledge to go directly to the Austrian Cancer Society.

There is good merit in securing financial assistance for women with breast cancer in need. However, none of the women with breast cancer I met had applied for financial assistance through these funds, even though a few mentioned that they were in need of money for a nanny to take care of their kids throughout treatment. Many mentioned in passing that it would have been helpful to receive assistance for rent payments or groceries, but that their treatment-related costs were adequately covered by their health insurance. The Austrian Cancer Society issued a press release on World Cancer Day

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[51] The bare minimum of costs for a wig is covered by the national health system. However, the process is not very straightforward. A prescription for a wig must be given to the patient by a doctor, which must also be approved by a health insurance group (of the province of Vienna, Vorarlberg, and so forth). All additional costs, including other wig care products or natural-hair wigs must be footed by patients. The health insurance group of Vienna supplies links to local salons that manufacture wigs. Prices for natural-hair wigs range from 1,000 to 2,000 Euros. Artificial-hair wigs cost between 400 and 700 Euros.

with examples of how the immediate financial assistance funds have benefitted women with breast cancer (APA Press, *Österreichische Krebshilfe*, February 4, 2010). These women must prove to the Austrian Cancer Society that they meet the criteria to require financial assistance. Karin, single mother of 5 children whose father is nowhere to be found, lost three teeth as a result of her chemotherapy. The funds covered Karin's necessary dental work, which added up to €2,000. Maria, a mother of 6 children with metastatic breast cancer and lymphedema, received €1,650 for a second brazier for her prostheses and lymphedema-related therapy. Thus, these funds do provide aid for women in desperate need.

While increasing information for breast cancer and providing some financial assistance for treatment-related costs are worthy goals, they do not address the issues in regard to the disparities in accessing quality-certified treatment, health illiteracy, and protection for women who lose their jobs after their diagnoses. In addition, the campaign, including its use of English, its lack of use of the term 'breast cancer,' its exclusive events and products, and emphasis on sexualization and a traditional trope of beauty stray away from the needs of average Austrian with breast cancer. Certainly any publicity regarding breast cancer can be effective for getting others to open up about it, but at the same time the campaign's and the media's emphasis on the exclusivity of the *Promi* world and an unattainable beauty standard elicits unfavorable reactions from women with breast cancer. On the one hand, the campaign fits squarely into the Austrian sense of apathy surrounding charities and health campaigns. On the other hand, the exclusivity of the campaign stands in stark contrast to the ubiquity of the disease among women in Austria from all social and cultural backgrounds. There are only scant opportunities for women to be forthright about their illness in a collective sense and identify with a movement.[52] The following section presents reactions from women with breast cancer to understand how they interface with the newly enacted breast cancer awareness campaign and how it fits into their needs both during and after treatment.

"It's not my world": Reactions from Women with Breast Cancer

My initial research hypothesis postulated that not all Austrian women would ascribe to the breast cancer awareness campaign and that the illness narratives collected among women with breast cancer would reveal significant differences in comparison to the ways in which breast cancer portrayed in the campaign. I based these hypotheses on my previous experiences in Austria and the oft-repeated sentiment that illness belongs to the private realm of life. While the latter hypothesis is the topic of chapter five, this section delves into women's reactions to the breast cancer awareness campaign and pink ribbons in their cultural landscape. Participant observation and interviews upheld my hypothesis that not all women would react to the campaign positively; however, with a crucial caveat: almost all of the women were in favor of making breast cancer a public topic and many wanted to take part in the campaign to raise awareness for breast cancer. That being said, women took issue with some aspects of the campaign, including its use of sexualized models to represent breast cancer. Women also spoke of their exclusion from noteworthy galas sponsored by Pink Ribbon Austria, to which some were indifferent and others disappointed.

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[52] This 'collective sense' is noted however to not reflect the heterogeneity among women (and men) affected by breast cancer. For instance, Jain (2007) offers a queer analysis of the breast cancer awareness campaign within the United States, which challenges the dominant image of the 'breast cancer survivor' as a well off, middle aged, heterosexual, successful woman whose life has been put on hold by cancer. Klawiter (2008) likewise has focused on various cultures of action and the role of difference in breast cancer activism.

To understand the attitudes of women with breast cancer towards the campaign, I first inquired about what they had heard about breast cancer in Austria prior to their diagnosis, their perceptions of breast cancer in Austrian society, if people talk about breast cancer in general, or if it is discussed in the media. It was certainly not a given that women would have familiarity with the pink ribbon, particularly those living outside of Vienna. “Oh the thing with the *Promis* on TV? The galas?” some would ask. Other women had never heard of it, and some could recognize it but did not know about its purpose. One woman explained that breast cancer only becomes a hot topic for a short time when an international celebrity like Angelina Jolie popularizes it, and then the theme is more or less forgotten. Some women were more comfortable with the fleeting discussion of breast cancer, as it required no disclosure of breast cancer on their part. Women across age groups expressed that they had seen public information of breast cancer prior to their diagnoses, but admittedly had never neither grappled with the topic nor wanted to. “You never think it’ll happen to you,” women often repeated to me.

Anna (64) found the actual campaign to be an excellent initiative, but took issue with the manner in which it is carried out. She explained, “Raising money for women with breast cancer and giving some money to research can’t be bad, right? But I mean, please, do they have to do it with these dramatic events and galas? Being *too* public just isn’t my thing.” Anna was however unaware that donating money to research is not a priority of Pink Ribbon Austria. For Martina, a 28-year old diagnosed with breast cancer during what she had hoped would be a prophylactic mastectomy, knowing that there is a campaign gives her the “sense of togetherness, but in another form. It’s the idea that you know it’s happening to other women, but you can experience it in your own personal way. But the pink ribbon events are just too ‘VIP,’ you know? I’m more for events that actually help women.” Likewise, Ilse (68) values her privacy in regard to her illness. She said, “It’s not really that I need solidarity with other women. I don’t need the sympathy or the pity…but that we could get out and talk about the reality of the situation, now that’s what we need. I don’t need to stand in front of a camera to do it.” In other words, Maria among others, are looking for a platform, a voice in the system, instead of a support group or a public display. She did not want to simply be represented as one of 5,000 pink balloons or cardboard cutouts.

Other reactions were polarized, evoking either a complete rejection of the campaign and the desire to be open with one’s illness or utter support and eagerness to take part. The desire to take part however remained for most women only a hypothetical possibility, meaning many replied to me with “No, I have never taken part in any events, but I would.” For instance, Susanne (27 at the time of the interview) and Laura (34) both likened the galas to the Life Ball and very much wanted to attend the kick-off event that I attended. But while anyone could attend the “Pink Ribbon Shopping Days!,” and “Pink Ribbon Tour Stops,” neither of these women would have ever received an invitation to the main gala, the event of their choice.

Some women bemoaned the emphasis on sex and beauty embedded within the campaign and in celebrity appearances. “It’s really admirable that model Sylvia van der Vaart [a young Dutch celebrity with breast cancer] can be on television shortly after her chemotherapy. But it’s also really unfair what the media is doing. No woman looks like that during her chemotherapy. I mean, that’s nothing but really great makeup. I’m not going to ever look like that, especially not during chemo!” Others like Eva (53) directly mentioned the burden of women being treated like sex objects for as long as possible throughout their lives, and now even when it comes to breast cancer and the photographs used in the campaign. “It gets even worse when you actually have breast cancer,” she complained.

In addition, money, time and travel were three reasons for shutting out engagement with the pink ribbon. Many stated that attending events or buying the products were prohibitively expensive. “I could never afford a ball gown,” or “If it costs more than €10, you can forget about it,” a young mother said honestly. Others from rural regions described how the fact that all events take place in Vienna would make it impossible to attend. Agnes (42), who grew up and lives in a small, rural town, laughed at the ridiculousness of my question when I asked if she would attend a pink ribbon event. “Pink Ribbon? Ha! No, it’s not my world.” On a visit to a rural alpine village, I gathered a small group to watch a media review of the 2012 Pink Ribbon Austria Gala on television. The national broadcasting station titled the spot as “High Society (said in English) in the Viennese Parliament Building,” showing its exclusive location in the big city, and curiously omitting the term breast cancer. “Always *Promis, Promis, Promis* and lots of mumbo jumbo,” muttered Isolde (65). “The show of it all! What it must have cost!” echoed her sister. “At least Eva Glawischnig (head of the political Green Party) said that breast cancer is a matter of life and death,” noted Thomas (40), the only man in the group.

Only one study participant had actually attended a gala. Christa (60) attended an event at one of Vienna’s many palaces five years prior to our interview.

> “I’ll never forget it,” she recounted, “They had lectures on medical advancements in breast cancer, so I went to hear that, and afterwards there was a reception in a different

> hall, but the *Promis* had already been and there was hardly anything left for us! I just had the sense that the whole thing was a *Promi* event and the women with breast cancer were just the hook so that the *Promis* could throw themselves in front of the camera. I mean, they could have easily involved those of us with breast cancer."

She went on to explain that a symbol like the pink ribbon is incredibly important for building a sense of solidarity, but "not when it's tied to these kinds of events." Yet, as described earlier in the chapter, *Promi* involvement in charity matters has a longstanding tradition in Austria. "Maybe it just has to be this way with the *Promis*," an acquaintance told me, "It's just a necessary evil." Or as Maria (58) explained, "Of course it's a good thing that the *Promis* are supporting the campaign because then we normal folks can say, 'Well look, they're getting involved,' and then they'll be more open about it. It's got to come from the *Promis*."

The desire to take part in such events is not shared equally among the women who participated in the study, as many preferred to uphold their privacy and not be burdened with more illness-related appointments. However, for those who expressed their support for the campaign and were either unable to attend due to location or cost, or never even considered the possibility of attending because they were not VIPs, the events do little to build a sense of solidarity. It is critical to keep in mind that events such as the gala I attended are invitation only (i.e. tickets cannot be purchased). If it is not, as Agnes said directly, her "world," just whose world is it? Who should be allowed to speak on behalf of the women who want their voices heard? Solidarity is not truly possible when real women with breast cancer have little to no say in the process and those speaking on their behalf are doing so from a position of sociocultural privilege.

The community of women with breast cancer, with whom the awareness campaign ostensibly wants to promote solidarity, have little to no social capital in the campaign. Products are sold on their behalf, companies selling pink ribbon products make profits, and celebrities build a positive image by appearing in the media at charity events. For the women content with upholding their privacy and keeping breast cancer publicity at an arm's length, the breast cancer awareness campaign is just another commonplace charity. But for those women looking to be engaged with the campaign and the cause, the breast cancer awareness campaign comes up short. Removing women with breast cancer from the heart of the campaign calls the public health impact and sociocultural contributions of the action into question. Thus, the breast cancer awareness campaign presents a case where a public health issue once intended to empower women has been transformed into a reassertion of traditional tropes of beauty, the extravagance of celebrities (and the invisibility of the Austrian woman), and a patriarchal medical system that profits from breast cancer.

Conclusion: An indiscriminate disease, a selective campaign

This chapter combined a host of related issues in order to evaluate the purpose of bringing breast cancer awareness to Austria and to grasp the impact of its global flow on Austrian women with breast cancer. It began by describing two different scenarios in which the pink ribbon was employed as a symbol for breast cancer, the first being an exclusive Pink Ribbon Austria gala, the second a mournful funeral of a women in her late 20s who died of the disease. This contrast was intended to highlight the party atmosphere of the campaign against the jarring reality that breast cancer still claims the lives of thousands of Austrian women, many of them like Susanne in the prime of their lives. But, it is also meant to show that the pink ribbon is becoming very real to women and their families who want to use it as an international symbol of hope and solidarity and want to be able to speak truth to the illness experience of breast cancer and express their grief over the many women who lose their lives to breast cancer.

The chapter followed with a description of the various advantages of the Austrian healthcare system, which on a global scale provides excellent cancer care. This begs the question as to why Austria would need awareness in the first place. More than remiss, it seems suspect to implement 'awareness' for breast cancer a.) in a country that is seemingly already 'aware,' b.) in a healthcare system not at all plagued by major problems in cancer care like some of its neighboring countries or those on a global scale, c.) while ignoring some potential aspects for improvement, like ensuring that all women are treated in quality-certified breast health centers. I then listed other structural and cultural ways that breast cancer care and attitudes towards breast cancer can be improved. I mentioned early in the chapter that true awareness and advocacy for breast cancer is sorely misplaced in this world. However, there is a strategic placement of 'new' awareness in high consumer contexts like Austria where campaign stakeholders can continue to turn over profits.

The chapter diverted slightly to mention the cultural aspects of health campaigns and charities within the Austrian/Viennese settings in order to better contextualize the breast cancer awareness campaign. While there is a history of celebrity involvement in health and charitable campaigns, hardly any of the issues addressed by these campaigns affect the health of Austrian women on such a broad scale as breast cancer. These two sections allowed for an appraisal of the breast cancer awareness campaign to assess whether its efforts, motives, and funds spent went towards rectifying the aforementioned issues and also the extent to which it fits into an existing cultural paradigm of celebrity-driven and cause-marketing charity. I set this up broadly by describing the main promoter of the breast cancer awareness campaign, Pink Ribbon Austria, and its affiliations, goals, events, products, printed materials. I supported this section with statements collected within interviews with personnel and during participant observation at related events. The organization provides funds to help those with financial difficulties during their treatment and has brought the pink ribbon (and to a lesser extent the term breast cancer) into the media and cultural spheres. On the other hand, the campaign remains largely exclusive, sexualized, and materialized, thus hindering solidarity with women with breast cancer and political involvement in breast cancer care. The real women lost behind the glitz and glamour are women from a lower socioeconomic status (often including women with immigrant backgrounds), and those in rural regions whose household and family demands coupled with the relative isolation from urban centers prevents their access to the campaign.

The chapter concluded with reactions from women with breast cancer. The general sense is that women are pleased that there is more discussion surrounding breast cancer in the public sphere. While some are content that the campaign allows for discussion of breast cancer ‘at a distance,’ others want to be more involved but cannot, either due to the campaign’s exclusivity, lack of time, distance from event locations, or prohibitive cost. Still, others expressed displeasure with the sexualization and *promi*tization of the campaign, thirsting for a platform to make clear the reality of having breast cancer and have a voice in the system. A campaign breaks the unwritten rules of good philanthropy when it claims to be building solidarity by presenting women with an unattainable standard of bodily perfection at a time when their bodies are in danger of disfigurement. Thus, the sexualization of breast cancer within the campaign and the chicness and hyperfemininity of its products hardly create an open space for women to be seen in public without a wig, which had so impressed a key staff member of the campaign.

Scheper-Hughes & Lock (1987) solidified *medicalization*, or the transformation of human conditions and/or social ills into physiological and medical problems, in the medical anthropological research agenda. The breast cancer awareness campaign's emphasis on mammograms is a form of medicalization in that pathologizes women's breasts and sends a message that breast tissue is like a ticking time bomb. The remarks in this chapter sought to build upon this notion by understanding the effects of coupling medicalization with commercialization and sexualization of women's health. As Klawiter (2008:26) aptly notes, medicalization privatizes, individualizes, and depoliticizes social issues surrounding women's health.

The global spread of breast cancer campaigns has intensified these troublesome processes while simultaneously creating more distance between the campaigns and the women for which they aim to speak. All the while, parts of the world in dire need hardly see any advocacy or awareness. Meanwhile, breast cancer incidence rates continue to increase, mortality rates budge only slightly, and women with breast cancer continue to endure stigmatization. The medicalization of women's breast health in the sociocultural domain, achieved through multiple actors including the biomedical practitioners, pharmaceutical companies, politicians, private foundations, and celebrities with little involvement from the community of sufferers creates a pernicious environment in which discourses of the real problems behind breast cancer are silenced. Worse, it gives the impression that serious issues can be solved by materialistic consumption and subscribing to a narrow standard of beauty. In addition, omitting direct involvement from those with breast cancer who *want* to take part not only removes agency, but also allows for the insertion of private interests on the part of industry as well as biomedical community (as will be discussed in chapter four). In conclusion, the presence of the campaign is better than nothing, so to say, but there is certainly much room for improvement if those behind the campaign truly want to fulfill their goal of destigmatizing breast cancer.

In the following chapter, we will examine the biomedical side of the breast cancer awareness campaign in order to evaluate its effect on raising Austrian women's understandings of breast cancer risk and the impact the rhetoric of risk imposes on those with the disease. Like this chapter, it follows the neoliberal paradigm of women's health, what it obscures, and how women with and without breast cancer are interpreting this discourse.

CHAPTER FOUR: THE ILLUSION OF RISK AND CONTROL IN THE BREAST CANCER AWARENESS CAMPAIGN

Losing a War with Cancer

In 1971, when President Nixon signed the National Cancer Act (i.e. The "War on Cancer"), he gave Americans and the rest of the world the impression that cancer could not only be controlled but defeated (Weiner 1999). But over four decades later, billions of research dollars spent, a staggering 14.1 million new cases of cancer and 8.2 million cancer-related deaths around the globe each year (Torre et al. 2015),[53] it is clear that efforts to prevent, comprehend, and treat cancer are failing. While there have been some gains, the American-spearheaded endeavor to end cancer is as oncologist Siddhartha Muhkerjee posits, like the "Red Queen" from *Alice in Wonderland*: it moves around incessantly just to stay in one place (2010: 444). For the medical community and lay alike, cancer remains a mystery yet to understood, let alone controlled.

Anthropologist Martha Balshem wrote, "if one is thinking about control, cancer is good to think with" (1993:89). Indeed, all of cancer is a struggle for control— from preventing cancer by identifying risks, to enacting surveillance to find it in its early stages, to halting its progression, and to socially labeling those with cancer for the remainder of their lives. Whereas the word cancer was barely whispered in the past, current efforts to proactively and publicly enact cancer control are fueled in part by the

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[53] Lung cancer is the leading cause of cancer death among women in developed countries (Torre et al. 2015). Breast cancer is the leading cause of death among women in developing countries (*ibid.*). According to the latest GLOBOCAN database estimates, there were approximately 1.7 million cases of breast cancer and 521,900 breast cancer-related deaths among women worldwide (*ibid.*).

public's general anxieties over cancer and biomedicine's ubiquitous authoritative knowledge, or the added weight and leverage attached to biomedical claims of truth.[54] In other words, convincing people that cancer can be stopped enhances the willingness to engage in cancer control.

The problem is that cancer control can never be fully effective without a better comprehension of the disease. The gaps in knowledge of cancer allow for speculation over cancer causes and risks. How people come to terms with the elusiveness of cancer sheds light on the production of risk and the particular social arrangements and cultural values in which risk is enacted (Balshem 1993). Chapter two described the traditional belief in Austria that cancer is a part of an unfortunate fate and is therefore governed by an intangible force outside of one's control. But the notion that destiny controls cancer clashes with the central tenet of modern biomedical risk, which rationally assumes that "people are supposed to live and die subject to known, measurable natural forces, not subject to mysterious moral agencies" (Douglas & Wildavsky1983: 49). Indeed, the tension between these two notions of risk and control are at odds in Austria, which has led members of the medical community to assert biomedical models of risk and educate women about breast cancer prevention and early detection.

The irony is that statistical models of risk, while not driven by "moral agencies," inevitably take on a sense of morality for their ability to determine harm that can be done to the self or someone else (Lupton 2013 [1999]). In other words, to avoid risk and risky

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[54] Brigitte Jordan and Robbie Davis-Floyd were major promoters of the notion of "authoritative knowledge" in medical anthropological work. Jordan and Davis-Floyd presented ethnographic accounts of birth in four contexts (Mexico, the United States, Holland, and Sweden) and revealed how the hegemony of biomedical practice established a "particular regime of power," which they deem "authoritative knowledge" (1993:215). Simply put, authoritative knowledge is knowledge or a 'take on reality' that is attached to those in positions of authority. Its use in medical anthropology is mostly centered on biomedical (and to a lesser extent) public health practitioners.

behaviors is to engage in a moral life. Convincing women in Austria that risk for breast cancer (and dying from breast cancer) is within their own control and not in the hands of fate is a key aspect of the breast cancer awareness campaign. But what can be accomplished in a public awareness campaign about prevention with only a partial understanding of what causes breast cancer?

This chapter examines the various points of translation of breast cancer risk, from epidemiological statistical models of risk, to the clinical implementation of risk, and finally to the lived experience of risk. The limitations in knowledge about the development and progression of breast cancer (and the majority of cancers) inherently create gaps in these various translations of risk. These open spaces allow for the insertion of various subjectivities and vested interests in the process of informing women of breast cancer risk. This chapter explores how these interests are reflected in the distribution of information about breast cancer risk and screening, how Austrian women understand their risk and the benefits of prevention, and the impact of this discourse on those women living with the disease.

One underlying factor in the rise of awareness campaigns for breast cancer is the shift towards a neoliberal arrangement of modern biomedicine and public health, which reworks bodily control and surveillance to be productive, moral, and part of one's individual responsibility (Chavez 2009; Heurtin-Roberts 2009). In the current neoliberal paradigm, ill health is considered to some extent to be in the control of the individual (Heurtin-Robert 2009). Within this discourse, risk is a means of labeling subjects that are in need of biomedical interventions (Chavez 2009). The assumption is that providing information is sufficient to have people control their 'risky' health behaviors and attend screening regularly (Armstrong 1993; Lupton 2013 [1996]; Peterson and Lupton 1996). Medical anthropologists and sociologists have documented how biomedical hegemony has aided in the construction of cancer risk and has influenced screening behaviors, despite the problematic aspects of both (Klawiter 2008; Lock 1998; McMullin & Weiner 2009).

In the shift towards promoting breast cancer prevention and risk reduction, the breast cancer awareness campaign changes healthy women into risky subjects, whereby the early detection of breast cancer itself becomes a health condition subject to the careful watch of biomedicine. As described in chapter two, these approaches to controlling cancer are grounded in oncology's tendency to instill values and morals in its patients (MJD Good et al. 1990).

Breast cancer presents a compelling case for studying cancer prevention and moral responsibility due to the advent of mammographic screening, which allows for the detection of malignant tumors in asymptomatic women. Mammography as a surveillance technique for breast cancer fits well in Foucault's notion of biopower and the medical gaze (see Foucault 1976),[55] particularly when nation states enact universal screening programs as a means of controlling the deviance of cancer (Kaufert 1996, 2000; Keating & Cambrosio 2000). It likewise invokes Rabinow's notion of "biosociality," (1996) which demonstrates how women are classified based on their increased risk for breast cancer through family history or genetic predispositions, or simply by virtue of being female. While statistics on the benefits of early detection are unclear, discourses of screening promote it simply as moral behavior (Kaufert 1996, 2000), even when the act

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[55] Briefly, Foucault's "biopower" is a means of understanding the transferring of power in the modern state to exercise control over the state's subjects through constant surveillance of the body. Rabinow's "biosociality" is the production of a social identity through common identification of a bodily condition.

of mammography is stigmatizing (Gregg & Curry 1993; Lende & Lachiondo 2007). Thus, a diagnosis of breast cancer that is diagnosed after its earliest stages can in part be considered one's failure to follow medical orders to prevent the disease or at the very least to detect it early. This reinforces biomedicine's ability to exercise its authoritative knowledge in correcting the body's own deviance (Lupton 2003). If health is considered to be within an individual's control, a diagnosis of advanced breast cancer appears (often incorrectly) that a woman did not take the necessary precautions to be screening regularly.

In Austria, this means that the doctors, or as they are part tongue-in-cheek, part truthfully referred to as "demigods in white," (German: *Halbgötter in Weiß*) hold power over the public's understanding of risk and the mandate to be screened. How people understand these risks and risk prevention is an ongoing process of negotiation, heavily influenced by a patriarchal medical community, media, personal experience, and most recently, informational sessions hosted by a variety of biomedically related organizations. This chapter proceeds by discussing the discordance between epidemiological and individual notions of risk in order to grasp why women overestimate risk and the benefits of mammograms. This is followed by a presentation of data collected from participation observation at informational sessions, an analysis of printed materials relating to breast cancer awareness, and a review of media reports featuring oncologists with the purpose of critically evaluating how information pertaining to breast cancer is shaped by biomedical and biotechnological interests and less by evidence-based medicine.[56]

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[56] I acknowledge the critiques from anthropologists of the problematic and subjective aspects inherent to the term "evidence-based medicine," including its neglect of clinical experience and local biologies, and the artificiality in creating groups to participate in epidemiological studies (Lambert 2006; Lock & Nguyen 2010). I also take into account the critique of evidence-based medicine whereby even its practices are not

I use 'campaign' as an umbrella term to describe the public agencies (e.g. the Austrian Cancer Society), private agencies (e.g. *Privatstiftung für Brustgesundheit*, English: Private Foundation for Breast Health), and various breast health and gynecological clinics in Austria. When necessary, I describe which agency is responsible for the information being spread. Otherwise, I use 'campaign' to speak generally about the increase of informational sessions, printed materials, and media presence. Pink Ribbon Austria is part of the broader breast cancer awareness campaign discussed throughout this work.

Engaging the viewpoints of women living with breast cancer also revealed how campaign discourse, particularly the emphasis on personal control over breast cancer risk, can negatively impact the illness experience. The shock of a diagnosis often leads to contemplation of the causes of one's cancer, which is then followed by an acceptance of the uncertainty and precariousness of recurrence. As I will describe, dealing with these issues is difficult, but doing so in a context where health is purported to be the responsibility of the individual creates a double burden for women with breast cancer. Thus, this chapter shows the dangers of overestimating the benefits of personal control and screening for this vastly enigmatic and elusive disease from the vantage point of those living with it.

How Probability becomes Certainty

The reason why the war on cancer drags on endlessly is not the public's lack of information on cancer risk or the public's unwillingness to attend cancer screening.

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standardized and are often dissociated from structural barriers (Lambert 2006). Nevertheless, I see the alternative, *eminence*-based medicine, or reliance of a medical expert's opinion in shaping health policy as more harmful than the problematic aspects of evidence-based medicine.

Cancer epidemiology is emerging and constantly changing in a complex interplay of genetic, epigenetic, sociocultural, structural, environmental and bio-behavioral factors. In short, we neither know for certain what causes cancer, nor how risk factors synergistically interact within the onset and progression of cancer. Even ostensibly obvious cases such as long-term heavy cigarette smoking and the development of lung cancer are ambiguous, as some who never picked up a cigarette may develop lung cancer and some “pack-a-day” smokers never do.

The term breast cancer is actually a misnomer. To say breast *cancers* would more accurately describes the dozens and perhaps hundreds of subtypes of this heterogeneous disease. A host of factors are associated with a statistically significant increased risk for breast cancer, including but not limited to: being a woman, older age, family history, history of benign breast disease, genetic mutations, being nulliparous, older age at first birth, exogenous estrogen intake, younger age at menarche, older age at menopause, being overweight or obese after menopause, high alcohol use, not breastfeeding, and exposure to ionizing radiation.[57] Having a host of factors does not necessarily mean a woman will develop cancer, nor does the absence of risk factors mean a woman will remain breast cancer free.

Even carriers of germline mutations in the BRCA gene are not absolutely certain to develop breast cancer in their lifetime, and a prophylactic mastectomy, made famous by Hollywood star Angelina Jolie, does not definitively prevent breast cancer (see

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[57] There are few reports and even fewer conclusive studies demonstrating a link between environmental factors and breast cancer risk. The neglect to investigate these links is criticized by some breast cancer activists as being a clear sign of the control of industry over the practice of medicine. Environmental epidemiology is also methodologically challenging due to quantification of exposure.

Kamenova et al. 2014).[58] There is no smoking gun for breast cancer. And yet, risk reduction is often spun as a matter of personal responsibility, causing some women to go to great lengths including receiving prophylactic mastectomies or taking estrogen-blocking medications to try to prevent breast cancer, while others change their diet in the hopes of preventing breast cancer or its recurrence. For carriers of the BRCA mutations, the outlook is quite complicated. In one respect, undergoing a prophylactic removal of the breasts and ovaries, while drastic, is the currently best possible option for reducing the overall risk of developing these forms of cancer. However, breast removal and reconstruction requires multiple surgeries with extensive recuperation, and are time intensive, not to mention carry the emotional burden of losing one's reproductive organs. There are valid reasons for undergoing and choosing not to undergo the procedures. However, this is not generally the way in which genetic testing and prophylactic mastectomy is conveyed at breast cancer informational sessions. One prominent oncologist who has taken the lead in genetic testing in Austria presented the procedure as "each woman's individual decision," and at the same time, "her responsibility to do the right thing and greatly reduce her risk." During a question-and-answer period at an information session, I asked him to elaborate on some of the potential complications of undergoing the surgeries, knowing that some estimates state that two-thirds of women undergoing a prophylactic mastectomy have at least one complication (e.g. infection, pain) following surgery (Barton et al. 2005). He replied that the complications were few,

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[58] This chapter does not explore the data collected on genetic testing and prophylactic mastectomy, which is also promoted by certain oncologists in Austria under the auspices of the breast cancer awareness campaign. In addition, my interviews with one woman who tested positive for the BRCAI mutation reveal confusion and contradictions on the part of her medical practitioners as to which steps she should take following her positive test.

and that "recuperation may be more difficult for smokers." I had the sense the oncologist had downplayed the severity of the procedure.

The problem of risk being understood as personal responsibility is that it makes the onset of disease appear as though a woman did not do enough to prevent breast cancer. This association is problematic considering how little is understood about personal risk factors and breast cancer, which is often obscured through campaign and media rhetoric.[59] One issue is the epidemiological worldview. Much of modern risk factor epidemiology is built upon a model that is insufficient to understand the intricacies of microlevel exposure to risk as well as the far-reaching (and even intergenerational) impact of macrolevel exposures (Krieger 1994; Susser 1998). This narrow focus may be the result of epidemiology's roots in the individualized focus of medicine, which can obscure the social structures implicated in the distribution of disease (Susser 1998). Epidemiology's gold standard of observing a single level of analysis and measuring the association of one particular cause to the development of disease crumbles in the etiologic complexity of cancer. The real danger arises when this overly reductionist conceptual framework is disseminated to the public, which is a key problem occurring in Austria.

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[59] For instance, a woman may hear on the news that women who drink alcohol have 1.5 times the risk of developing breast cancer. In fact multiple studies demonstrate the statistically significant association of a dose-response relationship between alcohol consumption and risk for developing breast cancer (Singletary & Gapstur 2001). While results for the actual point estimate of risk vary, all are modest increases in risk. This may however be unclear to an average woman unfamiliar with epidemiological notions of risk. It is also likely unclear that the exposure variable in these studies having three or more drinks *per day*, which may be far more than a woman would ever drink. If someday diagnosed with breast cancer, a woman may recall hearing about drinking and breast cancer and blame herself for having the occasional glass of wine she enjoyed. While excessive and binge drinking should be avoided for one's overall health, this is an example of the unnecessary blame and guilt in in fact what some women reported in interviews when asked about what they believed caused their cancer.

Another issue lies in the public's misinterpretation of epidemiological risk for personal risk. Epidemiological risk is a relative concept that is not predicated upon an assumption of cause and effect. Cognitive psychologist Gerd Gigenrenzer (2002) describes how people are inept at estimating personal risk. He suggests that people tend to reify relative notions of risk from aggregated population-level data into individual risk. Additionally, evolutionary biologist Stephen Jay Gould (1985) used his own experience with a rare form of cancer to show that medians and means fail to reflect the wide variation behind statistical data. On the other hand, epidemiologists are rather unskillful in reporting their findings in ways that are intelligible to the public. What is often omitted, however, is that this is before the age of 85, and that until women reach that age, many more will be diagnosed with heart disease and other health conditions. The combination of the human tendency to concretize the 'gray areas' of risk and the lack of intelligibility of epidemiological studies contribute to the misinterpretation and sensationalism of risk and risk prevention. For example, hearing the statistic that 1 in 8 women will develop breast cancer within her lifetime often makes women nervously look around to count how many of them will be affected by breast cancer. Anna (54) recalled looking around at the sixteen women in her office and wondering which two would be diagnosed with cancer. This interpretation is false. The oft-repeated statistic of lifetime risk actually means that given the current breast cancer incidence rates, one out of eight women in Austria will be diagnosed with breast cancer *before the age of 85* (i.e. before the end of her life). To compare 1 in 37 women before the age of 85 will die of breast cancer (Howlader et al. 2014). In other words, the "1 in 8" statistic does not apply to women before the age of 85. Risk also gets lost in translation by clinicians, who often inform women about breast cancer. The performativity and rhetoric on the part of clinicians at informational sessions for breast cancer impacts the ways in which women understand their role in the development of their breast cancer.

Women at the Forefront: Informational Sessions for Breast Cancer

As described in chapter three, many breast cancer awareness campaign events have a festive, chic, and party-like atmosphere. The events are mostly sponsored by Pink Ribbon Austria and its affiliates. One aim of these events is to market breast cancer prevention and screening as something cheerful, sexy, and beautiful. In terms of cancer and control, the campaign reduces the overall fear and angst surrounding breast cancer. The paradox, however, is that despite breaking the silence of breast cancer, the campaign simultaneously masks key aspects of the breast cancer illness experience in Austria. In addition, the exclusivity of the events inhibits effective participation on the part of average Austrian women, particularly those living in rural areas.

The second type of event under the umbrella of the breast cancer awareness campaign takes the form of informational sessions, lectures, and question-and-answer forums designed for the lay community. Not all events are associated with the pink ribbon, although many have adopted it outside of Pink Ribbon Austria as a universal symbol of spreading awareness for breast cancer. The data presented here are based on participant observation at fifteen informational events, twelve of which took place in Austria (table 4.1), while the other three took place at European-level advocacy events with Austrian women present. Austria lacks a single formal government public health institution, which explains its absence on the list of organizers. This leaves medical practitioners to explain public health risk, which allows for the opportunity to promote private interests. Another issue is the partnership with the pharmaceutical industry, which was explained by one prominent oncologist as a necessary evil to perform *any* cancer research in Austria, since government funding for cancer research in Austria is dismally low.[60]

Whether explicitly or implicitly stated, the overarching emphasis of these events is to put "women at the forefront." Placing women at the forefront is a phrase often used in conjunction with informational sessions, and it is intended to give the impression that these sessions are concerned with patient experiences and their needs and lingering questions. However, like the other Pink Ribbon events, the fact that the events take place in urban locations prevents rural women who have reduced mobility from attending. Furthermore, the events are advertised and conducted exclusively in German, which also excludes some immigrants, many of whom already have limited access to medical information in their native language. European-level advocacy events are conducted exclusively in English, meaning that Austrian delegates are cosmopolitan and highly educated. Thus, the idea of putting the "woman" front and center is not an all-inclusive one. Also, fulfilling the rhetoric of putting the woman at the forefront, hence giving individualized attention, is unfeasible in a city where approximately 950 socioculturally diverse women are diagnosed with breast cancer annually (Zielonke et al. 2014). Instead,

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[60] In a 2005 European Union-conducted study, Austria ranked below Greece among countries spending the lowest amount on cancer research (Eckhouse et al. 2007). The prominent oncologist made a plea to politicians to increase support for basic research at the medical universities, proclaiming, "The universities are starving." The oncologist made this plea at an exclusive 2012 pink ribbon gala in the Austrian Parliament shortly before a film about Estee Lauder's successful use of the pink ribbon and a choir singing a song entitled, "Don't close your eyes." While the oncologist's message is very important, it was overshadowed by the festivity of the evening and never mentioned again. While there is recognition for some of the key reconcilable issues in regard to cancer care in Austria, these issues rarely, if ever, are adequately addressed within the breast cancer awareness campaign.

the events are divided into various broad themes including mammography, breast cancer prevention, genetic mutations (BRCA I and BRCA II), compliance/adherence, the function of chemotherapy and radiation, pathology, complementary medicine, surgical options, multidisciplinary tumor boards, and occasionally a question-and-answer session between medical experts and one woman with breast cancer. There is a striking and disturbing lack of discussion on metastatic breast cancer, for which there is no cure, breast cancer mortality, and end-of-life issues. This outright denial of help for those most in need is a very troubling aspect of the campaign.

The expectation is that these themes covered address the bulk of women's questions and will be interesting to those with and without breast cancer. However, advertising for such events occurs mostly within medical settings, meaning that many of those who learn of the event have already been diagnosed and may not find information on prevention as useful. Additionally, many attendees are seniors, the age group most affected by cancer, and also the group that has more available free time to attend such events. Preventing cancer through personal behaviors later in life may however carry less of an impact than earlier in life. Thus, the emphasis on prevention and screening is less appropriate for the audience of the events.

Organizer	Location	Attendees	Themes discussed	Pharmaceutical Industry Involvement
Certified breast health clinic	Former Palace in Vienna	300 people, majority women over 60	Prevention, Early Detection, Treatment, Rehabilitation, Complementary medicine	Indirect
Certified breast health clinics in Vienna, Vienna Hospital Organization	Conference room in a Viennese skyscraper	70 people, mixed ages, men and women present, by RSVP only (for medical practitioners but open to the public)	Pre-invasive vs. invasive breast cancers, Targeted therapy, Endocrine therapy as prevention	Direct sponsorship
Austria-wide medical education group for the community	Ballroom of an event center in Vienna	100 people, majority women over 60	Breast cancer and lifestyle, Breast health centers, Side effects of chemotherapy, Screening, Pathology	Indirectly (direct mention of brand-name chemotherapy drugs)
Breast cancer self-help group	Public school classroom in Vienna	12 women, all over 50	Yoga as complementary medicine	None
An initiative of the Austrian Cancer Society and Cancer Center	Famous theater in Vienna	300+ people, equally split between men and women, majority over 60	Breast cancer screening, prevention and therapy, Colon cancer, Leukemia and lymphoma	Direct sponsorship
Breast cancer self-help group	Small office space in Viennese suburb	10 women, all over 50	Alternative medicine	None
Private patient consulting group	Hotel in a resort town near Vienna	5 women over 50 (room was set up for 50 attendees)	Breast cancer prevention and its limitations, screening and its downsides, treatment, Side effects	Indirect
City of Vienna, Early Detection Screening Program	Conference room of a theater building in Vienna	20 women, ages ranging from 25-65	Breast cancer screening	None (no mention of brand names)
National newspaper and pharmaceutical company	Event hall in Vienna	75 women, ages ranging from 35-65	Patient experience, Genetic testing, Treatment	Direct
Umbrella Association for Oncological Societies in Austria	Conference center in Vienna	25 women and men, all over 40, by invitation only	Quality of life, Patient rights, Social issues and access to care	None, excluded from event
Certified breast health clinic	Former Palace in Vienna	350 people, majority women, age range from 30-70	Prevention through weight loss, Screening, Pathology, Genetic screening, Therapy, Rehabilitation	Indirect
Pharmaceutical company	Hotel and conference center in Salzburg	50 women, all part of breast cancer support groups and one advocacy group	Pathology, Psycho-oncology, Genetic testing, Adherence, Living with metastatic breast cancer	Direct

Table 4.1. Breast Cancer Informational Sessions in Austria

Informational sessions take place in some of Vienna's finest locations, including the famous City Hall, historical university lecture halls, former palaces, and elegant hotels. One annual event takes place in one of the finest former palaces in Vienna in the posh city center. There is an air of grandeur upon entering the palace. Attendees walk up a wide, red-carpeted staircase with shallow steps once intended to accommodate ball gowns. They then enter a corridor where catering is arranged before passing through a massive wooden door with intricate molding and gold handles into the imperial-style ballroom. The grand hall is a spacious 450-square meters (4,844 square feet) and two-stories high. Palatial chandeliers and wall sconces on the marbled walls emit a soft, stately light, warmed by the herringbone hardwood flooring and red chairs filling the room for guests. Being privy to such locations is no everyday event for many women. Informational sessions are also advertised as being entertaining events that women can attend with their friends, daughters, and mothers. Three events even featured raffles with wellness-related prizes for women who stay until the end.

Prizes and beautiful venues aside, treatment for breast cancer is incredibly time consuming, which begs the question as to why women are willing to take even more time to attend the informational events. Women often reported feeling relatively uninformed and lost following a diagnosis. For those without private insurance, receiving a diagnosis can be rushed and curt. In addition, women are often shocked and unable to formulate necessary questions after hearing the diagnosis. One doctor lamented the short amount of time he has for patients and explained to me, "I tell them they should just pay the €100 and come to my private practice so that I can take my time to explain everything and answer their questions." It needs little explanation that footing the bill for private consultation is not possible for every woman, particularly for self-employed women who earn little money during their treatment.

These sessions offer an opportunity for women to feel reassured following a diagnosis. Women also reported wanting to attend in order to try and understand why they were diagnosed, why particular treatment regimens failed, and how they can restructure their lives to prevent breast cancer recurrence. Some come with the expectation that they may be able to ask questions pertaining to their actual diagnosis, but these questions are brushed off swiftly by event hosts with the request that women ask only more general questions. General answers are of course little help to those women experiencing real concerns and worries during the time of uncertainty.

At the same time, presenters and organizers reported the need to empower women and give them the sense that their health is “in their own hands.” For instance, one top-ranking, demure, and kind pathologist who appears often at informational events said quietly to me after a lecture, her long gray hair hanging over her face, “Not being a clinician, I never get to connect with the patients. I want to know them.” Her patient and well-planned lectures are one means of keeping the human aspect of her work present. Additional presenters include gynecological oncologists, surgical oncologists, clinical study nurses, medical doctors with training in complementary medicine, psycho-oncologists, staff members of the Austrian Cancer Society, local fitness personalities, and representatives from oncology rehabilitation centers.

Many of the speakers were middle-aged male doctors in expensive suits and ties who appeared for their given time slot and left shortly thereafter. The doctors are often prominent local personalities, and I often found myself surprised at the women who would lean over to say, “That’s the head of the clinic. He’s big in the United States too, you know.”[61] And the doctors are not shy about it. “Our breast health centers are state of the art because we go to the U.S. a few times of year and bring back the best practices.” Top oncologists are seen in the Austrian media rubbing elbows with Viennese *Promis* (VIPs) at chic galas. This reputation feeds into an image of the doctors as being larger-than-life, or “demigods in white.”

Although the doctors are practiced at delivering lectures, they do not always tailor the presentations to the lay audience. After a long day of work in the hospital clinic and in private practice, doctors appear exhausted. Some presentation slides are left in English and require a hefty amount of hand-waving explanations for their statistical jargon. These aspects of the presentations left women in the audience to drop their pens and ask their neighbor if she had understood. “I didn’t get it,” one woman whispered disappointedly to me, as if to say she regretted her own limited knowledge in understanding what I first learned during my second semester of study in an Epidemiology program.

It is no secret that speakers sometimes receive substantial payments for their talks at certain events sponsored directly or indirectly by pharmaceutical companies. Aside from financial benefits, emphasizing the benefits of adherence to chemotherapy and radiation and the latest methods in breast reconstruction is one means of increasing patient compliance, which is spun as the patient’s responsibility[62] and ensures full participation in clinical trials. Some doctors even have the audacity of advertising brand names of pharmaceutical drugs, despite some event organizer’s request not to do so, not

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[61] I cannot confirm that these doctors are well known in the United States

[62] One Viennese psycho-oncologist reported full patient compliance, which often includes at least five years of adjuvant therapy, of 50%.

to mention the legal implications of advertising pharmaceutical drugs. Informing women in this sense appears to be little more than creating obedient, trustful patients who are open and willing to being compliant in treatment regimens and in pharmaceutical trials.

Some events are more connected with patient needs, concerns, and the actual statistics of cancer prevention and screening than others.[63] One such event organizer described feeling "disillusioned" by her career in pharmaceuticals and the pharmaceutical industry's emphasis on profits at the expense of understanding the patient experience. After leaving her job, she founded her own not-for-profit organization to provide as much value-free information about a host of health conditions as possible. I attended one event of her organization, which featured a lesser-known, iconoclastic medical practitioner who at the risk of coming across as pessimistic explained that the benefits of mammography and the role of personal behaviors in the onset of breast cancer are grossly overestimated. At a different event, I heard a clinical study nurse, who is constructively critical of her own discipline, who went to great lengths to situate patient compliance within a host of structural and social factors, thereby removing the blame from individual patients. The same nurse has also been a pioneer in providing information about a diagnosis and treatment in five different languages, helpful tips for physical and mental rehabilitation, and a follow-up care plan for women in Austria diagnosed with breast cancer. She continually gathers questions and concerns from her patients and assembles the questions and answers into short, accessible books. These advocates are however up against the

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[63] One particular course called the "Cancer School" (the English name is used) hosted by the cancer center and teaching hospital was not included in this ethnography. The Cancer School is geared for those diagnosed with a variety of forms of cancer and their family and friends. It allows interested parties access to hands-on learning in the field of oncology, including visits to the library, pathology laboratory, accessible lectures on cancer biology and treatment, and workshops on doctor-patient communication. The Cancer School is well attended and receives relatively high ratings from its attendees. This demonstrates the desire and need from those with cancer to be able to access information about their disease.

goliaths of Austrian medicine. Both camps claim to pursue medical progress, one through exercising power and the other through empowerment. Unfortunately, the events with the most widespread presence, funding, and advertising remain the former.

The following section draws upon the rhetoric of mainstream informational sessions, printed informational materials, and media reports featuring prominent oncologists to contextualize Austrian women's (mis)understandings in regard to breast cancer risk and screening. It is important to keep in mind that these findings are from the time when advertisements and awareness for the universal mammographic screening program were at their highest (2012-2014) and women would theoretically be exposed to information, even if only passively.

The Illusion of Control and the Reality of Guilt

As a medical anthropologist with dual training in public health, it felt important to ask if the increased awareness of breast cancer had actually made women better informed. To explore this, I distributed 137 questionnaires across Austria, often asking friends and contacts to pass them out to their family members, neighbors, and colleagues. The questionnaire included basic demographic data (table 4.2),[64] true/false, fill-in-the-blank, free-list and multiple choice format questions. Some questions test knowledge of breast cancer risk and screening, while others pertain to a woman's personal opinion and screening behaviors. None of the women surveyed had breast cancer. When possible, I engaged women in a short interview to elicit further opinions and perceptions of breast

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[64] The glaring bias in this sample is that 40% of the sample has a university degree. The latest estimates from 2011 state that only 11.6% of women over 20 years of age has a university degree. Interestingly, one might expect that highly educated women would be more aware of breast cancer risks, but this does not appear to be the case. The age range is also admittedly skewed, which is due to a sampling bias.

cancer in Austria, and also explained the answers to the questions pertaining to epidemiological data on breast cancer.

This section is organized by respondents' answers to select questions, which serve as the headings. The heading is supported by data gathered from participant observation, content analysis of printed materials, and interviews with respondents. As this section demonstrates, campaign material and discourse at informational events is often contradictory and incomplete, leaving women to formulate their own notions of risk.

Age:	**Education Level:**	**Region:**	**Breast cancer among family or close friend**
18-29: 22% (n=30)	No secondary education: 7% (n=10)	Urban: 49% (n=67)	Yes: 47% (n=65)
30-39: 28% (n=38)	High school diploma: 18% (n=24)	Suburban: 15% (n=20)	No: 52% (n=71)
40-49: 29% (n=40)	Secondary school: 7% (n=10)	Rural: 36% (n=50)	
50-59: 18% (n=24)	Vocational School: 27% (n=37)		
60-69: 3% (n=5)	University degree: 40% (n=55)		

Table 4.2. Basic demographics of Questionnaire Respondents

Misunderstanding #1: 61% (n=84) of surveyed women think that mammograms prevent breast cancer.

Mammographic screening presents a problematic issue in regard to conceptualizations of risk. In Austria, the U.S., and other wealthy nations where screening is available, the main message is that "mammograms save lives." While the benefits of screening are heralded, recent robust epidemiological studies reveal ambiguity or overestimation in the actual reduction of breast cancer-related mortality rates from the universal screening of asymptomatic women (Autier et al. 2012; Bleyer & Welch 2012; Jin 2014; Kalager et al. 2012, Miller et al. 2014). Thus, contrary to popular belief, mammography is an imperfect and debatable method of screening.[65] It is important to

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[65] What is most debatable is the age at which a woman should start attending mammograms as well as the intervals (one year or two years) with which she should attend. Canadian researchers for instance found no benefit of regular screening of women 40-59 aside from physical examination (Miller et al. 2014). Most current biomedical practice recommends screening after 40 or 45.

note that breast cancer metastasis is not always the result of breast cancer being found too late.[66] Screening has had a clear impact on the average size of breast tumors at the point of detection, but cannot differentiate a 'small but latent' tumor from a 'small but aggressive' tumor. Despite the overall impression that screening is saving lives, these improvements are largely due to therapeutic improvements (Autier et al. 2014; Munzone 2014). As Kaufert succinctly notes, "To pretend that screening is not influenced by corporate and commercial interests, the drive for profit rather than health, would be naïve" (2000: 178).

In some cases, the timing of the mammogram has no effect on the prognosis of the tumor. In fact, mammograms can also introduce a form of bias called *lead-time bias*. Lead-time bias makes it appear as though a woman received a routine (i.e. asymptomatic) mammogram has survived her cancer longer, even though the outcomes of her cancer (e.g. death) would have occurred at the same time point, had she waited until she was symptomatic. *Length-time bias* is also introduced because slow-growing tumors are both more likely to be detected by mammograms and have better prognoses (irrespective of the screening test) than fast-growing tumors, which are likely to become symptomatic more quickly. Mammograms can also lead to false negatives (not finding a tumor when a tumor is actually present) and many more false positives (detecting a tumor that does not actually exist). False positives generally mean unnecessary anxiety and treatment, which is costly both to women and to the healthcare system. At any rate, it is unclear if

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[66] During my fellowship at the U.S. National Cancer Institute, Dr. Barry Kramer, director of the Division of Cancer Prevention, shared a wonderful analogy for understanding the three basic patterns of cancer detected in screening. He stated that cancer can present as "turtles, bears, and birds." The idea is that turtles are the tumors that grow so slowly that they likely will not become dangerous (but are often treated anyway). "Bear" tumors *can* escape, but can be caught and treated. "Bird" tumors are gone too quickly before one has a chance to treat. The effectiveness for breast cancer screening only comes for "bear" tumors. Detecting "turtle" tumors for screening does not save lives. Dr. Kramer has since shared this in multiple media formats, including the New York Times and National Cancer Institute informational videos.

mammographic screening causes more harm than good, and if universal screening is still a reasonable undertaking (Gøtzsche & Jørgensen 2013). Mammographic screening is one such area where blind faith in medical technology and the desire to control cancer leads women to underestimate the hazards and overestimate the benefits of this form of secondary prevention.[67]

There is one indisputable fact about mammograms: They do not prevent breast cancer; rather, they can detect breast cancer before it becomes symptomatic. Shortly after arriving in Vienna, I spoke with a middle-aged woman at a café about breast cancer. "Frau Bouskill, I just don't get it," she said confused. "I know women who went to get mammograms and *still* got breast cancer!" I was as befuddled as she, but upon sharpening my German skills, it became clear that much of the confusion stems over the use of the term *Vorsorge*, meaning prevention or precaution, instead of *Früherkennung*, which literally means early detection, in conjunction with mammograms (see Jäger 2011). It was October and breast cancer *Vorsorge*, meaning mammograms, was everywhere in the media. Informational websites including the Austrian Cancer Society and province-controlled regional medical insurance groups listed *Früherkennung* under the heading *Vorsorge*, or at best grouped the two terms together on their websites and printed materials. Even the Vice President of the Austrian Cancer Society claimed in a presentation at the Umbrella Association for Oncological Societies in Austria (German: *Dachverband onkologisch tätiger Fachgesellschaften Österreichs*) stated "1/3 of all

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[67] Despite these flaws, the current gold standard in the European Union calls for universal screening programs in each member state. After much deliberation between radiologists and the Austrian Ministry of Health over cost coverage, the program went live in Austria in January 2014 for women 45 to 69. It allowed women to attend screening only with a written invitation every two years. As described throughout this dissertation, the program failed only a few months after being enacted. But Austrian women face an even more basic misunderstanding in regard to breast cancer screening, namely, the belief that screening for breast cancer can actually prevent breast cancer.

cancer cases could be prevented (German: *vermieden werden*) through: 1.) A healthy lifestyle; 2.) Warding off infection and viruses; and 3.) The early detection of cancer. While some cancer screening tests such as the colonoscopy can detect precancerous lesions, thereby preventing colon cancer, mammograms do not prevent the development of a breast tumor.

In public health terms, primary prevention is avoiding the onset of a disease. Secondary prevention indicates efforts to detect a certain disease while it is still asymptomatic to prevent disease-related complications. Without knowing what combinations of factors cause breast cancer, primary prevention for breast cancer is speculative at best. Mammograms belong under secondary prevention. Adding to the confusion are frequent news reports from the Austrian Broadcasting Corporation (like that on May 7, 2014) stating, "Women should attend mammographic screening every two years in order to reduce the incidence rates for breast cancer." As counterintuitive as it is that finding cancer could reduce incidence rates, such reports contribute to the 61% of surveyed women who believe that mammograms can do just that. Furthermore, women like Margret (57), who was diagnosed with breast cancer following a mammogram, expressed their shock in saying, "I went to get a mammogram every year. I always took care of myself. I'm just not sure how this happened." The intermingling of media and campaign rhetoric casts women into even more confusion following a diagnosis. When the dominant discourse promotes mammograms as preventive, it is understandable that women would not call such misleading claims into question.

This confusion is neither unique to Austria nor to breast cancer. Medical anthropologist and physician Jessica Gregg's work in a Brazilian *favela* demonstrated how information from cervical cancer awareness campaign led women to believe that a pap smear is curative and intended only for sexually-active woman (Gregg 2003). As screening for cancer continues to take hold in global contexts, there is a heightened need to improve communication and transparency in regard to the benefits and purposes of performing early detection. In Gregg's work, however, the result was a false sense of security, whereas among Austrian women it meant not only a false sense of security for those without breast cancer, but also confusion and guilt for those living with it.

I do not claim that radiologists and medical practitioners want women to believe that mammograms will prevent breast cancer, but I do believe that this belief certainly played into some women's decision to attend screening, which is an overall gain for radiologists and manufacturers of screening technology. In an interview, a representative of the Austrian Cancer Society admitted the problem of *Vorsorge* versus *Früherkennung* and described how the organization has been actively striving to exclusively use the term early detection in association with screening. In fact, all printed materials of the newly-enacted universal mammographic screening program not only avoid using the word prevention but also describe the potential issues of false positive and false negative findings, provide an explanation that tumors can grow aggressively between screening intervals, and states directly "Early detection cannot prevent the development of breast cancer." However, women invited to take part in the program had been told for the majority of their adult lives that they should "go to prevention (German: *Vorsorge*)." Women's reluctance to attend screening is understandable, particularly if they had a different expectation for the procedure all along, or if they were told they should go annually to get screened and were now being told they could only have the procedure done every two years.

I can only speculate as to why women did not readily participate in the universal screening program, and why universal mammographic screening program became defunct as of July 2014. However, it could be that finally using accurate, evidence-based public health approaches may have backfired and been the Achilles heel of the program. I recall traveling to a rural Alpine village shortly after the rollout of the program where I was inundated with questions about this “other test for breast cancer.” The program began by inviting women in the oldest age group (late 60s) to attend screening, and these women in the village turned to me to help with their confusion over the terms used for mammography. Instead of clearing up some of these critical misunderstandings, the president of the Austrian Cancer Society shook his fist and told an audience at Cancer Day in Vienna’s City Hall in April 2014 that “it is absolutely undeniable that screening saves lives!” and that “women will be *drafted* (German: *einberufen*) into attending mammographic screening!”

The claim that women must be drafted into screening the same way young men are drafted into the Austrian military came across like the desperate swan song of a dying program. In any event, major amendments to the program took place. However the authorities choose to proceed, they will have to somehow undo the misleading rhetoric in relation to women’s personal behavior (e.g. diet and exercise) and the overestimated benefits of mammographic screening propagated throughout the breast cancer awareness campaign. In any event, it is clear that the estimated €20 million program was largely ineffective. Moreover, such fundamental misunderstandings reveal that women are in fact highly misinformed as to the purpose of mammograms, leading to confusion from women with and without breast cancer.

Misunderstanding #2: 55% (n=75) Breast cancer affects more 40-year old women than 65-year old women.

Misunderstanding #3: 96% (n=126) believe that regular mammograms for women 40-45 reduce mortality rates.

These two misunderstandings are part of a broader misconception that breast cancer is a problem among younger women, which creates unnecessary worry for younger women and a false sense of security for older women. The issue is also not unique to Austria; for instance, a study conducted twenty years ago in the United States demonstrated how younger women overestimated their risk of dying from breast cancer within ten years by more than twenty-fold and overestimated the benefits of screening by six-fold (Black et al. 1995). On average, only 1.45% of 40-year old women will be diagnosed with breast cancer in the next ten years, as opposed to 3.49% of 60-year old women (Howlader et al. 2012). While breast cancer affects women at all ages, risk increases as women age until around 70 (*ibid.*).

While it may seem surprising that almost the entire sample of surveyed women believe that regular mammograms reduce mortality rates for younger women and over half believe that there are more 40-year old women with breast cancer than 65-year old women, these false impressions make sense in the context of the images and key actors featured in the awareness campaign. For instance, Marlene, an outspoken advocate diagnosed with in situ (stage 0) carcinoma, proclaims often at campaign events “A mammogram saved my life!" Printed campaign materials prior to the January 2014 start of the Early Detection Screening Program are highly inconsistent in regard to when women should start attending regular mammograms. A brochure from a well-known radiology center is dotted with pink ribbons and states, "women should attend screening by the age of 40 at the latest." Campaign materials sponsored by the Austrian Cancer Society suggest that women attend screening at the age of 40, while others including the Austrian Society for Gynecology and Obstetrics neglect to state a recommended age. Mini-interviews with women following a survey revealed that many women under 50 who believe that screening should start earlier draw from examples of younger women with breast in their social network. Not surprisingly, younger women with whom I spoke opportunistically were outraged that they could not take part in the universal mammographic screening program. With the implementation of the program, the Austrian Ministry of Health had taken away the sense of security and morality women had attached to mammograms, even though they were moving closer to following public health guidelines.

Mammograms for average women under 50 (i.e. those who do not have a high risk for breast cancer) do not convey an overall public health benefit. On a population level, screening for women under 50 does not reduce mortality (Gøtzsche & Jørgensen 2013). Mammograms become relevant in terms of the reduction of mortality for women between the ages of 50 and 69 (*ibid*.). Cost is another important factor in considering the benefits of mammograms for women under 50. Estimates prior to the implementation of the universal mammographic screening program state that Austrian health insurances pay over €57 million for mammograms and breast ultrasounds. The link between exposure to ionizing radiation and breast cancer risk among younger women has been well established, which suggests that women who regularly attend mammograms from a younger age may face a greater burden of breast cancer (Berrington de González & Reeves 2005; Preston et al. 2002).

I do not mean to suggest that younger women are not affected by breast cancer or that younger women should not begin to think about their breast health. The youngest woman to take part in this study was 27 and there is currently an 18-year old patient being treated at Vienna's General Hospital. [68] The problem arises when mainstream campaign images almost exclusively feature younger women. Beyond the clear issues of unnecessary anxiety, starting routine mammograms is expensive for the system and costly in terms of false positives, unnecessary biopsies and treatment, and increased exposure to radiation.

Tasten Sie die gesamte Brust mit allen Fingern der flachaufliegenden Hand ab. Üben Sie in kreisenden Bewegungen Druck auf die Brust aus, um Veränderungen unter der Haut zu spüren. Für tiefere Gewebebezirke brauchen Sie etwas mehr Druck. Tasten Sie jedes Viertel sorgfältig ab und achten Sie besonders darauf, ob sich Gewebe unter der Haut nur schwer verschieben lässt.

Heben Sie einen Arm und untersuchen Sie mit der gegenseitigen Hand die in den Achselhöhlen gelegenen Lymphknoten mit leichtem Druck. Gewöhnlich sind Lymphknoten nicht tastbar, achten Sie daher besonders auf ein Neuauftreten von Verhärtungen oder Knoten. Wiederholen Sie die Untersuchung auf der anderen Seite.

Teilen Sie Veränderungen **sofort** Ihrer Frauenärztin/Ihrem Frauenarzt mit!

Figures 4.1-4.3: The first two images are brochures from the Pink Ribbon Austria/Austrian Cancer Society about breast cancer and cancer prevention and screening. The last is a brochure on self-breast exams from the

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[68] The Austrian healthcare system provides screening as a diagnostic test for women of any age who present with a symptom(s) of breast cancer, including but not limited to a lump, swollen lymph nodes, or a change in size, color, or texture of the breast

Private Foundation for Breast Health, which is in part sponsored by an oncologist at a major breast health clinic in Vienna.

The three images featured here exemplify the use of young women in the awareness campaign and may explain in part why people often see breast cancer as an issue among younger women. These brochures featuring nude models are eye-catching, but it is doubtful that they are attracting the age group of women most at risk for developing breast cancer. The first brochure, which is specifically about dealing with the diagnosis, treatment, reconstruction, and follow-up, shows a young woman looking serious, as if she had been diagnosed. In the second image, we see a mother and her young adult daughter. The daughter is seated in the foreground as her mother embraces her, as if to seem that the mother is supporting the daughter. One interpretation is that the mother is encouraging the daughter to love and take care of herself, which is of course a warm message. But considering the brochure is for cancer prevention and early detection, it seems as though the mother is encouraging her young daughter to attend screening, not vice versa. The last image is from a brochure about self-breast exams. Aside from featuring a model who almost certainly has fake breasts, she is again quite young. The previous chapter revealed the issue of showing young, sexualized women as a means of objectifying women rather than supporting them and connecting with Austrian women affected by the disease. The case can and should be made for encouraging women to be aware of changes in their breasts throughout adulthood; however, the issue here is a public health one, whereby screening is over-utilized by the wrong age group and under-utilized by the appropriate age group.

When organizations involved in the breast cancer awareness campaign appeal to younger women, it may have the positive impact of having women consider their overall health. However, in this case, it led to unnecessary anxiety and misinformation regarding breast cancer risk. On another level, it vastly increases the medicalization of the female body and solidifies the formation of the "risky subject" in the regime of biomedicine (Klawiter 2008).

Misunderstanding #4: 62% (n=85) think that more women die of breast cancer than heart disease.

Estimates from 2009 state that cardiovascular disease accounted for 45% of deaths among women in the European Union and 43% of deaths in Austria (Thümmler, Britton & Kirch 2009; Statistik Austria 2014). Breast cancer, while also a major public health problem, accounted for 17.4% of deaths (*ibid.*). In terms of actual burden of disease, cardiovascular disease is far more of a threat than breast cancer. Furthermore, smoking prevalence rates among women in Austria are some of the highest in the European Union (WHO 2010). The link between smoking and cardiovascular disease is clear, while there is no such evidence to suggest a link between smoking and breast cancer. And yet in comparison to breast cancer, there is hardly any media attention to heart disease. Virtually no headlines read, "Celebrity dies of heart attack!" while Austria's most widely read news magazine, *News*, is full of headlines such as "The Scourge of Cancer!" in next to photographs of celebrities such as Linda McCartney, who died of breast cancer. Heart disease, although it claims many more lives, does not incite the same sense of fear and uncertainty inherent to cancer (Weiss 1997). The lack of ambiguity in treating and preventing cardiovascular disease may be the reason why there is only a minimal heart disease niche within the health-marketing sector.[69] Shedding light on the high percentage of women who grossly underestimate the problem of heart disease (or overestimate the burden of breast cancer) demonstrates how seriously women are misinformed about their most basic health risks. In addition, it points again to the medicalization of the female body, and particularly the female breasts, in which the body becomes a source of pending danger that should be under surveillance and control. This is heightened by the sexualization of the breasts within Pink Ribbon Austria's breast cancer awareness campaign, where the breasts are not only placed under the biomedical gaze, but the patriarchal male gaze.

Partial Misunderstanding #5: 49% (n=67) believe that poor diet and exercise can increase the risk of developing breast cancer.

In the questionnaires, respondents free-listed what they believe to be risk factors for breast cancer. Unhealthy diet, overweight/obesity, and lack of exercise were mentioned in 49% (n=67) of the responses. This may of course be that women simply wrote down the 'usual suspects' of chronic disease— smoking, drinking, and being overweight. It is also likely that the frequency of these responses is the result of widespread campaign messages and media reports that tout the importance of diet and exercise. For instance, one large-scale informational session dedicated an entire lecture from a Viennese exercise guru on how to reduce breast cancer through weight loss.

Eating a healthy diet and exercising are vital to one's overall health. Furthermore, there is some evidence to suggest a link between breast cancer and a poor diet/lack of exercise. Adipose, or fat tissue, is metabolically active and produces excess estrogen in

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[69] See Einstein (2012) for a description of Coca-Cola's campaign for heart disease.

the body (Kershaw & Flier 2004), which may drive certain hormone-receptor positive breast cancers (Kaiser & Bouskill 2013). In addition, a recent meta-analysis of physical activity shows that women who performed an hour of physical activity per day reduced their risk of breast cancer by 12% as compared to the group with the least physical activity (Autier et al. 2014).[70] This effect is canceled out in women who take hormone replacement therapy (*ibid.*). However, diet composition and risk for breast cancer and breast cancer recurrence is controversial and complex (Michels et al. 2007). In addition, studies about weight and body mass index and breast cancer risk vary based on menopausal or pre-menopausal status, and like other risk factors, do not provide incontrovertible evidence (Cleary & Maihle 1997). The medicalization of women's diets and body weights in regard to breast cancer risk is as Gordon describes a "tenacious assumption" of western biomedicine (1988), despite the fact that evidence remains unclear.

I interviewed Gerlinde, a highly educated, vibrant 40-year old who was diagnosed one year prior to our meeting. Over lunch, she leaned in, tilted her head and lowered her voice as if to signal that she wanted to tell me a secret. "I can't stand October, all this breast cancer campaign stuff. It's so unfair. 'Eat right, exercise!' Yeah, great. I've always been fit. I rode my bike along the entire St. James Way[71] a week after my last chemo treatment. What about those of us with breast cancer? How are we supposed to feel when we hear that?" She knew she could not have prevented her cancer with an

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[70] For Austrian women, particularly employed women with families and multiple responsibilities, an hour of physical activity is difficult to factor in to each day. In addition, it is a significant time commitment for what could be considered a modest risk reduction.

[71] The St. James Way or, *El Camino de Santiago*, is a series of pilgrimage routes in Spain that lead to the supposed burial site of the saint for whom it is named. It is a difficult voyage for any athlete, let alone someone who just finished chemotherapy.

even better diet and exercise regime, and yet for one month a year, she is surrounded by the reminder to eat a healthy diet and exercise for her breast health. For example, *Europa Donna*, a European-wide breast cancer advocacy group, uses a campaign that shows a bird's-eye view of two apples with stems to symbolize a pair of breasts above the slogan, "eat right and exercise for her breast health." A healthy diet and regular exercise will improve everyone's overall health, but women should not be led to believe that diet and exercise can have a major impact on whether or not they develop breast cancer.

While Gerlinde felt empowered enough to speak against the aspects of prevention she deemed "unfair," other patients described their guilt for not having been healthy enough. Julia, a 28-year old mother with an aggressive form of breast cancer explained, "My diet was completely wrong. I ate too many snack foods." Fifty-five year-old Hermine speculated that her cancer must have been caused by the piece of chocolate she ate every night, while 63-year old Christine told me, "Well, you know, I'm more of a bacon eater myself. Not every day, but still, that whole yogurt and muesli diet wasn't my thing. I suppose that's the reason why I got breast cancer." It need not be asserted that a small piece of chocolate or the occasional piece of bacon was likely not the tipping point in the onset of cancer, but it certainly caused these women unnecessary grief.

For a public grasping for anything to help them understand why the specter of breast cancer looms large, diet and exercise seem like simple, commonsensical, easy fixes. Medical practitioners in the media and at informational sessions have no qualms about spreading the idea of an "Anti-Cancer Diet," complete with menu plans rich in broccoli, cabbage, and kohlrabi to reduce one's risk of getting breast cancer. Prominent oncologists posed for the magazine next to headlines heralding, "Never get cancer!" and promising that fresh-pressed juices can prevent cancer. These claims could be filed under charlatanism, but the presence of oncologists within the articles raises the authoritative knowledge and legitimacy of such declarations.[72] For the average reader unfamiliar with the debates in diet and exercise, if the "demigod in white" says it, it must be true.

Other women, through their own experience of knowing they ate healthfully and exercised, call such claims into question. Like Gerlinde, they take issue with the nonchalance with which diet and exercise are promoted within the breast cancer awareness campaign. Again, one must question why breast cancer prevention has such a prominent role at breast cancer informational events considering that it is too late for the majority of the audience to prevent the onset of their disease. I met 40-something Agnes at an informational session, which was so well attended that we had to stand in a back corner. She was quite thin, bald from chemotherapy, and clearly exhausted. As the doctor explained that the majority of women are afraid of gaining weight as a side effect of their treatment, she rolled her eyes and blurted out, "Who cares about gaining a little weight? It's about living!" She shook her head and whispered "nonsense" as the young, chic doctor proclaimed that "being overweight and developing breast cancer go hand in hand!" She wished me well and walked out.

Organizers of informational sessions claimed to have the goal of having women take their health into their own hands. However, when claims are made overemphasizing particular aspects of cancer risk, some women are made to feel as though they did not do enough to reduce their own risk. For women who develop breast cancer despite being the poster child of health, the sense of personal control for breast cancer either loses its

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[72] Oncologists are routinely available for interviews and pose for photographs for the magazine *News*. Often the same prominent doctors are cited, which shows that these practitioners likely take less issue with the magazine's sensationalism.

credibility, or they turn to alternative, interpersonal explanations for the onset of their cancer.

Conclusions: Lack of Awareness and Guilt in the Breast Cancer Awareness Campaigns

"You always think, "It's my own fault. I could have done more." " –Helga, 45-years old

In its latest incarnation, biomedicine has to some degree relied on its hegemonic position to relentlessly turn the gaps in its ability to understand, prevent, treat, and cure diseases like cancer into moral imperatives with little scientific backing. The rollout of Austria's breast cancer awareness campaign mirrors the shift in western medicine towards what Klawiter terms "the regime of biomedicalization," in which women are subjected to a permanent "risk role"[73] and the moral duty of engaging in breast cancer prevention and early detection (2008). The example from Austria however demonstrates the central issues and misunderstandings that occur when evidence-based public health is left out of the discursive practices and rhetoric of breast cancer awareness promotion.

With a nod to Foucault, we can understand how "at-risk" women seek out information on breast cancer and interpret their own risk-reducing behavior as self-evident, good moral practice. For some, having the illusion that living a healthy life and

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[73] Klawiter's "risk role" (2008) is a tip of the hat to Talcott Parson's notion of the "sick role," which is discussed in chapter two. Parsons (1951) outlined four major components of the sick role: ill persons are exempted from the performance of social obligations which they are normally expected to fulfill; they are not blamed for their condition, and need not feel guilty when they do not fulfill their normal obligations; however, ill people must want to try and get well- if they do not, they can be accused of malingering; and being sick is defined as being in need of medical help to return to 'normality'- the sick must put themselves into the hands of medical practitioners to help them get well again (adapted from Lupton 2003). The risk role includes all symptomatic and asymptomatic women, and requires women to seek out potential danger through surveillance (screening). In addition, they are expected to take on new forms of breast cancer-related biosociality outside of the medical setting (Klawiter 2008:39, see also Rabinow 1996).

attending regular screening can prevent breast cancer acts as a form of security and confidence in one's body. The problem with creating the permanent risk role is that some of these 'at-risk' women will be faced with breast cancer. Turning for answers as to why it happened to them, some women with breast cancer are unnecessarily and unfortunately buying into the "tenacious assumptions" of risk propagated within the biomedical paradigm (Gordon 1988, see also Chavez 2009). Thus, the biomedical reductionism within breast cancer prevention is negatively impacting the patient illness experience for what is already a stigmatizing disease.

Just as the glamorous VIP galas are failing to establish solidarity with women affected by breast cancer, so too is the campaign failing to create helpful awareness for those seeking to understand the disease. There are multiple reasons for why women are relatively misinformed: First, people in general have a tendency to incorrectly translate a 'fictitious average' of epidemiological risk into individual risk (Gifford 1986, Gigenrenzer 2002), which in this case often led women to overestimate their breast cancer risk and the benefits of screening. Secondly, Austria lacks a centralized public health institution, which hinders evidence-based medicine and leads to mixed messages from various stakeholders in breast cancer screening and treatment (Jäger 2011). This leaves open spaces for the production of *eminence*-based medicine, which is evident in claims made by oncologists in regard to mammographic screening, precisely when such practice is being called into question (Biller-Andorno & Jüni 2014). An additional related issue is the dearth of public funds for cancer research outside of the influence of the pharmaceutical and biotechnology industries. Although the industries are apparently committed to corporate social responsibility, at the end of the day they likely have shareholders in mind, not women like Helga struggling with the role she thinks she played in the onset of her breast cancer. Helga shows that the other side of the coin from the over-promotion of personal control is the unwarranted remorse for not having done enough.

The chapter began by describing the substantial amount of work left to be done to understand why women from widely heterogeneous backgrounds and lifestyles get breast cancer. Biomedicine offers one means of understanding health and disease, and has as of late emphasized personal responsibility as well as adherence to screening and treatment (Klawiter 2008; Peterson & Lupton 1996). In addition to problematizing the illness experience, this prioritization prevents a substantial examination of the role of social determinants and inequality within the development of breast cancer. As Gifford noted in 1986,

> "the uncritical acceptance of an objective, scientific meaning of risk…has resulted in greater control on the part of the medical profession over the diagnosis and treatment of risk in individuals….it has allowed the focus to be directed towards the medicalization of risk within individuals" (239).

It is critical that biomedical practitioners acknowledge the complexity of breast cancer etiology, and all that is yet to be discovered in regard to the onset and development of breast cancer. Furthermore, they ought to be forthright with women regarding the limits of personal behavior and screening on breast cancer risk. One practical way would be to resist appearing in the media next to misleading rhetoric of cancer prevention and breast cancer screening. Another would be to be mindful of the models used in campaign images, especially considering the fact that these models appear on physician-approved informational materials. Younger, attractive models may create more visually appealing brochures, but an average 55-year old woman may give women a more accurate depiction of the group of women most at risk for developing breast cancer. Lastly, there should be more attention placed on the lived experience of risk among women with and without breast cancer.

In the next chapter, I will draw upon in-depth interviews among women with breast cancer to examine how women make sense of breast cancer after biomedicine fails to provide a clear explanation for their illness. Far more often than feeling guilty, women are resisting biomedical knowledge and models of risk by situating breast cancer within the structural, social, and cultural constraints of their lives.

CHAPTER FIVE: "CANCER IS THE BODY CRYING OUT": SITUATING BREAST CANCER WITHIN WOMEN'S LIVES

Introduction

> "In our society, bio-medical science and practice may provide satisfactory explanation and resolution for a wide range of afflictions, often (but not always) seeming to render more thoroughgoing metaphysical speculation redundant. But precisely because of its apparent wide applicability in everyday life, particularly in the wake of the decline of overarching cosmological systems, we are especially bereft when we have to face events for which no rational explanation of remedy is forthcoming. The search for meaning, in short, becomes a conscious problem under such conditions" (Comaroff & Maguire 1981:119).

Although advancements in cancer treatment are limited, they have exceeded gains in understanding the etiology of cancer. In other words, how breast cancer develops in some women and not others is poorly understood (see chapter four). Jean Comaroff and the late psychiatrist Peter Maguire (1981) explained how the more biomedicine is invoked to explain human health, the more frightening and critical are diseases like cancer that persistently evade biomedicine's grasp. Where notions of causality are unclear and the limitations of biomedical knowledge become more glaringly apparent, the human propensity to search for meaning interpersonally and intersubjectively grows.

This chapter looks at how a sample of fifty-four Austrian women with breast cancer (ages 27-84) fill in the gaps of biomedical knowledge of breast cancer etiology by turning to their own lives and interpersonal experiences. In particular, this chapter centers on the belief that breast cancer is caused by emotional distress, which women often cast as the result of tensions between their own desires and needs and the expectations required of them as women. Breast cancer in turn became a metaphor for the unease a woman bears in her life. In fact, 57% (n=31) of the women who participated in lengthy narrative interviews declared that they believed distress (caused for example by marital issues, a death in the family, or work-related burnout) was implicated in the development of their cancer. Similarly, 62% (n=94) of long-term breast cancer survivors also believe that emotional distress or a stressful phase in their lives could have played a role in the onset of their cancer. While not all women share this belief, to many it represents a meaningful aspect of the breast cancer illness experience.

Much of medical anthropological work has centered on understanding the difference between biomedical classifications of disease and the meaning of illness and suffering from the perspective of the afflicted (see Good 1994; Kleinman 1988). Put succinctly, disease is a deviation from a biomedically-defined state of normality, whereas illness reflects the sociocultural and cognitive constructions of mental and bodily distress (Eisenberg 1977; Helman 2014 [1984]; Kleinman 1978; Lock & Gordon 1988; Young 1982).[74] Illness reflects the social and cognitive existence of being sick and the ways in which we make sense of being sick in the larger scheme of our lives (Strathern & Stewart 1999).

Where the two differ is often in theories of causality, as a state of illness often signals spiritual, psychological or social distress, which is not readily recognized or categorized in biomedical terms of disease.[75] For diseases with complex and unclear etiologies like breast cancer, the disease/illness distinction becomes even more blurred. Physician and anthropologist Cecil Helman described how highly charged diseases like

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[74] Medical anthropologists generally subsume both illness and disease under the umbrella term "sickness." *Curing* reflects the process of addressing pathophysiological problems, while *healing* denotes the process of healing body, mind and spirit (Young 1982).

[75] A classic example of the disease/illness distinction is outlined in Anne Fadiman's *The Spirit Catches You and You Fall Down* (1997), which describes the struggles of a young Hmong immigrant in the U.S. who is diagnosed with epilepsy. Her treatment is complicated by the fact that her parents, still immersed in Hmong cultural models, understand her condition to be the result of intense spiritual aptitude.

cancer can be interpreted as “folk illness,” in which they become symbols of the broader anxieties of a society. In turn, these diseases become “metaphors for many of the terrors of daily life” (Helman 2014 [1984]: 99). As a result, the inability to identify the cause of cancer diffuses an underlying anxiety of cancer into society. Whereas heart disease and diabetes can to a large extent be controlled, cancer remains an unpredictable, dreaded threat.

‘Explanatory model’ is the classic term for the construction of beliefs by an individual regarding the etiology, expression of symptoms, physiological mechanisms, prognosis, and treatment of an illness (Kleinman 1988).[76] Although Arthur Kleinman spearheaded this concept of understanding the experiential aspects of illness, it harks back to Clifford Geertz’s interpretivist approach of using cultural symbols as a means of constructing reality (Geertz 1973; see also Young 1982). One benefit of the approach is grasping the semantic networks at hand within the illness experience and the process of meaning making (Good 1977), which is central to understanding cancer illness experiences. However, the idea of selfhood or expressing one’s self cannot always be reduced to a narrative (Zahavi 2007). Likewise, anthropologists resisting the “medicalization of medical anthropology” critique its stripped-down clinical usage that fails to take into account the vicissitudes of the illness experience and the role of structural inequalities in the interpretation of disease and health outcomes (Browner 1999).

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[76] Kleinman’s (1988) explanatory models approach has also been incorporated into clinical settings. With this approach, a clinician establishes a dialogue with a patient in order to understand a patient’s interpretation of their condition. These questions are: 1.) What do you call this problem?; 2.) What do you believe is the cause of this problem?; 3.) What course do you expect it to take? How serious is it?; 4.) What do you think this problem does inside your body?; 5.) How does it affect your body and your mind?; 6.) What do you most fear about this condition?; and 7.) What do you most fear about the treatment?

Michael D. Jackson reminds us that all subjective lived experiences are bound to intangible *virtual* realities of culture, history, and biology (1998: 3). The subjective expression of an illness narrative is itself an artifact, for the self is constantly existentially reciprocated to other *selves* and the "overlapping and contending frames of social reference" in which we are suspended (*ibid*: 10). In addition, the processes of economic globalization and modernization are making and remaking the self within drastic historical and political changes, shifting morals, and new desires (Biehl, Good & Kleinman 2007). Hence, by the time this work is read, the study participants described in this chapter may have already remade their lived experiences of breast cancer.

Despite the limitations of the explanatory models approach, life is rich with attempts to seek explanations for the human experience, from the mundane to the profound. One means of approximating how people make sense of why and how sickness happens is through 'illness narratives,' which seek to contextualize an illness experience into a coherent story (Garro & Mattingly 2000). Kleinman (1988) and Lawrence Kirmayer (2000) have outlined the inherent struggles in expressing the subjective illness experience, particularly when the ill person is seeking out biomedical treatment while ascribing to a non-medical etiology for their condition. In this case, one can be *cured* of disease and return to a physiological state of normality, but to be fully *healed* is to have addressed the underlying illness and thus one's intersubjective emotions and beliefs of what caused the illness. This is often where biomedicine's staunchly Cartesian view of the body and mind fails to resonate with belief systems that collapse the dualism of mind and body (Scheper-Hughes and Lock 1987).

Phenomenological anthropology, drawing from phenomenological philosophers like Maurice Merleau-Ponty and Hermann Schmitz, draws on the distinction in the German language between *Körper*, or the tactile, measurable, aesthetic corpse, and the *Leib*, the flesh, or the point at which intersubjectivity becomes embodied (Csordas 1990; Desjarlais & Throop 2011; Lammer et al. 2007; Ots 1994; Stoller 1997). The *Leib* is the person-self that experiences emotions, afflictions, and sensations, whereas the *Körper* acts as a container for the functional body to be filled with a spirit (Ots 1994).[77] One *has* a *Körper* (German: *Körperhaben*) or a material body, but one *is* a *Leib* (German: *Leibsein*), or 'alive' (Gugutzer 2002). While the two terms are expressed as a duality, they are inextricably linked. The critical phenomenological anthropological approach is useful for understanding breast cancer in terms of the experiential aspects of suffering vis-à-vis gender and structural conditions (see Biehl 2005; Good 1994; Willen 2007). The explanations within this chapter show how women negotiate between the *Körper*, upon which treatment was administered, and the *Leib*, which harnessed the emotional anguish that many women claim caused their cancer. It furthermore demonstrates how closely the two are intertwined in breast cancer (Lammer et al. 2007), and how women draw from both in understand the etiology of breast cancer.

This chapter continues with a description of how the diagnosis of breast cancer represented a point at which women's lives began to take a new course, thereby separating their pre- and post-cancer lives. This is followed by a depiction of how

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[77] To the best of my knowledge, using the term *Leib* to directly speak of one's body carries more religious connotations in Austria and is not readily used in common parlance. However, when I asked people to show me where the *Leib* is located, many pointed to the trunks of their body and particularly the chest, belly, and pelvis. In other words, the *Leib* is the indefinite flesh. Moreover, the term *Leib* is present in various phrases and conjunctions pertaining to bodily experiences. For instance, a *Leibwächter* is a bodyguard and brand name of an herb liqueur.

women seek and form explanations for breast cancer etiology. Particular attention is given to the idea that interpersonal relationships and stressful life events can catalyze the onset of breast cancer. My intention is not to prove the link between emotional distress and the onset of breast cancer as a scientific fact. That is outside of the scope of this study and directs attention away from my main concern, which is to understand how a particular belief can arise within this particular sociocultural setting and what it actually means to women enduring breast cancer. This also raises interesting questions as to what women believe is at stake following a diagnosis, and how women use sociocultural reactions to breast cancer as leverage to instigate new changes in their lives. The fact that women find a renewed sense of purpose, and possibility in their lives despite the social suffering they endure(d) opens up new means of interpreting agency following the uncertainty of cancer (Honkasalo 2008). Furthermore, this analysis shows how medical anthropology can turn to the processes of meaning-making as a way of illuminating agency and resistance to narrow biomedical definitions of cancer, such as those employed by the breast cancer awareness campaign in Austria.

Life, derailed

Breast cancer does not knock before it enters. While it can strike a woman of any reproductive and post-reproductive age, breast cancer on average hits women in their 60s, just as they may have finally retired, achieved financial stability, or can enjoy grandchildren. For many of the fifty-four women[78] who took part in this aspect of the

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[78] Note that these are women who took part in formal interviews and social network descriptions at the Vienna General Hospital. I also interviewed an additional five women with breast cancer, but due to the unstructured nature of the interviews and lack of social support maps, omitted them from this aspect of the analysis.

research, breast cancer was something that "only happened to other women." Whether the presiding oncologist patiently and solemnly delivered the diagnosis or did so hastily and brashly,[79] hearing the words, "you have cancer" marked a diving between their pre- and post-cancer lives.

As described in chapter two, metaphor is a means of comprehending a meaning-laden and enigmatic phenomenon like cancer. It came as no surprise that women recounted the moment of diagnosis in the form of metaphor. For Anita (50), the brief period in between having a routine mammogram and receiving her diagnosis was like being "perched atop a volcano and all of a sudden the supporting branch was gone." Others "just felt emptiness," that "it was the end of the world," like they "fell from the 10th floor of a building," or were on a "horrible trip." One oft-repeated metaphor was that the diagnosis "derailed" women's lives. Like a derailed locomotive, this metaphor demonstrates how so many of life's plans and expectations are abruptly replaced by the insecurity and unpredictability tied to cancer. For some like Anna (55), who recalled looking at a tree from her window in winter and thinking she would never see it blossom again, hearing cancer alone dredged up feelings of finality and resignation.[80]

Shortly after the diagnosis, women were shuffled into a dizzying array of tests, doctor's appointments, surgery, breast prosthesis fittings, weeks of daily radiation treatments, learning the jargon of their tumor biology, applying for a reduction in work,

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[79] Study participants revealed wide variation in the style with which oncologists shared a breast cancer diagnosis. Some women were outraged at the way with which the oncologists (mostly younger) briskly and coldly stated, "You have cancer," vacated the office and left room for the presiding nurse to explain the following steps and procedures. Other (mostly older) oncologists even went so far as to make 'pacts' with their patients, literally stating, "If you give 50% and I give 50%, you will be healthy again."

[80] Certainly some women who received a diagnostic (as opposed to routine) mammogram after feeling a suspicious lump had suspected it could be breast cancer. For some, receiving the diagnosis was less of a shock, while others expressed sentiments such as, "I knew the diagnosis was coming. I mean, I felt the lump. I repressed it. I had other things to worry about, like my daughter's injury from mountain climbing. But let's face it; you just don't want to admit that the diagnosis is real." (Hermine, 60)

cycles of chemotherapy, and then another set of appointments to deal with chemotherapy's often brutal side effects. The idle time spent in waiting rooms or fighting off fatigue at home was when women explained that they felt faced with the questions "Why me? Why now? Why cancer?" most often.

I explored this question while conducting narrative interviews by asking women if they believed something in particular caused their cancer. My hypothesis was that more women would answer this question in the negative, citing either uncontrollable fate or simply no reason at all for their cancer. I based this hypothesis on my casual conversations with women and men with multiple forms of cancer (including brain cancer, leukemia and colon cancer) prior to conducting this research. These respondents were adamant about the fact that their cancer was simply caused by chance. For example, Josef (35) stated "it is a simple statistical reality that thousands of Austrians will be diagnosed with cancer this year. I just happened to be one of them." In addition, the lack of the 'hero-survivor' metaphor suggested that cancer would not be seen as a "challenge from God" or a "journey," as I had often heard from women with breast cancer in the United States. Contrary to my initial hypothesis, 57% (n=31) explained that their breast cancer was at least in part the result of emotional distress, which pointed to the need to understand what was particular about the case of breast cancer in Austria.

Women also cited alternative reasons for their cancer, including the use of hormone replacement therapy, environmental pollution, or genetic mutations. However, women still spoke in relation to the belief that emotional distress can cause cancer either by refuting it or amending it by saying that while it is true, it did not apply in their case.

In short, the emotional distress explanation is a commonly understood facet of Austrian cultural interpretations of breast cancer.

Medical anthropologist Deborah Gordon noted that Italian women also attributed sorrow, worry, and an inability to fulfill socially ascribed roles as a potential source of cancer (Gordon et al. 1991). Akin to the Austrian construction of cancer, women saw their diagnoses as fate and a part of life. While this finding is now decades old, it is interesting to consider the links between the emotional distress explanatory mechanism and women's lives in Catholic, patriarchal societies like Austria and Italy.

I have organized the responses to the question of etiology by age group (table 5.1) and categorized the responses into four main categories: no explanation; biomedical (such as genetic mutations, poor diet, or hormone replace therapy use); environmental pollutants; and emotional distress. I chose to not include environmental pollution as part of the biomedical explanations because it often stands in contrast to the predominant epidemiological paradigm (see Brown et al. 2006). Environmental pollution and degradation are often not readily taken into account and/or are covered up in biomedical accounts of the disease (McCormick 2009; Schrader-Frechette 2007). Epidemiological evidence supporting the link between environmental pollutants and breast cancer is inconsistent and fraught with methodological errors (Brody et al. 2007). Another issue is that these studies (such as Brody et al. 2007), while published in reputable journals, are biased in that they are in part funded by organizations that produce environmental toxins.

I hypothesized that not seeking an explanation is part of the cultural norm of accepting fate and misfortune as a part of life (see chapter two). On average, women over 60 did not mention a reason for their breast cancer in comparison to younger women

(χ^2= 7.00, p=0.0081).[81,82] Older women may represent the traditional cultural norm of accepting cancer as fate, whereas younger women are more apt to seek out a reason for their diagnosis. Hence, this finding may provide evidence for a generational transition in regard to constructions of cancer in Austria.

Biomedical explanations for breast cancer (e.g. diet) were discussed in chapter four, where the overemphasis on personal behaviors in cancer risk is deemed problematic. In addition, the environmental degradation explanation, which I do not describe here, is not unique to Austria (Brown et al. 2006; McCormick et al. 2003), but does fit well to the Austrian propensity to value environmental preservation (Skrentny 1993).[83] The attribution of emotional distress to breast cancer is a compelling means of understanding the tensions inherent to balancing women's many roles in their private lives.

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[81] In the oldest age group, 10 out of 26 women did not mention a potential cause for their breast cancer. For women between 45 and 60 years of age, 3 out of 18 did not cite a potential cause. All younger women believed in a specific cause of their breast cancer.

[82] Prior to data analysis, I specified alpha at 0.10 given the fact that the sample size is relatively small in statistical standards. Therefore, these findings should not be taken as generalizable to the broader population, but as initial findings with which to pursue broader-scale studies on the topic.

[83] Two women under the age of 45 in particular saw the 1986 nuclear power plant disaster in Chernobyl, Ukraine as the particular cause for environmental degradation and their exposure to radioactive carcinogens.

Table 5.1. **Study Age, Explanatory Model for Breast Cancer, and Life Changes Post-Diagnosis**

Study Group by Age (A: ≤45, 45< B ≤ 60, 60 < C)	**Explanatory Model**	**Life Changes Post-Diagnosis**
A1	Bad breakup, BRCAI Mutation (confirmed by genetic testing)	Has become more easy going
A2	Extreme psychological distress over the previous two years	Lives with more awareness for her needs
A3	Bad breakup	Feels more at peace with herself, has a better relationship with her mother, eats healthier and exercises
A4	Birth control pill, cancer in the family	No changes
A5	Environmental pollution following the Chernobyl nuclear meltdown	No changes
A6	Repressed her emotions	No changes
A7	Environmental pollution following the Chernobyl nuclear meltdown, immense pressure at work	Feels stronger, found more loyal friends
A8	Six years of “psychological terror” from a boss, poor diet	Now spends more time at home with her family
A9	Pain from family problems and relationships	Has more harmony with family
A10	Breakup, death of both parents, death of a friend	Changed job and lifestyle
B1	Random chance	Focuses on the positive, not the negative and traveled by herself to exotic countries
B2	Always felt stressed and as if there were “something wrong with [her],” environmental pollutants	No changes
B3	Burnout and depression	Takes more time for herself
B4	Psychological stress and pressure from taking care of aging parents and in-laws in addition to working	Takes more time for herself
B5	Always took care of others and never herself, including her schizophrenic son	Felt motivated to receive psychological therapy, can finally say “no” without having a bad conscience
B6	No way to tell	Thinks more positively

B7	*Prellbock* (English: Bumper stop on a train track) in the family, stress from working and caring for aging parents	Feels able to help herself and others with cancer
B8	Lack of sleep and aggravation in her social life	Rediscovered old hobbies, bought her first new car
B9	Hormone replacement therapy	Takes more time for herself
B10	Always had a hard life, husband was an alcoholic	No changes
B11	Random chance	Lives more aware
B12	Did not pay attention to warning signs in the body caused by daily stress	Takes better care of herself and is more aware of her needs
B13	Possible genetic defect	Stopped smoking and takes better care of herself
B14	Emotional distress from her mother's difficult death	Starting a new business with her husband
B15	Shock from unexpectedly losing her job	Lives more aware
B16	Emotional distress lasting years from her mother's difficult death	Makes fewer compromises in her private and professional life
B17	Burnout, stress, pressure, lack of sleep	Does not always feel like she has to be there for others, exercises
B18	Benign breast cysts throughout her 40s	Stopped smoking
C1	Her son's painful divorce	Lives more consciously and with more appreciation for nature
C2	No explanation	No changes
C3	No explanation	Can put things in perspective better
C4	Death of her son two years prior	Lives more spontaneously
C5	Death of her mother-in-law from whom she never felt accepted	No changes
C6	Death of her mother, difficult relationship with her son	No changes
C7	Marital problems, stress from owning her own shop, potential environmental pollution	Unknown
C8	Strained relationship with her daughter, husband's infidelities, stress of running her own restaurant	Travels, enjoys life, rekindled relationship with ex-husband
C9	Believes firmly that cancer came from the mental, emotional, and psychological drain of her partner's illness	No changes
C10	Unsure	No changes

C11	No reason	Can enjoy being by herself, takes time for herself
C12	Stress from her father's dementia	Able to speak up for herself and define what is important to her, feels stronger
C13	No reason	No changes
C14	No reason, but added that she has a happy marriage	Exercises more and has a healthier lifestyle
C15	Possible genetic defect	No changes
C16	Benign breast cysts	No changes
C17	Unsure, but noted that she had a normal marriage with normal arguments	No changes
C18	Possible genetic defect, poor diet	No changes
C19	Stress from mother-in-law's dementia	Takes more time for herself
C20	Nothing in particular	No changes
C21	Unsure	No changes
C22	Unsure	Is more hopeful
C23	Stress over her entire life course, starting with her father's early death	No changes
C24	Unsure	No changes
C25	Stress at work, felt generally unhappy and believes cancer is an expression of unhappiness, stress following retirement	No changes
C26	Hormone replacement therapy	Exercises

The metaphor of eating everything up inside: Connecting mind and body in breast cancer

Despite variation in the emotional distress explanation, the central point of women's explanations is that they are tied to their roles as mothers, daughters, wives, workingwomen, and at times, all of these roles at once. It relates to tension women feel between seeing their tasks and responsibilities as natural and normal, and yet simultaneously feeling overextended and never being able to put their care first. This process of continually repressing one's feelings and needs, or "bottling everything up inside," which is expressed in German as *alles in sich hinein fressen*, or "eating everything up inside." Like many German equivalents to English phrases, to "eat everything up inside" creates a more visceral reaction and one that more directly summons the *Leib*, or subjective body-self.

Two broad distinctions can be made within this explanatory model. The first links breast cancer to emotional stress related to traditional women's roles of caring for a family, a bad marriage, problems within the family, the death of a parent, sickness of a child, and being the *Prellbock*, a term for the one who is first to take on the worries, problems, and needs of others. The word *Prellbock* literally refers to a buffer stop or bumper on a train track that prevents locomotives from going off the track. Hence, before the family 'runs off the track' or suffers, the mother usually acts as the *Prellbock* and absorbs the shock. An alternative explanation would see the underlying causes of stress to be linked with newer, more modern women's roles, including late work hours for international companies, disconnection from family and friends, lack of free time and instability in partnerships. These two forms of stress-induced breast cancer exist on a continuum, with the former relating more to a traditional, conservative, patriarchal family structure and the latter suggesting a connection to the broader processes of globalization, cultural change and expanding neoliberal practice in the workplace.

In interviews, women mentioned losing their jobs or feeling more pressure in their workplace in the aftermath of 2008 Global Financial Crisis. They expressed their grief over their alcoholic husbands, whose substance abuse was hidden behind the cultural acceptance of binge drinking. In addition, they attributed their cancer to bad breakups and other relationship problems, cheating husbands, irascible bosses, the death of a parent, and a general state of feeling unhappy. The following quotes illustrate how women understand the embodiment of the tensions in their lives:

> "I know exactly what caused my cancer. It was most definitely the death of my stepmother. She never accepted me…I cried so hard and my husband always had to work so much and well, let's just say, I ate everything up inside me…Between her death and the funeral is when I had the breast sonogram. That was it." (Liesl, 64)
>
> "In all of my efforts to help others, I always came up short. I was always the one at work to say, 'Me over here! I can do it!' I always offered my help to others. And on top of it, my adult son has Schizophrenia, and I've been caring for him his entire life." (Maria, 53)
>
> "I really struggled with my mother's death from an incurable disease. You don't wish that kind of death on your worst enemies. So I'm thinking that at least contributed to me getting cancer….but I've never told anyone that." (Irma, 60)
>
> "I worked as a secretary for six years for a choleric, chaotic mega-asshole and I for sure cried every day for two years. Psychological terror. I'm never going back there. That's what caused my cancer. I'm absolutely sure." (Katharina, 28)
>
> "I can't say for sure what caused my cancer. I keep looking for a definitive answer and can't find it. Of course I asked myself, 'why me?' 'how come?' and 'what did I do wrong?' The easiest way to go about it is to think that there isn't an answer, that it's just bad luck. (I asked her: May I asked you why you pose the question, 'what did I do wrong?') Well, maybe I didn't exercise enough or had a bad diet. Maybe I didn't take care of myself like I should have, or didn't take enough vacations away from work. No idea. Then there are people that say that it's fear of separation, so like, my breakup or the pain from all of that. I don't know. Normally I'm too rational or realistic to believe that, but I really don't know. So many relationships end, so I don't really see that as a factor, but of course I think about it as a possibility. No doubt." (Susanne, 27)

With the exception of some mentioning that they "ignored" the warning signs in their body, women did not speak of their distress with a sense of guilt for not being able to change or better cope with circumstances. That is to say, women did not seem to outwardly blame themselves for their illness; rather, they understood their hardships in terms of their compulsory roles as mothers, wives, daughters, and workers. Brigitte (60) shared the narrative of the emotional hardship and depression she endured following her mother's death. I asked Brigitte if breast cancer can be prevented, to which she replied:

> "No I don't believe so. I think that a death in the family can cause breast cancer, because I've heard that before. People asked me if I had breast cancer in the family of if I worked in front of a computer all day and exposed to all that radiation, and then I thought maybe that was the cause of my cancer. But it's not like you can change anything. These things are just a part of life, and if it doesn't cause breast cancer, it causes depression. So you can't prevent it, or at least that's my thinking. I mean, it's not like this belief has been proven, but you know, these kinds of strokes of fate are inevitable. You can't avoid it. Of course there's some work-related stress where someone would have some sort of influence, but the kind of stress that managers have can't be avoided."

Brigitte's take on ability to prevent cancer not only removes the culpability of women diagnosed, but it also reflects the connection of cancer to fate and resignation in Austria. Interestingly, she also describes the potential overlap between the onset of breast cancer and depression, which also links breast cancer back to emotional distress. Brigitte also combines women's traditional roles of caring for ailing mothers, as she did, as well as modern roles, such as women in managerial positions.

In addition, many women in this sample used the explanation that their immune systems simply "gave out" under the stressful circumstances in their lives. In other words, they seek to debunk the notion that they were responsible for their psychosocial malaise or inability to cope with distress. Instead, it was the *Körper* and the immune system that failed. This is a powerful transformation from the stigmatization of the so-called weak personalities Susan Sonntag so adamantly rejected in *Illness as Metaphor* (1990 [1977]). This also integrates the duality of the *Leib* and the *Körper* in the onset of cancer. In this paradigm, emotional distress felt within the subjective, fluid *Leib* becomes embodied into the corporeal functions (*Körper*) (see Csordas 1990). In this explanation, the emotional distress felt within the *Leib* creates a disturbance in the functioning of the *Körper*, whereby the immune system is unable to fulfill its function of attacking cancerous cells. Christine (53), a laboratory scientist, explained the link between her sleep disorder caused by her neighbors and the onset of cancer:

> "It's incredible loud in my apartment. My neighbors are so inconsiderate. I've constantly fought and fought with people since I moved in. Even now I can't sleep that well, but back then I had a sleep disorder. I think that when you're just constantly at your limit and you have this constant tension, I mean the idea that you can't even relax in your own apartment because you think to yourself, 'It's happening again.' Whenever the body (*Körper*) is weak, then the cells cannot communicate properly….You always have cancer cells in your body, but there comes a point when you are under so much stress that your immune system just has had enough."

Christine, like others, used a complex means of linking the stress of not being comfortable in your own home, constantly fighting, and a weakening of the body that leads to miscommunication within the immune system cells. For her, there was a critical mass of stress that allowed for the onset of breast cancer.

Rather than isolated incidents of a cheating husband or the illness of a child, women in this sample displayed a pattern of wearing themselves too thin while striving to meet the demands of their home, work, and personal lives. The sense of "eating it all up inside" was modified in these illness narratives not as an inability to express grief or sadness, but by the necessity to suppress emotions and push aside one's needs and desires to maintain the family status quo. Hence, they were deflecting the blame and disabusing themselves of the notion that they could have changed their circumstances or prevented their cancer.

Responding to emotional distress

Relatively speaking, Austrian women live very well. They have access to clean water, abundant food, safe roads, and excellent healthcare, among many other luxuries. With Austria's progressive economic and social status in world rankings, it seems strange to speak of Austrian women as disadvantaged. On a global scale, they are not. Still, their relative marginalization within the patriarchal and hierarchical Austrian society does make women to some extent feel disadvantaged. I met numerous women throughout the research period whose families are plagued by alcoholism, which is generally cloaked under the cultural norm and ritual of drinking. Others sacrificed advanced degrees or career advancements to help their families. I became acquainted with one woman who left her university at her older husband's behest to have a family. Another with a similar background worked minimum twelve-hour days in the agricultural tourism industry before collapsing into psychological strain and spending month-long stints in the hospital. Hers is an extreme example, but the constraints she was under are common, particularly among rural women. Thus, aggregate statistics of progress (e.g. gross domestic product, literacy rates, and so forth) can mask the struggles, suppression and oppression, and the quotidian pains people face.

Generally speaking, Austrian society, like many Catholic countries, remains hierarchical. Patriarchy is paramount, and even as corporatism and women's involvement in the labor force has grown in the last five decades, the mentality has remained "non-egalitarian and paternalistic" (Appelt 1998:86). Paternal figures reign in family life, where a workingwoman is still likely expected to sort out the childcare, parental care, and house work. This is not to say that more gender equality has not been achieved or that the topic has not reached the public's consciousness, but the subtle politics of women's marginalization persist (Dvorak 1996; Fodor 2003). Women are both central to the functioning of society and upholding cultural values, and yet marginal in holding power and social capital.

On average, more younger women reported emotional distress as a potential cause for their cancer than women over 60 (χ^2= 4.68 p=0.031). I am however cautious in making the claim that older women do not share in this belief, considering that older women may have been socialized to not speak of their problems or not to see social and gender issues *as* problems. For instance, five women in the oldest age group replied to my question, "Do you feel like people understand what you are going through?" by directly stating, "But I haven't gone through anything!" To this, women explained that they did not mean to trivialize breast cancer, but that they had endured other hardships throughout their lives that a problem like breast cancer pales in comparison to the others.[84] The women in the oldest age group tended to downplay their diagnoses in relation to the misfortunes of others, or problems they had faced in their lives. For instance, Gerda (71) said, "I know someone with pancreatic cancer. And what about childhood cancers? Those are much worse than breast cancer!"[85] Otherwise, they spoke of how breast cancer was nothing to complain about, or that it was "just another problem" in their social circles.

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[84] In order to get a better idea of what women who grew up in post-war Austria endured, I made a point of reaching out to 15 women over the age of 65 through snowball sampling in both rural Alpine villages and in Vienna. Rural women matter-of-factly mentioned the fact that "all seven children bathed once a week using the same water," and while they may not have been hungry, food in the winter months was often moldy and in short supply. After World War II, people died of preventable illnesses and complications from injuries due to a lack of medical treatment. Families huddled close to the radio in hopes of hearing that soldiers had returned home alive from Russian prisoner of war camps. A Viennese woman recalled her parents sending her away with other young children on a train headed to the Netherlands to escape the pending danger of a war. She returned home after living with a Dutch foster family to an impoverished, destitute city with little hope for a bright future.

[85] I often encountered this type of reaction from older women (and men) while working alongside them in the mountains. I have a rare condition that causes restricted blood flow and numbness in my fingers and toes when exposed to cold, damp weather. If left untreated, it can result in permanent loss of my extremities. I never recall complaining and never took any flak for leaving work to go into the stable to warm up my hands and feet. But after the work was finished, people made it a point to remind me of how fortunate I was to not have a "serious issue like Susi's cancer," or a "child with Cystic Fibrosis like Frank." They were of course right, but interestingly, I had never expressed frustration with my condition. They preemptively wanted to categorize the condition as a low-priority in relation to others, which I assume was a way of keeping me quiet and working. Thus, this form of social control discouraged any complaining and reminded people to be satisfied with their lives, despite less-than-auspicious circumstances.

While younger generation will never know the hardships of war, younger women do face challenges particular to their generation, including greater work demands in light of the neoliberal processes and the Europeanization and globalization of Austria. Some younger women worked 70-hour weeks that involved extensive travel, knowledge of multiple languages, and constant pressure to keep up with their male peers. In addition, women's demands at home have only slightly been reduced, which either has the effect of women delaying partnership and motherhood, or facing the double burden of proving oneself in the workplace and keeping up the home and childcare.

The observed differences in how age groups expressed the breast cancer illness experience are mediated through their own struggles as well as those of their peers, family, and friends. Known as *response shift* theory, it describes how social interactions can change the cognitive adaptation of the meanings, internal standards, and comparisons across social groups in relation to one's illness or condition (Maes et al. 2010; Schwartz & Sprangers 1999). Pierre Bourdieu's concept *habitus* is also critical as a means of grasping how women could internalize their subtle silence and denial of their own hardship or marginality as an unquestionable and natural (Bourdieu 1990; in relation to women's roles and cervical cancer, see Gregg 2003).

Women's Roles and breast cancer stigmatization

While at a conference for self-help and patient advocacy groups, an Austrian psycho-oncologist giving a talk to breast cancer self-help groups claimed, "a heart attack is to men what breast cancer is to women." This resonated well with the support group members. A heart attack for a man, they explained, means years of hard work and a man who used his bodily "machinery" to its limits. For women, breast cancer is years of stress and strife harbored inside until her body erupted. "We don't legitimately talk about cancer personalities per se," the psycho-oncologist continued,

> "but we [Austrian society] constantly talk about women with breast cancer as needing to take better care of themselves, as if again the blame is on them. As if we put them in that position and then tell them to get themselves better."

Breast cancer is the cultural reminder of the precarious positions in which women find themselves and yet have difficulty escaping. "Cancer is the body crying out," as Heidi (48) succinctly described after having the sense that she could "neither fight nor flight."

As mentioned, while some women expressed guilt for not taking better care of their body and mind, they often cast it as not having any other option at the time. Work needed to be done, children needed their mother, and elderly parents needed their daughter. Although the stigmatization of cancer is distinct (see chapter two), I hypothesize that the stigmatization of women with breast cancer stems relates back to the problematic aspects of women's roles and gender relations in Austria.[86] If the breasts represent the symbolic *Leib* of womanhood, then breast cancer becomes a metaphor for all that a woman withstands and all that can go wrong. As if to fit the metaphor of "eating everything up inside," the cancerous breast swells up and spreads. If left untreated, a breast tumor will burst through the skin, representing the extreme excess of emotions. Some women reported feeling as though others saw them as "already dead" (Maria, 53). Anna's (32) experience speaks to the interpersonal and social exclusion inherent to cancer stigmatization:

> "What I really noticed was that I had far less contact with people I used to see all the time. There was a friend of mine who had a problem with my diagnosis because she lost

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[86] The structural form of stigmatization through job loss is briefly discussed in chapter three.

> her mother to cancer. She told me, "I don't want to lose a friend to cancer too," and then she completely cut off all contact because she couldn't handle it psychologically." (Anna, 32)

The stigmatization of breast cancer is in many ways like any other; the process of ostracizing the afflicted acts to shut out the societal fear of the disease. But unlike other conditions, the culturally understood risk factor of emotional distress is shared and experienced among many. The stigmatization of these women systematically allows for the cultural avoidance of all that others have to "eat up inside."

Arthur Kleinman recently articulated his stance on abandoning the "psychologized and conventional" concept of stigma in favor of emphasizing an ontological, experiential understanding of social death and an entirely new way of functioning in the world (2012: 185). Although Kleinman's charge was intended for studies of mental health issues, applications to a wider range of illnesses may prove useful. Only having the opportunity to interview almost all women in this sample one time, it was difficult to parse apart the process of stigmatization, whereby women either isolated themselves, are ostracized by others, or lose their jobs because of fear of breast cancer or death, or if women's notions of stigmatization were influenced by the long history of breast cancer stigmatization in Austria.

Therefore, it is not surprising that women without breast cancer who experience the same kind of emotional distress in their lives levy the blame against women with breast cancer. These women shut out their own fear of breast cancer by ostracizing those they feel are in similar circumstances. This is exemplified well in the account of Sigrid (56), whose former best friend suspects that her cancer was caused by martial problems. The following quote is also telling because at first Sigrid shrugs off the accusation that she had martial problems (what her former friend is convinced happened), but then attributes her cancer to the blameless but nevertheless stressful circumstances in her life, such as caring for her ailing mother. Also worth noting are the many qualifiers she adds within her narrative:

> "What caused my cancer? Oh, I don't know. A friend, an acquaintance, well let's just say a woman because she used to be my best friend, but she cut off all contact with me. She thinks that you get cancer from having marital problems. But my husband and I don't have any issues and we've had a good marriage for 27 years, so I have no idea how she came to that. Maybe she was envious. She's got some pretty bad marriage problems. And you know, I really had to think about what she said, but then I got the idea out of my head pretty quickly…The doc tells me I really shouldn't think that I'm guilty for having cancer, but I still ask myself all the time why I got cancer. In a medical sense, I really think that when you're not doing well, your immune system can't work as well, and then there's that one split second where the cancer cell can reproduce. But you know, with stress, well, let's just say it's not like I don't have a lot to do. I have to take care of my 90-year old mother. It's not like she's exhausting, but the fact that my husband and I were never alone had a bit of an impact on our marriage. So, my child was young, I had to look out for my mother and child. I mean, don't misunderstand me, one does that stuff gladly, I mean, it's just the way it is...I'm not going to say it's as bad as being the boards in an ice hockey rink, but you know, sometimes my life is just like "boom, boom!" It never stops…But I'm doing well now. The docs suggested I go to oncological rehabilitation, but I didn't. A child I teach told me he prays for me every night. That's all the rehabilitation I need."

This example shows how angst and insecurity in one woman's life translates into exclusion for Sigrid, who wavers in between believing that stress caused her cancer, while at the same time seeing her position in her family as the *Prellbock* as normal and necessary. She later added that instead of taking the option to attend three-week oncologic rehabilitation where Sigrid would be completely cared for, she returned to work, stating that the prayers of a young child was all she needed to keep going.

As the psycho-oncologist mentioned, women are constantly told to take better care of themselves by taking a vacation, making time for exercise, or visiting with friends. Yet for many, such suggestions, often coupled with the charge to "think positively" was little more than an agitating reminder of all that is left to be done and all the lingering problems. Many women are afraid of breast cancer because they do believe in its link to emotional distress. As a result, they shun those with the disease or avoid discussing it as a means of blocking out their fear. The following section looks in part at the consequences of breast cancer stigma on social interactions, particularly those among women with breast cancer, and what this may indicate about the process of coping with breast cancer.

Social Connections after Breast Cancer

The rise in awareness of breast cancer has opened up spaces for women with breast cancer to reach out to one another and to find empathy, tips, and aid in the coping process (see Bouskill 2012). One main interest I had going into this research was to understand interactions among women with breast cancer, considering that it had been so important to American women with breast cancer. In order to further explore this topic, I developed a social support map in which I asked women to simply tell me about the people with whom they spoke about their breast cancer. In a bull's-eye format, I asked all women in this sample (N=54) to stratify their contacts across three categories (often, sometimes, and less frequently) (figure 5.1). In a fourth category outside of the bull's-eye, I asked women to name those with whom they purposefully never spoke of their breast cancer. I designed the social support maps to function as an elicitation technique to grasp how women engage others in their post-diagnosis lives.

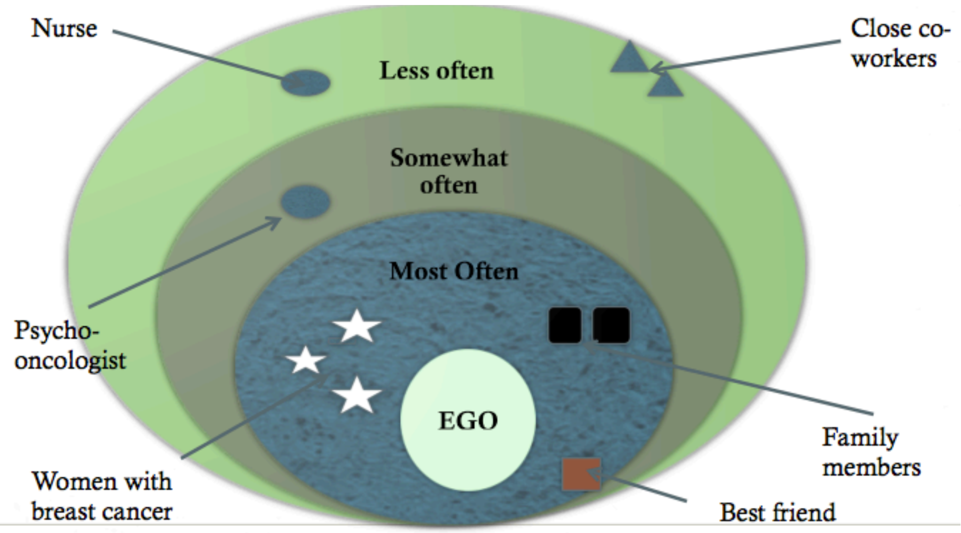

Figure 5.1. Example of a social support map

Having the visual cue of the bull's-eye helped women to parse apart the intricacies of their discussions about breast cancer. For instance, Julia (28) spoke about her "fun-loving" husband throughout the interview, but did not place him on her map. Having the visual allowed me to probe her on the subject further, to which she initially acted surprised that she did not list him, but then came to the conclusion that she in fact could not discuss her illness with him because it was too much for him to handle. In addition, I observed Julia hesitate over how she should classify friends and acquaintances on the map. This led into a conversation about having breast cancer in rural Austria, where it is nearly impossible to live anonymously, and where she parsed apart gossip and chatter from actual support:

> "[Living in the countryside] has pros and cons. It's definitely a con if all you want to do is go shopping and everyone looks at you to see if you have hair or if you're wearing a wig...All the gossip got on my nerves, simply because I knew what they were all saying. But on the other side, it's positive because out of the blue someone you hardly know calls to ask how you're doing and if they can help, or they send you a book with funny sayings. You get support when you never thought you would." (Julia, 28)

Another use of the social support maps was to elucidate how and to what degree women with breast cancer connected with others in a similar situation. I asked women directly about their contact with other women with breast cancer, which they then pointed out on the map and explained how they met and in what capacity they spoke of breast cancer together. In total, 28% (n=15) of women listed another women with breast cancer within the “most often” category, 33% (n=18) in the “somewhat often” category, and lastly 24% (n=13) in the “less often” category. Due to the fact that only women with supplementary private insurance have private hospital rooms, women often met and maintained contact with their roommates in the hospital. In addition, those on similar radiation or chemotherapy schedules often opened up to one another in the waiting rooms. For instance, Pauline (44) complimented another young woman on her ability to keep her hair so beautiful throughout treatment. “That was when she wiggled her wig back and forth on her scalp and winked,” she explained, before they started to giggle, struck up a conversation about where to find a good wig, and are still in contact today. In some cases, women in the village disclosed their previous diagnoses to women recently diagnosed. In others, a close friend or family member put two women in contact. Interestingly, while self-help groups exist and have loyal members, not one woman in the sample attended a self-help group. These findings demonstrate however that social support does not have to come from organized meetings. Rather, informal means of contact, such as a brief chat in a waiting room or a phone call, even if women were previously unknown prior to the diagnosis, can also be meaningful and helpful in the process of coping with breast cancer.

My hypothesis was that women who actively took part in buying pink ribbon products and attending pink ribbon events would have more contact with other women with breast cancer. However, since most women were either indifferent to the presence of pink ribbon, had never heard of it, or could not attend pink ribbon events (see chapter three), I omitted this factor from the analysis. As mentioned in chapter three, only one 54-year old woman showed me that a pink ribbon keychain. I furthermore hypothesized that women in the older two age groups as compared with the youngest group would have more contact with others with breast cancer, simply due to the fact that there are more women in the age group who are affected by breast cancer. However, age at diagnosis was not a significant predictor for having contact with other women with breast cancer. Reporting stigmatization was also not a significant predictor for contact with other women with breast cancer. It is encouraging that experiencing stigmatization from others in a social network does not necessarily obstruct women from being able to reach out to others who could convey a positive sense of camaraderie and understanding.

Additionally, experiencing a form of stigmatization is associated with listing people in the "never" category, or having the sense that one needs to purposefully keep their illness private or secret from certain individuals (χ^2=7.4, p=0.06). In total, half (n=27) women listed at least one person in the "never" category. While in many cases women did not want to burden or worry extended family members or neighbors, others listed the 'perpetrator' of emotional distress whom they believed caused their cancer. For example, Natalie (41) blamed her cancer on her difficult breakup following the birth of her first child. Ashamed to let her former partner know of the pain he caused her, she painstakingly hid her treatment from him as they shared custody of their young daughter.

Natalie likewise felt ostracized from her circle of friends, which perhaps influenced her to keep her illness secret from her ex-partner. Julia, the 28-year old rural patient blamed her tyrannical boss for her diagnosis explained,

> "I definitely don't want my former boss to find out. He just wants to know so he can gossip about it all over town. So this guy is going to terrorize me for six years and then all of a sudden say, 'Oh you poor girl, so sad!' Nope."

In one sense, keeping cancer secret is a means of avoiding negative or superficial reactions from those who have inflicted hurt on a woman's life.

The reason to avoid neighbors or extended families may be a practical means of avoiding constant telephone calls, not causing unnecessary worry, or simply not always having to talk about breast cancer. However, secret keeping also reflects an anxiety of constantly having to suppress, avoid, and shield one's self from disclosing a perceived weakness (Finkenauer & Rimé 1998). Sigrid (56), who explained that caring for her mother was a burden in her marital life, coincidentally put her mother in the "never" category. She explained, "There's just no sense in telling her. It's not like it's her fault. Even if she were all there mentally, I still would not have told her. It would have broken her." For Sigrid, hiding her diagnosis from her mother was a form of protection for both her and her mother.

When I asked Inge (64) if people in Austria talk about breast cancer, she replied "Everyone just represses it. Basically, it can affect everyone, and no one knows what can happen tomorrow. That's exactly the taboo, that's what people are trying to hide." When we discussed the people with whom she talks about breast cancer, she had more nuance to offer. In the "less often" category, Inge only listed people who approach her about the scars from her mastectomy and reconstruction in the locker room of her tennis club and in the sauna.[87] She continued:

> "If I take a shower at the tennis club, some women look at me and say, "What happened there?"…People stare at you, it bothers me, it's uncomfortable. I can't change it and I can't get rid of it. I mean, it doesn't bother me *that* much, but I see some other people in the sauna and think, "Man, they shouldn't be in the sauna either!" I've got what I've got, and I've got to live with it. It's definitely not easy and there are people who wouldn't do it the way that I do [go into the sauna]. I just say it like it is. People react differently too. Some say, 'Oh yeah, I had something like that too,' and others say in shock, 'Oh my God.' I always tell them that I'm doing well. I would never say, 'Hey, it's none of your business,' because gathering experiences is always better than when someone tells you it's none of your business."

Inge knows that being nude in a sauna is risky and that others may make her feel uncomfortable by staring or reacting in shock. Whether or not these kinds of social interactions can be classified as a form of stigma is not the pressing issue per se. It is important to recognize that breast cancer has changed the ways she is able to participate in her favorite hobby, and despite her discomfort, she speaks truth to her illness and tries to show others that breast cancer does not need to be as frightening as it is in people's imagination.

With 40% (n=22) of the sample reporting some form of stigmatization, the need to revamp the public image of breast cancer and to remove the taboo of receiving psychological therapy for those undergoing emotional distress is pressing. This ought to be recognized by organizations such as Pink Ribbon Austria and biomedical personnel who have the power to speak more directly to the needs of women going through breast cancer.

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[87] In Austria, visiting a co-ed, nude sauna is a popular activity among adults, so it is important to know how breast cancer impacts this quotidian wellness activity for women. Maria (28) told me for instance that she avoids going to saunas in the area where she lives, for fear that she may be recognized.

Eating everything up, spitting it back out: Making life changes after breast cancer

As much as women described their lives being derailed following a diagnosis, they also spoke of breast cancer as an opportunity to bring positive change into their lives, or to use the metaphor, get themselves on a new track. Sixty-five percent (n=35) of women who participated in narrative interviews cited some form of positive change in their lives brought on by having breast cancer.[88] Women most commonly mentioned living more consciously, more aware, or with more purpose. In a less spiritual sense, others took on more health-promoting behaviors, including adopting a healthier diet, an exercise routing, or quitting smoking. Alternatively, some women reported no changes, which could be out of a personal choice, a perceived inability to change one's circumstances, or the fact that treatment still dominated one's life. Women faced a major transition after receiving their diagnoses, and again as they came to terms with living with breast cancer. For many women, the silver lining after the negative disruption of breast cancer was counteracted by the changes made that resist confining social roles.

Interviews demonstrated that women who cited emotional distress/stress as part of the cause of their cancer were statistically more likely to make positive changes in their lives. These changes included paying more attention to their needs, learning to say no, living more spontaneously, and making fewer compromises. Some even made drastic changes, such as Michaela (40), who after experiencing a breakup and losing both parents suddenly, left her job as a high-powered lawyer to become a performance artist (table 5.1). Even more surprising were two women in their 60s at the hospital clinic who

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[88] In the youngest age group, 70% (n=7) of women made positive changes in their lives. In the middle group, 89% (n=16) of women made positive changes. In the oldest group, only 44% (n=11) of women (I was unable to ask one study participant) made positive changes.

became dominatrices following treatment, explaining that it was something new and a fast way to make money.[89]

Women regained or found their voices and refused to always attend to the needs of others over their own needs. If having breast cancer denotes a special identity status, then it appears as though some women are able to use this status to resist constraining gender roles. Birgit (64) told me of her constant struggles, including a "selfish" daughter, a husband who cheated with her best friend, and a family business that left her with just enough to scrape by before she explained her transformation:

> "It was just the entire situation I was going through. I've gotta say, I've had to go through a lot, and I definitely wasn't taking care of myself, and I surely didn't love myself the way I do now. I can say that I'm satisfied in all aspects of life. I have a new lease on life and I don't need all that negativity. Now I can shop for myself, now I can afford it, now I can *just do it*. Now I can go dancing and have a ball. I only get a miniscule social security check, but you know what, I'm happier and more satisfied than ever before. I always wanted to do things for myself, but I always had to be there for others. If I wasn't there, whatever it was just never worked. Now I can say to my daughter, 'No, I'm not doing that for you.' I'm not dropping what I'm doing to run over to you. I'm not doing it anymore!"

Birgit called cancer "her friend," which she explained gave her a reason to change her life. She openly tells others about her "friend cancer." She continued:

> "I really think that women 'eat everything up inside' and can't get it out, can't talk openly about it. It's a huge problem in Austria. This is a generalization, but I think it's worse in the countryside. When I say, 'My friend, cancer,' people stare at me and say 'what did you just say??' They don't get it. People are all really, really negative. It's definitely to some degree *schein und sein*, you know, that people would want to hide themselves from reality. Other people were really reserved when I talked about my cancer. It was really hard for them. When it comes to breast cancer or prostate cancer, it's still really, really taboo. It's much easier to talk about lung cancer."

Birgit was rather defiant and open with her cancer, despite resistance from her circle of friends. She also mentions the distinction between *schein und sein*, or appearing one way and actually being another, which meant that people found it easier to pretend like

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[89] The exchange of money and goods for sexual services is conditionally legal in Austria.

nothing was wrong or that the threat of cancer did not exist. In this vein, lung cancer may have been easier to discuss openly for its clearer association to smoking. In contrast, breast and prostate cancer still come across to Birgit's social network as an uncontrollable threat.

Like Birgit, Maria (53), whose family and work demands exceeded her own personal satisfaction, learned to "finally say 'no' without having a bad conscience." To my surprise, I even heard multiple women tell me in formal interviews and informally that they "needed breast cancer to change their lives." I found this unsettling and recalled an anthropologist/physician who told me that after his wife's breast cancer diagnosis, he came across the work of 'self-help' proponent Dr. Bernie Siegel, who before treating patients, asked them to first grapple to the question, "Why did I need this cancer?" (see Siegel 1986). "Can you imagine the pain? The burden? The gall to think my wife *needed* cancer," he said to me in his quiet but powerful tone. While some likely benefit from the positive self-transformation within Siegel's message, it can also lead to unwarranted blame on those who understandably have difficulty finding anything positive about the experience of having cancer, or worse, lose their lives to it. The first handful of times that women told me in retrospect that they "needed cancer," I could not erase the image of his clenched jaw and hands pressing against each other. I too felt uneasy, as it seemed to me that families needed to change their mentality about the wife and mother's work, rather than she needing to go through breast cancer. However, many women proclaimed that they needed cancer in order for the circumstances in their lives to change, if only slightly.

These findings relate well with Linda Hunt's work on the "strategic suffering" of Mexican men and women with cancer, which showed the personal empowerment gained following a diagnosis (2000). She illustrated how men and women with reproductive cancers were able to shirk their gender roles, either as the macho man or the sexually available wife. In other words, cancer's highly charged meaning and its evasion of the regimented 'sick role' (see chapter two) can also confer perceived positive gains and emotional wellbeing in the life of the afflicted.[90] The advantage of an anthropological perspective is an in-depth understanding of the sociocultural factors that drive the direction of emotional wellbeing following a diagnosis. For example, a study of benefit finding among women with breast cancer in the U.S. was unrelated to distress or wellbeing (Cordova et al. 2001), whereas the present study demonstrates a statistical correlation between experiencing emotional distress and instigating positive life changes (χ^2= 2.81, p=0.093). On average, more younger women made positive changes following their diagnoses than women over 60 (χ^2= 7.66 p=0.0057), which corresponds to the fact that older women reported emotional distress as a cause for their breast cancer less frequently than younger women.

The persistence of breast cancer stigmatization and the emotional distress explanatory model make for compelling narratives. But to focus solely on these factors would be remiss and would ignore the incredible potential cancer, or simply being confronted with a life-threatening illness, can have to positively change lives, shedding light on previously repressed issues, and helping women to gain more agency. This is

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[90] Some of the psychological literature refers to these changes as *posttraumatic growth* (Calhoun & Tedeschi 2006). There is contention over the legitimacy of attaching cancer to trauma and potentially mistaking posttraumatic growth with emotional wellbeing (Sumalla et al. 2009). This issue is discussed in more detail in chapter six.

where the highly charged meaning of breast cancer denotes a specialized sociocultural identity, which then relieves women in part from their prior constraints.

The following section is a brief aside intended to situate the emotional distress explanatory model within a biomedical perspective; that is, to bring the emotional distress explanatory model into the realm of disease.

Cancer, the mind, and the *Leib* in biomedical perspectives

Until this point, I have given the impression that the emotional distress explanatory model belongs to the realm of illness. This is misleading, however, given the host of biomedical studies seeking to establish a link between the so-called "cancer personality," emotional distress, and chronic life stress and the onset and prognosis of breast cancer. In addition, this point is particular important to the Austrian context, where some medical practitioners in oncology, including oncologic surgeons, espouse the connection between emotional distress and breast cancer. These biomedical practitioners contend that breast cancer stems from negative emotions and energy imbalance in one's life, and treat breast cancer by simultaneously healing the body, mind, and soul under the paradigm of "holistic medicine" (German: *Ganzheitmedizin*). Instead of being designated to complementary or alternative medicine, many of these doctors hold prestigious positions and are highly regarded in the Austrian healthcare system. In other words, while many colleagues may dismiss their beliefs and practices as pseudo-science, these are influential people, not quacks.[91]

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[91] Lynn Payer (1996) outlined the varying "cultures of medicine" around the world. I think it would be highly unlikely that a medical doctor could obtain such prestige by so outwardly being a proponent of such complementary and alternative methods of healing in the U.S. Complementary (and to a much lesser

A critical view might see the physician's dual function as a surgeon and therapist as a lucrative way of reaching out to vulnerable women. By ascribing to the belief that emotional distress can cause breast cancer, these physicians' approach resonates well with many women. However, this kind of personalized treatment comes along with out-of-pocket costs.[92] All insured patients in Austria will receive very good care for breast cancer without any additional out-of-pocket costs. However, if a patient wants the individual attention required of the 'holistic' physicians, she will have to pay for appointments in private hospitals and clinics. Appealing to women through 'holistic medicine' could be seen as effective competitive marketing in a two-tiered healthcare system that is becoming increasingly privatized (Versicherungsverband Österreich 2013).

The other problem is that the mind-body connection and cancer is not statistically supported by available data, despite the fact that the topic has been investigated on record since 200 A.D. (Butow et al. 2000). Even until the late 1990s, women's health magazines in the U.S. were heralding the negative impact of stress and arguing on immune function (McKenna et al. 1999). This is not to say that stress or emotional distress is not at all implicated in the development of cancer, but that data from robust epidemiological studies examining the link with breast cancer have found inconclusive evidence at best.

To be clear, the field of psychoneuroimmunology has made great advances in demonstrating how persistent activation of the hypothalamic-pituitary-adrenal axis through chronic stress suppresses natural killer cell activity, interferon-gamma and

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extent alternative) medicine does however appear to have a good footing in Austria. Therefore, this approach may very well fit into the culture of Austrian biomedicine.

[92] I do not claim that these doctors promote this view to swindle vulnerable patients, but I cannot say for sure that it is not the case, considering that these biomedical doctors can make good money seeing patients in their private offices.

interleukin-2 synthesis, and CD4 and T-lymphocytes counts, which can reduce immune responses to cancerous cells (Kiecolt-Glaser and Glaser 1999; Lutgendorf et al. 2007; Vissoci Reiche et al. 2004).[93] To reiterate, psychoneuroimmunological studies have largely been inconclusive in regard to how emotional and psychosocial factors influence the onset of cancer. In fact, a Danish study demonstrated that increased stress is associated with *lower* risk for estrogen-receptor positive breast cancer (Neilsen et al. 2005). The mechanism is thought to be reduced estrogen production due to stress, which would then lower one's risk of developing estrogen-receptor positive breast cancers (*ibid*.). Additionally, systematic reviews of epidemiological research, including prospective and retrospective cohort studies, have also failed to uphold the hypothesis that stressful life events, emotional distress and certain personality types are risk factors for breast cancer (Bleiker & van der Ploeg 1999; Dalton et al. 2002; Duijts et al. 2003; Garssen 2004; Nakaya et al. 2003; Schernhammer et al. 2004). Where a difference is observed however is in breast cancer prognosis and mortality, but the link to etiology remains unclear.[94] Simply put, when a biomedical practitioner draws on his or her

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[93] One of the most powerful modulators of the stress response, arguably interpretable within this context, is the outlet of social affiliation and support (Sapolsky 1994: 262). This is where links can be drawn between psychosocial stress and the occurrence of peer assistance in coping, regardless of the actual physiological indices at hand. A greater quality of social support has been demonstrated to lead to lower mean concentrations of cortisol, the hormone implicated in the stress response. This suggests that social support as a coping mechanism carries implications of stress buffering among physiological pathways and overall better health (Cohen and Willis 1985; Dunn et al. 2002). Social support of non-household kin is related to decreased cortisol production (Reynolds et al. 1994; Waxler-Morrison 1991; Weihs et al. 2005).

[94] Turner-Cobb et al. (2000) found that metastatic breast cancer patients who reported less social support had significantly higher mean cortisol levels. Stress can be measured not only by examining mean cortisol levels, but also through a lack of diurnal rhythm in cortisol levels. Dis-regulation of the circadian cortisol rhythm has been used as a marker of HPA axis imbalance and states of adverse health (Sephton et al. 2000). In a study examining abnormalities in cortisol circadian rhythm, metastatic breast cancer patients with flattened cortisol levels (indicating an abnormal diurnal variation) had a significantly higher rate of early mortality, lower natural killer cell counts, and more rapid disease progression (Sephton et al. 2000). Abercrombie et al. (2004) also noted that in breast cancer patients, flattened diurnal cortisol slopes

authoritative knowledge to tell women that they can reduce their risk of breast cancer by leading more harmonious lives, they are either ignorant of the breadth of data on the matter or willing overlook it. A less cynical view, however, might say that a doctor is willing to set aside the epidemiological findings in order to make patients feel understood. Although the 'human' side of clinical treatment is absolutely critical, the process of healing emotional scars is best kept from being subjected to medicalization. I do not mean to suggest that every woman ascribing to this belief should see a psycho-oncologist. Empathy is critical in the clinical encounter, as is determining what is most at stake for the afflicted (Kleinman & Benson 2006). To be fair to the practitioners who take on this approach, most would outwardly say that there is no scientific evidence to show that healing emotional wounds can better a woman's prognosis, but would rather take improvements in quality of life as paramount. With that point I can only agree. At the same time, to even give women the slightest impression that they can cure their cancer through spiritual healing is a claim best treated with caution.

It is important to note the methodological difficulty of operationalizing a predictor variable such as emotional distress, especially given the inherent subjectivity in experiencing and expressing it. Moreover, there are multiple modes of expressing distress, also known as "idioms of distress" in regard to the illness experience (see Nichter 1981). There is a constant push in the literature to refine the measures used in these studies in order to better investigate the link between distress and breast cancer. However, as McKenna et al. (1999) rightfully caution, "If such a connection exists, further research is decidedly warranted; if not, it is questionable practice to allow women

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correlated with greater perceived stress and lower perceived social support. A flattened cortisol slope has also been implicated in the survival time of cancer patients (Sephton & Spiegel 2003).

to continue to assume that they can significantly affect their physical health by simply arguing less, talking more, or changing a specific aspect of their personality?" (520). In other words, if there are no robust data to show an association, why continue misleading women into thinking that inner harmony can prevent breast cancer, or alternatively, that it is their fault if the develop the disease? This is precisely the blame of breast cancer being a "disease of insufficient passion" that Susan Sontag disavowed decades ago (1990 [1977]: 21). In addition, it is also what women were emphasizing in their narratives about the etiology of their breast cancer. While some imposed self-blame for not taking better care of themselves, many women who believed emotional distress and stress caused their cancer highlighted the fact that they did the best they could, given the circumstances.

Biomedical practitioners in Austria who choose to make claims about the link between personality, coping mechanisms, and distress and breast cancer should be forthright in claiming it is an opinion of *eminence*-based medicine. As stated in chapter four, the public messages of breast cancer risk impact the breast cancer illness experience and can make women feel unnecessary guilt and stigmatization. Furthermore, it is important to keep in mind that the *habitus* of expressing distress, grief, sadness, and frustration are highly mediated by structural and sociocultural contexts. Thus, while this chapter depicts the salience of the mind-body linkage in many women's breast cancer illness narratives, biomedical thinking on the matter ought to be mindful of reporting or promoting a link where it in a scientific sense cannot be supported or where there is wide cultural variation in experiencing and expressing distress. The overall attention should be placed on understanding how to improve women's emotional wellbeing throughout the life course, breast cancer or not.

Conclusion: Constructing Austrian breast cancer illness experiences

This chapter sought to explain the illness experience of breast cancer and how women make sense of breast cancer in their lives, both in the events leading up to their diagnosis and how they lay out the course for the rest of their lives following the diagnosis. Like any portrayal on the topic, this work is incomplete. However, it does present a poignant example of how the meaning of breast cancer reflects women's roles and gender relations. It furthermore reveals how the biomedical ambiguity of cancer allows women to construct explanations of cancer that are meaningful to their own lives. Important to note is that these meanings and beliefs about causality for a grave disease like breast cancer are never constructed in a vacuum, but rather are constructed intersubjectively (Garro & Mattingly 2002; Kleinman 1988).

There is perhaps no disease or state that better mirrors the complicated ambiguity of intersubjectivity and the blurry lines between self and other than cancer. Cancer cells stem from one's own somatic cells and yet simultaneously acts as a foreign invader inside the body. But how cancer emerges, either from an internal malfunction with the body's immune system, external insults to the body inducing oncogenic mutations, or likely a blend of both, is unclear. The same ambiguity is mirrored in some women's accounts where their mental health, intrinsically wrapped up in the wellbeing of others, is stretched to its limits. This is exemplified well in the ways in which women in this sample connected their emotional distress to malfunctions in the immune system. In doing so, they sought an intelligible explanation for the damaging effects of constantly having to "eat everything up inside."

This chapter also attends to the persistence of breast cancer stigmatization, which was observed in this sample as well as in the media and Austrian literature (see Langbein 2012). That being said, most study participants and Austrians in common parlance were quick to note that the stigmatization of people with cancer has waned in the last twenty years. Interestingly, I often heard that lung cancer is not as stigmatized as breast cancer, due to the sense that it is an adverse consequence of cigarette smoking, which is considered normal behavior for many Austrians (Euro-barometer 385 2012). I speculate here that breast cancer stigmatization is fostered through the widespread belief that breast cancer is linked with negative emotional and stressful psychosocial circumstances in women's lives. Avoiding contact with women with breast cancer is one means of repressing and hiding the worry that breast cancer could strike others. Intuitively, experiencing stigmatization appears to add additional burdens in the process of coping with cancer. Speaking directly about breast cancer stigmatization at breast cancer awareness events, including Pink Ribbon Austria events open to the public (see chapters three and four), could help to assuage its negative impact on women with breast cancer. However, this is yet to be realized.

Another point of this chapter is that anthropologists readily consider an integrative mind-body connection to be a non-Western epistemology (Scheper-Hughes & Lock 1987). This work shows otherwise by demonstrating how emotional distress is believed to be implicated in the onset of breast cancer. In addition, it provides the example of the handful of prominent oncologists who promote a holistic blend of biomedicine and complementary healing methods from traditional medical systems in order to treat breast cancer. While some patients do find this method effective, this analysis cautions against the overall utility of this model and the potential it may have to place unwarranted blame on women with breast cancer. It also warns against prematurely purporting the link between emotional distress and breast cancer. That is to say this chapter again counsels against the misapplication of knowledge on epidemiological risk factors for breast cancer.

For 57% (n=31) of women in this study, the continual relinquishing of the self in order to fulfill the needs of others went disregarded or repressed until the gravity of their diagnoses made the issue glaringly apparent. Relinquishing the self to the needs of others, as overlapping and non-discrete as these domains are, is a destabilizing factor in establishing a sense of equilibrium (Desjarlais 1992; Jackson 1998). But as these accounts demonstrate, the recognition of one’s personal needs opened up new opportunities for women to make positive changes in their lives and to more strongly voice their needs and desires. It is particularly telling that the changes women made in their lives– taking more time for themselves and bucking their traditional roles– was a form of resistance against the traditional order. It also acted as a form of resistance against being a classic productive, efficient neoliberal subject.

This represents a hopeful new direction in the wellbeing of Austrian women with breast cancer and suggests that women can rework their suffering in order to reclaim their lives. Unfortunately, organizations like Pink Ribbon Austria say little about breast cancer survivorship issues and the actual lived experiences of women with breast cancer. These organizations could establish a better sense of solidarity and help inspire other women to make positive changes in their lives. As discussed in chapter three, the breast cancer awareness campaign in Austria has set destigmatizing the disease as one of its central goals. It is however unsuccessful in reaching this goal in part because of its failure to include women with breast cancer as a central part of its events. If the faces and voices of the women going through breast cancer were brought to the fore, there is no reason not to think that the fear surrounding the illness would begin to break down and women could gain a better sense of empowerment by following the lead of others who have been able to change their lives post diagnosis.

The following chapter looks at women's quality of life years after their initial breast cancer diagnosis. It uses standardized instruments to quantitatively assess the relationship between both the negative impact of cancer– as well as the positive– on long-term mental and physical quality of life. Aside from emphasizing the need for better and more systematic care in long-term cancer survivorship, this section demonstrates how sociocultural beliefs surrounding breast cancer can shape the personal perceptions of the illness experience, in turn impacting measures of quality of life and wellbeing.

CHAPTER SIX: AN EPIDEMIOLOGICAL VIEW OF THE LONG-TERM BREAST CANCER ILLNESS EXPERIENCE

Introduction

A breast cancer diagnoses made many women feel as though their lives had "derailed." This life disruption made them call into question the circumstances of their lives that led to the development of cancer. For some, the traditional roles of constantly putting the needs of others before their own put them at risk for developing breast cancer. Others believed that being women in an increasingly complex and fast-paced world was the cause of their cancer. Despite the strife many women had felt prior to their diagnoses, being derailed meant that they could start on a new track. In other words, a cancer diagnosis provided leverage for negotiating new social roles and instigating positive changes in their lives. At the same time, I also heard of women's experiences with stigmatization, the shock that cancer brought to their lives, and how the process of rebuilding their lives post-treatment was not always straightforward. Thus, learning to live with cancer is a complicated, continuous process.

Entering the state of remission (signifying that no cancer can be detected in the body) places people "in a foggy space between the comfortable assumptions of your old life and the uncomfortable expectations of your new life" (Stoller 2009: 35). The emotional and physical side effects of cancer do not always fade over time (Manderson 2005; Stoller 2009). For women with breast cancer, finding new terms to describe the space where the breasts used to be can be a burdensome and emotional process (Manderson 2011). People living with cancer must also come to terms with the permanent uncertainty of cancer's return (Hansen & Tjørnhøj-Thomsen 2008; Honksalo 2008). In this sense, cancer remission is a permanent liminal state (Stoller 2004). Victor Turner (1969) outlined how our lives are filled with ritualized transitional or *liminal* states in which we enter with one status or identity and emerge with a new one. A cancer diagnosis poses an interesting example of liminality because it rarely allows those affected by the disease to fully enter into a new state. The capriciousness of cancer remission is mirrored by the instability of people's sociocultural identities.

In the United States, people with cancer are given the permanent label of being a "survivor" from the moment of diagnosis until death, irrespective of the cause (Twombly 2004). The United States spearheaded cancer survivorship studies to understand the psychosocial wellbeing and the overall health and functioning of those living with cancer (Rowland et al. 2013). Cancer survivorship, particularly for breast cancer survivors, receives an incredible amount of attention both socioculturally and medically in the United States (Bell 2014; Rowland et al. 2013). In the U.S., rhetoric surrounding breast cancer survivorship outlines a new biomedical and psychosocial set of roles (Bell 2012; Klawiter 2008).

In Austria, the biomedical and sociocultural label of "survivor" is not readily ascribed to women with breast cancer.[95] Given the differences in constructions of cancer as well as the vast changes that breast cancer brought into women's lives, I set out to explore what happens to women years after their initial diagnosis. A longitudinal ethnographic study would have been the ideal method to sketch out the intricacies of

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[95] A team of biomedical personnel, social scientists, and I struggled to find a good term for "long-term survivors of breast cancer." In German, women undergoing treatment are referred to as either patients (*Patientinnen*) or women affected by breast cancer (*Brustkrebsbetroffene*). The term "survivor" (*Überlebender*) is loaded with connotations of war and the Holocaust.

dealing with breast cancer from the initial diagnosis to long-term survivorship.[96] In lieu of more extensive ethnographic work, this portion of the research used epidemiological surveys to explore the relationship between how women interpret the impact breast cancer had on their lives– both positively and negatively– and measures of physical and mental health-related quality of life.[97] Epidemiological studies are helpful for understanding the correlation between sociocultural, behavioral, and demographic factors, as well as well-accepted, standardized measures of health and wellbeing.

My central hypothesis was intuitive: Those who reported an overall negative impact of cancer would also score lower on measures of physical and mental health-related quality of life. I also hypothesized that an overall high score on the positive impact of cancer would correlate with higher measures of physical and mental-health related quality of life.

With that, I note that this is a small glimpse into the lives of long-term survivors of breast cancer, not only because of the small sample size (n=152), but also because questionnaires only offer a limited insight into a complex experience like cancer survivorship and quality of life. Quality of life itself is a psychological construct that can be critiqued for its oversimplification. The other issue is that those who survive cancer longer were often diagnosed with far less aggressive forms of breast cancer, so to speak of breast cancer survivorship is really only representative of a subgroup of those with breast cancer. Additionally, although the response rate was high (52%), it is entirely

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[96] While there is no set definition for long-term survivorship, it is generally accepted that once a cancer survivor has been disease free for at least five years, he or she is classified as a long-term survivor (Gotay & Muroka 1998).

[97] Portions of the methods and data presented in this section are also published in my Master of Public Health thesis at Emory University entitled *The Impact of Cancer and Quality of Life among Long-term Survivors of Breast Cancer in Austria*. See: http://pid.emory.edu/ark:/25593/pgppg

possible that the women who did not respond were mentally or physically worse off (or better) than those who did. I also did not explicitly consider using a comorbidity index as a potential predictor of physical and mental health-related quality of life. Despite these limitations, the findings described here point to the potential link between the ways in which women perceive their diagnosis long after the initial diagnosis and quality of life. The converse could also be true, in that current perceived quality of life could shape the way that women perceive the impact that cancer has had on their lives. In any event, it points to the need to further understand how socioculturally mediated perceptions of cancer color women's subjective quality of life.

Breast cancer mortality rates are declining, which is contributing to a burgeoning population of breast cancer survivors. There are currently an estimated 64,000 women are 'survivors' in Austria (Zielonke et al. 2014). Breast cancer survivors are often faced with an array of long-term physical health concerns such as neuropathy, lymphedema, fatigue, and sexual health issues, as well as mental health issues including depression, anxiety, fear of recurrence, and body image concerns (Ganz et al. 2008; Grunfeld et al. 2011). It is important to note that physical and mental health outcomes of long-term survivorship are affected by social support (Bloom et al. 2001), living situation and partnership status (Mols et al. 2005), sexuality issues (Park et al. 2007), socioeconomic status (Ashing-Giwa & Lim 2009), ethnicity (Ashing-Giwa et al. 2004) and fatigue level (Deimling et al. 2007).

An earlier comprehensive review of quality of life among a range of cancer survivors showed wide variation in the impact of cancer five to ten years after a diagnosis (Gotay & Muraoka 1998). This suggested that the nuances of the impact of cancer had not been well captured in more generic scales to measure quality of life as well as those scales designed for cancer survivors closer to the initial diagnosis. Thus, while there is evidence to demonstrate that cancer is a serious stressor in one's life (Culver et al. 2002), there are also data to suggest that the experience of having cancer can bring out positive changes in one's life, including personal growth, a renewed sense of purpose, positive relationship changes, and overall 'benefit finding' (Carver et al. 2004). For instance, in the U.S., cancer is often seen as a positive "journey" (Coreil et al. 2012), or as a challenge that can eventually enrich one's life.

Cancer as trauma or growth?

A host of studies have assumed a priori that cancer can be interpreted as a psychological "trauma" (see Kangas et al. 2002). There are a few key issues with filing cancer under the umbrella of trauma: First, it medicalizes a normal reaction to a life-threatening disease. That is to say, there is nothing pathological about responding to a life-threatening disease with fear. Those undergoing chemotherapy treatment for instance have to brace themselves every few weeks for another onslaught of weakness, nausea, hair loss, neuropathy, and 'chemo-brain,' or reduced memory due to chemotherapy. This represents a fear of future events, which is not the case with posttraumatic stress disorder (PTSD) (Coyne 2013). Second, PTSD has historically been fluid and the lived experience of it is intricate and often severe (Finley 2011). Feeling distressed cannot per se be equated with having PTSD. Third, there are no robust data to suggest that people with cancer suffer from PTSD or that the percentage of people with cancer who have PTSD is higher than in the average population (Greimel et al. 2013; Palmer et al. 2004).

The other side of the PTSD-cancer model is the opportunity for posttraumatic growth (PTG), which refers to the positive psychological change following a 'traumatic' event (Calhoun & Tedeschi 2006). The issue with PTG is that it first assumes that cancer is a form of trauma. Additionally, I am also cautious of conflating PTG for the restoration of emotional wellbeing. Considering the changes women have instigated in their lives, personal growth is occurring for many women shortly after their diagnosis. In fact, for many women, cancer was the catalyst that helped them to come to terms with preexisting emotional issues. That does not necessarily mean that cancer itself was traumatic, nor does it mean that women were able to maintain these changes in the long term. Thus, the findings from chapter five for instance show that breast cancer was often the end to perceived emotional distress in women's lives.

This aspect of the research seeks to build upon the results in chapter five to provide a glimpse into how the impact of cancer, both positively and negatively, affects long-term survivorship. Moreover, it offers initial insights into how the socioculturally shaped lived experiences of breast cancer impact health outcomes downstream.

Methods

Study Population: The study population consisted of women diagnosed and treated for breast cancer in the Vienna General Hospital (*Allgemeines Krankenhaus der Stadt Wien*). This facility houses a certified breast health clinic, which services women from Vienna and nearby rural municipalities. In this study, long-term survivors are defined as women who first received surgical treatment for breast cancer between 1995-2008. All women were covered by the national health insurance at the time of the surgery. It is possible that some women have an additional private insurance where they would have received additional follow-up treatments, but I could not distinguish this at the time of the study. A study nurse with access to hospital database randomly searched hospital databases for women treated for their first breast cancer diagnosis in the clinic within the chosen time frame. Within the list, she included 100 women who participated in a 2004 study comparing patient and doctor post-operative satisfaction following a mastectomy or lumpectomy. Since demographic data were collected at this time point, medical personnel had hoped to compare this sample ten years later and evaluate the relationship between certain demographic variables and recurrence and mortality rates. Unfortunately, hospital databases were often unreliable in regard to recurrence and mortality, so this portion of the research could not be assessed. This remains a future avenue for research. In total, 230 women were recruited to join the study and sent three questionnaires (described below) with a randomized study number, a letter explaining the study, and a self-addressed stamped envelope.[98] At 66% (n=152), the response rate was very high. This may represent the salience of the study to long-term survivors, and/or the excellent reputation of the study nurse who assisted with recruitment. Study participants were excluded if they had a relapse or new diagnosis at the time of being surveyed, or if they had recurrence after 2010, as this would not be classified as long-term survivorship.[99] Descriptive statistics on select independent variables are shown in table 6.1.

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[98] *Europa Donna Austria* generously donated to help cover postage for this aspect of the research.

[99] This is an arbitrary mark of long-term survivorship.

Measures: A general questionnaire gathered basic demographic (e.g. age, marital status, education), clinical (e.g. treatment received, year of diagnosis, recurrence), and behavioral health (e.g. alcohol consumption, exercise routine, attendance of a self-help group) data (see appendices G & H).

The Short-Form-36 (SF-36) scale is a standard instrument for assessing health-related quality of life (Hays et al. 1993). The SF-36 has been translated into German, validated, and widely used within the German-speaking world (Bullinger et al. 1995), including Austria (Ware 2004). The instrument consists of 36 questions in 8 different domains. These domains contribute to two meta-domains, the physical component summary (PCS) and the mental component summary (MCS). PCS contains the domains: physical functioning, pain, general health perceptions, and physical role functioning. MCS assesses vitality, emotional role functioning, social role functioning and mental health. The score for each factor ranges from 0-100, with 100 reflecting the best possible functioning and health and 0 the poorest.

The Impact of Cancer Scale (IOCv1) is a self-report instrument that measures the impact long-term survivors attribute to their experience of having cancer (Zebrack et al. 2006, 2008). The benefit of this scale is that it focuses on the long-term changes and issues incurred from the experience of having cancer, rather than just in the short-term. The IOCv1 was created out of extensive qualitative research among long-term cancer survivors in the United States, although this scale and its shortened version (IOCv2) have been used in a range of settings including Italy (Muzzatti et al. 2013), Norway (Dahl et a. 2012; Gudbergsson et al. 2007; Nesvold et al. 2011), and the Netherlands (Oerlemans et al. 2013). The IOCv2 (see appendices E & F) has also been used in cross-national studies comparing a Dutch and American sample (Oerlemans et al. 2013). The items are asked in a five-point Likert scale format ranging from strongly disagree to strongly agree. Mean scores are assessed for each domain and then aggregated into the two meta-domains including the "Positive Impact of Cancer" and the "Negative Impact of Cancer." The domains were validated using factor analysis and demonstrated good internal validity (Zebrack et al. 2006).

From the original 81-measure scale, Crespi et al. (2008) performed exploratory factor analysis, cross-validation, and psychometric evaluation to refine and shorten the scale. The IOCv2 was also examined for internal validity (Crespi et al. 2008). The IOCv2 consists of 41 measures across various subscales including: Health Awareness, Body Changes, Health Worries, Self-Evaluation, Negative Self-Evaluations, Positive Outlook, Negative Outlook, Social Life Interferences, Value of Relationships, Meaning of Cancer, Employment and Relationship Concerns. The subscales pertaining to the positive impact of cancer (PIC) are Altruism and Empathy, Health Awareness, Meaning of Cancer, and Positive Self-Evaluation, which yield a mean score with a range of 0-5. The subscales pertaining to the negative impact of cancer (NIC) were Appearance Concerns, Body Change Concerns, Life Interferences, and Worry. This also yielded a mean score from 0-5.

To the best of my knowledge, the IOCv2 had not been translated into German prior to the start of the study. I translated the questionnaire into German, had it back-translated by two scholars in the field who are fluent in English and German, and pilot tested it on five people who work in cancer care and/or have had cancer.

Analyses: The study participants (N=152) varied based on the following predictor variables: age (years), year of diagnosis, age at diagnosis (years), geographic setting (rural or urban), alcohol consumption (from seldom to daily), perceived stress level (low to high), use of complementary and alternative methods (yes or no), marital status (married/in a long-term partnership or single), salary (under €1,000; between €1,000 and up to €2,000; and €2,000 or more), use of chemotherapy (yes or no), body mass index, regular exercise (yes or no), highest level of education attained (based on the Austrian education system), and whether or not a woman believes emotional distress could have caused her cancer (yes or no). All observations were independent. Descriptive analyses of the study variables were performed for the overall sample (table 6.1). After checking the dataset for implausible values and extreme outliers, normality statistics were assessed for gross violations. In some cases, predictor variables were deemed to be slightly skewed using the Kolmogorov-Smirnov or the Shaprio-Wilk tests. However, based on acceptable levels of skewness in the social sciences (Cameron 2004) and after reviewing residual plots, only the BMI variable was log transformed. Table 6.2 summarizes the key predictor variables of interest (the positive and negative impact of cancer) and key outcome variables (physical and mental health-related quality of life) across select independent variables. The multiple comparisons drawn from t-tests, ANOVA, and Pearson correlation coefficients were exploratory and initiated the selection of select predictor variables in the multivariate analyses. Bivariate analyses were also performed through simple linear regression to assess the relationship to the outcome variables and key study predictors. Predictor variables such as stress and the negative impact of cancer were also examined as interaction terms, but none were applicable.

Variables that were significant in both bivariate analyses were considered to be potential confounders and tested in the final multiple linear regression models. Predictors that were also significant predictors of physical and mental health-related quality of life were considered for the final multiple linear regression models.[100] Regression models are useful for understanding the relationship between independent and dependent variables. In this case, it allows for an analysis of the impact of cancer on quality of life while accounting for other independent variables such as body mass index, marital status, age, and so forth. All-possible-regression analyses using all predictors was then constructed and evaluated based on adjusted-R^2, Mallow's $C(_p)$ and MSE values. Models assessing physical health-related quality of life and mental health-related quality of life were then created with all significant predictors and all potential confounders of the relationship of the impact of cancer and quality of life. Model diagnostics, including collinearity issues, were assessed on the final model by examining residual plots, partial plots of the predictors, and the variance inflation factors (VIF). Significance tests were performed at $\alpha=0.05$. Statistical analyses were performed with SAS 9.2 (SAS Institute, Cary, NC).

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[100] Model parsimony was also considered when evaluating all possible models. Since the positive and negative impact of cancer were primary predictor variables of interest, an associative manual model-building strategy was used to measure changes in the beta estimates of the predictors. Predictors that changed the direction of the beta estimates of the negative impact of cancer or positive impact of cancer or changed the estimates by more than 10% were identified as confounders. The interaction term was depicted through an interaction plot (not pictured).

Demographic, Clinical, and Behavioral Characteristics of the Study Sample

Geographic location			
Rural	55 (37%)	**Emotional distress belief**	
Urban	94 (63%)	no	55 (37%)
Occupational status		yes	94 (63%)
Full-time	32 (22%)	**Exercise 2+ per week**	
Part-time	22 (15%)	no	50 (34%)
Unemployed	4 (3%)	yes	99 (66%)
Retired	88 (60%)	**Used complementary/alternative medicine**	
Education		no	94 (65%)
No advanced high school degree	19 (13%)	yes	51 (35%)
Advanced high school degree	14 (9%)	**Perceived stress level**	
Secondary school degree	56 (38%)	seldom	63 (47%)
Professional school	42 (28%)	often	57 (43%)
University degree	18 (12%)	daily	13 (10%)
Salary (total household)		**Breast cancer recurrence**	
< €1.000	14 (10%)	no	118 (84%)
€1.001≤ €2.000	48 (36%)	yes	22 (16%)
>€2.000	73 (54%)	**Had chemotherapy**	
Marital status		no	87 (60%)
single	49 (32%)	yes	57 (40%)
Married/long-term partner	102 (68%)	**Age** (Mean)	61.25 (SD: 9.67)
BMI (Mean)	26.84 (SD: 6.10)	**Age at Diagnosis** (Mean	48.78 (SD: 8.79)

Table 6.1. Demographic, Clinical, and Behavioral Characteristics of the Study Sample

Comparing Physical and Mental Health-related Quality of Life and the Impact of Cancer across select independent variables

	Positive impact of cancer (key independent variable)	Negative impact of cancer (key independent variable)	Physical health-related quality of life (outcome variable)	Mental health-related quality of life (outcome variable)
Geographic location				
Rural	Mean (Standard Deviation): 3.49 (0.81)	2.32 (0.78)	54.09 (6.81)	47.80 (10.96)
Urban	3.53 (0.82)	2.49 (0.83)	49.98 (10.27)	47.31 (10.16)
p-value	NS	NS	0.0048	NS
Marital status				
single	3.53 (0.87)	2.45 (0.83)	50.45 (9.48)	43.78 (11.23)
Married/long-term partner	3.51 (0.80)	2.41 (0.81)	52.02 (9.20)	49.17 (9.62)
p-value	NS	NS	NS	0.0087
Chemotherapy				
no	3.50 (0.85)	2.24 (0.75)	53.32 (7.80)	48.47 (9.35)
yes	3.53 (0.79)	2.71 (0.85)	49.12 (10.36)	46.35 (11.56)
p-value	NS	0.0007	0.0125	NS
Breast cancer recurrence				
no	3.54 (0.80)	2.41(0.79)	51.94 (9.19)	47.60 (10.52)
yes	3.32 (0.96)	2.46 (0.85)	51.22 (9.58)	48.25 (8.85)
p-value	NS	NS	NS	NS
Salary (total household)				
< €1.000	3.56 (1.25)	2.56 (0.88)	48.09 (9.35)	44.77 (10.32)
€1.001≤ €2.000	3.54 (0.66)	2.50 (0.79)	49.78 (9.55)	43.31 (11.97)
>€2.000	3.49 (0.82)	2.35 (0.81)	54.08 (8.44)	50.58 (7.92)
p-value	NS	NS	0.0119	0.0004
Perceived stress level				
seldom	3.47 (0.94)	2.28 (0.71)	50.92 (9.23)	49.79 (9.16)
often	3.60 (0.67)	2.48 (0.81)	52.89 (8.86)	47.02(9.54)
daily	3.79 (0.54)	3.02 (0.74)	53.26 (7.37)	38.82 (14.34)
p-value	NS	0.0079	NS	0.0028
Used complementary/alternative medicine				

no	3.43 (0.89)	2.29 (0.81)	52.00 (8.72)	48.94 (9.36)
yes	3.64 (0.63)	2.67(0.79)	51.40 (9.91)	45.88 (11.24)
p-value	NS	0.0080	NS	NS
Emotional distress belief				
no	3.31 (0.77)	2.12 (0.72)	50.35 (9.08)	50.28 (9.78)
yes	3.65 (0.78)	2.60 (0.83)	52.07 (9.43)	46.10 (10.43)
p-value	0.0097	0.0004	NS	0.0205
Exercise 2+ per week				
no	3.42 (0.83)	2.48 (0.82)	47.30 (10.55)	45.10 (11.84)
yes	3.58 (0.77)	2.39 (0.80)	53.37 (8.03)	48.76 (9.44)
p-value	NS	NS	0.0010	NS
Education				
No advanced high school degree	3.63 (0.84)	2.58 (0.78)	50.49 (8.59)	47.35 (11.06)
Advanced high school degree	3.63 (1.13)	2.29 (0.82)	56.01 (6.02)	48.37 (7.50)
Secondary school degree	3.50 (0.80)	2.35 (0.74)	49.37(10.56)	46.33 (11.33)
Professional school	3.49 (0.81)	2.40 (0.99)	51.57(8.46)	49.90 (10.56)
University degree	3.70 (0.57)	2.68 (0.65)	55.28 (8.42)	45.99 (9.06)
p-value	NS	NS	NS	NS
Age	-0.20	-0.18	-0.31	0.014
p-value	0.016	0.026	0.0002	NS
Age (Diagnosis)	-0.16	-0.10	-0.29	-0.0035
p-value	NS	NS	0.0008	NS
Body mass index (BMI)	-0.16	-0.09	-0.36	-0.0002
p-value	NS	NS	<0.0001	NS

Table 6.2. Comparing Physical and Mental health-related Quality of Life across select independent variables. T-tests were used to compare mean values of covariates with two values (e.g. marital status); ANOVA was used when covariates had more than two values (e.g. Education). Continuous covariates (e.g. BMI, age) were assessed with Pearson correlation coefficients.

Results

Mental health-related quality of life: The mean score for mental health-related quality of life (MCS) was 47.34 (SD: 10.40), which is lower the standardized mean population score on the SF-36 (Gruber et al. 2010). Of the demographic and clinical variables, women with a spouse/partner, higher salary, lower stress level, and those who rejected the belief that emotional distress was associated with the onset of cancer reported better mental health-related quality of life (table 6.2). Bivariate analysis showed a significant correlation between the negative impact of cancer (NIC) and MCS. Current age was also retained in the model because of its correlation to both the positive and negative impact of cancer and its salience to long-term survivorship. Since the negative impact of cancer differed significantly between respondents who believed that emotional distress caused their cancer and those who did not, as well as those with higher stress loads, I chose to retain these predictor variables in the final model. Results from the all-possible-regressions strategy showed the negative impact of cancer, high stress level, and having a spouse/partner to be significant. The positive impact of cancer however was not significant, but was retained in the model because of its centrality to the research topic. In the final model, a one-unit increase in the negative impact of cancer decreased the MCS by 5.75 points (SD: 1.14; $p<0.0001$). Experiencing daily stress also lowered MCS, but having a spouse/partner was associated with increased MCS. The adjusted-R^2 for the model was 0.39 ($p <0.0001$).[101]

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[101] Variance inflation factors (VIFs) in the final model ranged from 1.06 to 1.40, which posed minimal collinearity issues.

Regression model examining the Impact of Cancer and select independent variables on Mental Health Functioning (SF-36, MCS)			
Covariate	Coefficient	Standard Error	p-value
Intercept	68.31	7.67	<.0001
Positive impact of cancer	-0.38	1.07	NS
Negative impact of cancer	-5.75	1.14	<.0001
Age (10-year intervals)	-1.15	0.92	NS
Having a spouse/partner	6.91	1.68	<.0001
Emotional distress	-2.33	1.72	NS
Stress (frequent)	-2.21	1.73	NS
Stress (daily)	-7.73	2.86	0.007
Model F Statistic	11.83		
Adjusted-R^2	0.39		
Model Significance	<.0001		

Table 6.3. Regression model examining the Impact of Cancer and select independent variables on Mental Health Functioning (SF-36, MCS)

Physical health-related quality of life: The mean score of physical health-related quality of life (PCS) (51.64, SD: 9.26) centers on the standardized mean score for population norms on the SF-36 (Gruber et al. 2010). Of the demographic and clinical variables, physical health-related quality of life was higher among women who lived in rural regions, were younger at the time of study and diagnosis, had a higher salary, did not receive chemotherapy, had a lower BMI, and exercised at least twice weekly (table 6.2). Having received chemotherapy and older age were correlated with the negative and positive impact of cancer, and were retained in the model to control for confounding. In the bivariate analysis, both the positive and negative impacts of cancer were significantly correlated with PCS. In the final model, a one-unit increase in the positive impact of cancer was associated with a rise in PCS of 2.68 points (SD: 0.82, p=0.0014), while a one-unit increase in the negative impact of cancer was associated with a decrease in PCS by 6.20 points (SD: 0.84; p<0.0001) (table 4). As expected, older age, higher BMI, and having received chemotherapy also lowered PCS. A regular exercise regime of two or more times per week was associated with increased PCS. The adjusted-R^2 for the model was 0.47 (p < 0.0001).[102]

Regression model examining the Impact of Cancer and select independent variables on Physical Health Functioning (SF-36, PCS)			
Covariate	**Coefficient**	**Standard Error**	**p-value**
Intercept	68.31	7.67	<.0001
Positive impact of cancer	2.68	0.82	0.0014
Negative impact of cancer	-6.20	0.84	<.0001
Age (10-year intervals)	-2.59	0.66	0.0001
Received chemotherapy	-2.50	1.28	0.05
Regular exercise	3.18	1.72	0.0174
BMI (log transformed)	-21.84	6.82	0.0017
Model F Statistic	19.27		
Adjusted-R^2	0.47		
Model Significance	<.0001		

Table 6.4. Regression model examining the Impact of Cancer and select independent variables on Physical Health Functioning (SF-36, PCS)

The long-term impact of breast cancer

These exploratory analyses demonstrate a relationship between the predictor variables of interest, the positive and negative impacts of cancer, as well as key sociodemographic, clinical, and behavioral independent variables and physical and

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[102] VIFs in the final model ranged from 1.05-1.33, therefore posing minimal collinearity issues.

mental health-related quality of life. These results suggest that the ways in which long-term breast cancer survivors interpret the impact of cancer in their lives, both positively and negatively, may affect physical and mental health functioning. With that, it is important to take the relationship between having a spouse/partner and high stress levels and mental health functioning into account. It is also worth noting the negative impacts of chemotherapy and higher BMI on physical health function, as these are two clinical variables that can be addressed at follow-up treatments. In contrast with other studies (Zebrack et al. 2008), the positive impact of cancer was only associated with physical health-related quality of life, not with mental health-related quality of life. Overall, this study points to the need to understand that the impact of cancer does not stop upon completion of adjuvant therapy for women with breast cancer.

It is interesting that the positive impact of cancer did not impact mental health-related quality of life. I can only speculate, but this may point to continual struggles women face to implement the positive changes they experienced shortly after diagnosis (as described in chapter five) in the long-term. The clear association of the positive impact of cancer to physical health-related quality of life is also telling of the potential of a cancer diagnosis to impact the decision to engage in more health-promoting behaviors. This was confirmed by women undergoing treatment who took up an exercise regimen or quit smoking following their diagnosis. Future studies could also examine the impact of visiting a state-sponsored *Kur* (visit to a health spa) or oncological rehabilitation center on the impact of cancer and quality of life. In addition, future studies could also focus on specific side effects of breast cancer treatment, including breast surgery/reconstruction, shoulder and arm pain, and lymphedema as they pertain to the impact of cancer and quality of life.

This cross-sectional study misses how the impact of cancer and quality of life can change over time. It also makes it impossible to know if the perceived impact of cancer has an effect on the mental and physical health-related quality of life, or if self-reported mental and physical health-related quality of life can influence the ways that survivors reflect on their experiences with breast cancer. Thus, it may be worthwhile to perform a prospective study to understand how these perspectives change over time and how the relationship to quality of life is altered. It may also be useful to consider potential clinical interventions that take seriously the perceived impact of cancer for women with breast cancer. As noted in the literature, the Impact of Cancer scale may be an applicable instrument for monitoring these effects (Muzzatti et al. 2013; Zebrack et al. 2008).

From an anthropological viewpoint, this study suggests the role that cultural constructions of cancer can play in shaping the perceptions of long-term impact of cancer, both positively and negatively. The public health and health psychology literature tends to prioritize interventions that promote cognitive reframing for long-term breast cancer survivors (see Badger et al. 2004, Mishel et al. 2005). In my previous research in the Midwestern U.S., I demonstrated how the socioculturally mediated abilities for women with breast cancer to connect with one another formally and informally contributed to the use of humor as a coping mechanism for breast cancer (Bouskill 2012). This was achieved not through direct aid of clinical interventions, but rather from simply creating a social space where women with breast cancer and long-term survivors alike could gather.

Anthropology has contributed much to understanding how people come to terms with the vicissitudes of cancer survivorship. Ethnographically informed understandings of the factors that shape cancer survivorship are key to understanding quality of life issues as women with breast cancer come to terms with the permanence of their diagnoses. The link between the negative impact of cancer and physical and mental health-related quality of life forces a critical reevaluation of the usefulness of a breast cancer awareness campaign in attending to the challenges facing long-term survivors.

As mentioned, I caution against medicalizing or pathologizing the negative impact of cancer, as this may represent a logical reaction to enduring negative changes in one's social life (e.g. embarrassment from others seeing a mastectomy scar, losing a friend over fear of breast cancer) and living with permanent uncertainty. While I do see integrated cancer survivorship care as an important goal for a health system, my experience suggests that this implementation should be accompanied by concurrent shifts in the sociocultural visibility of cancer survivors. Unfortunately, long-term survivors are currently not readily visible within the breast cancer awareness campaign in Austria. With the growing population of women living with breast cancer, it is critical to consider how culture, healthcare structures, and global phenomena like the breast cancer awareness campaign are acting upon long-term survivorship.

Conclusion

Social epidemiology assumes that diseases, including mental health and quality of life issues, are the result of complex, multilevel interpersonal, structural, and environmental interactions. Medical anthropologists inclined to establish a working dialogue and collaborative work with social epidemiologists (see Gravlee 2009; Hahn 1995; Nations 1986; Trostle 2005) act not only as ‘cultural translators,’ but also try to move beyond the sense that culture can boil down to merely a set of measureable factors.

Thus, medical anthropologists also seek to build on an understanding, assessment, and interpretation of the “locus of where culture is acting” in regard to the “individual, microsocial and macroscocial levels” within epidemiological studies (Kohrt, Hadley & Hruschka 2009: 233). This is particularly relevant to stigma, or the ontological experiences of social exclusion (Kleinman 2012). With the exception of a few choice sociodemographic variables, surveys without accompanying ethnographic work provide only partial explanations to questions of the long-term impact of cancer. In addition, medical anthropological work can continue to understand how structural health policies of cancer survivorship “influence cancer survivors’ deep-rooted norms of conduct” (Hansen & Tjørnhøj-Thomsen 2008: 375).

The ethnographic finding of the emotional distress belief for the onset of cancer illustrates the need for dialogue between medical anthropology and social epidemiology. Had I started with the assumption that cancer itself is the source of trauma, I would have missed the critical point that cancer is often a way to end preexisting ‘trauma,’ emotional distress, et cetera in women’s lives. In addition, this ethnographic research also allows for the possible interpretation that the negative impact of cancer could stem from a prolongation of the stressful or distressing factors in a woman’s life.

In order to resist a narrow view of the sociocultural and health aspects relevant to cancer survivorship, it may be worthwhile to perform a cultural consensus analysis of cancer survivorship. The concept of cultural consonance could then be applied to understand to what degree cancer survivors can approximate these cultural models (see Dressler 2001, 2005; Dressler & Bindon 2000). This would contribute not only to a culturally grounded understanding of survivorship, but it would also lead to an understanding of the factors that either enhance or diminish a survivor's ability to achieve the expected notions of breast cancer survivorship.

Despite the widespread sentiment that women with breast cancer simply would like to "put the illness behind them," this study suggests that not all have the ability to do so. This warrants a more in-depth understanding of how long-term survivors interface with their clinical care, their social worlds, and the changing sociocultural representations of breast cancer. Thus, there is a need to understand what matters to women who continue to live with side effects of breast cancer, including learning to live with the liminality of cancer survivorship and possibility of recurrence (Stoller 2009) as well as the new awareness of the body and self that can accompany a breast cancer diagnosis. The presence of the breast cancer awareness campaign could potentially serve as a catalyst for helping women reach out to one another, which could aid in more positively shaping the impact of cancer.

This aspect of the research served as the final perspective through which to view the illness experience of breast cancer and the shortcomings of the breast cancer awareness campaign. The following concluding remarks provide suggestions for improving the efforts to control breast cancer in Austria, which could have the potential to better the lives of the thousands of women confronted with breast cancer each year as well as the burgeoning population of breast cancer survivors. In addition, I offer potential avenues for medical anthropological research in order to understand the impacts of the collaboration (or collusion) of business and biomedicine in constructing women’s health.

CHAPTER SEVEN: CONCLUSIONS

In Vienna, a nearby subway stop was close a large radiology clinic. I often saw women exiting the clinic and heading home. Those walking out all carried flat orange bags containing films of test results, as it is customary to take test results with you. I knew for many, the orange bags contained results of a mammogram, and the potential to temporarily 'derail' a woman's life. I thought about how a woman's family and friends would react to her diagnosis, if she would keep her job, and if she had an aggressive form of cancer. I thought about how different her experience with breast cancer would have been thirty, forty years ago, but also how much would be exactly the same. Cancer is still a frightening, terrible disease. It still has the ability to make permanent changes to one's health, social life, and emotional wellbeing. She and her doctors still would not be able to say for sure what caused her cancer. But now, they would tailor her therapy to fit her form of breast cancer, relieving her of the burden of unnecessary and drastic treatments like the Halsted radical mastectomy. She might even be able to feel a sense of solidarity with other women who know what she is going through, that is if she feels as though she can come forward with her illness. While much has changed, there are still many improvements that can be made both biomedically and socioculturally.

Forty-four years have gone by since Richard Nixon exercised his power to declare "war on cancer" and end the wretched disease once and for all. Americans held out for the same amount of time during the Cold War, but never at any point lost over 585,000 lives in one year like those that are lost to cancer. Instead of growing discontent or demanding more political action and accountability, Americans picked up the fight themselves, donating their time and money, running, shopping, fishing, bowling, rowing, cooking and cycling all with the strong belief that a cure would be found. No longer in solely the control of the State, the softer, friendlier war is now in part waged in our shops, neighborhoods, college campuses, and community centers.

This research project began by asking first *why* the breast cancer awareness movement and the pink ribbon would, or should, be imported to Austria, a country that already seemed 'aware' of the disease, and offered far better access to healthcare than contexts like the United States. Secondly, I drew upon my previous research on the complicated relationship American women with breast cancer have to the campaign in order to ask what the consequences could be of spreading a very American approach to cancer into a new context. As much as ending cancer is a common global goal, the forces behind cancer control are rarely neutral or unbiased. The uniform spread of the pink ribbon to represent global experiences of breast cancer can in effect be used as a lens through which to view difference and heterogeneity in global cancer experiences.

In her critical work on the rise of cause marketing for breast cancer, Samantha King (2006) traces the shift from the top-down approach to controlling cancer to more dispersed efforts whereby the "war on cancer" is fought on public and private terrain. Participation in awareness campaigns through purchasing products or participating in a 5k race and so forth, is more than a means to an end, she notes. Instead, it is a method of producing citizens who can uphold the increasingly privatized public sphere under the auspices of civil engagement (King 2010). These insights are indebted to Nikolas Rose's *Powers of Freedom: Reframing Political Thought* (1999), in which Rose demonstrates how the once hegemonic role of the state has been transformed into complex web of state and non-state powers. Rose writes:

> "State institutions certainly extend the scope of their operations and the depth of their penetration into the lives of their citizen subject. But they do so by a complex set of strategies, utilizing and encouraging the new positive knowledges of economy, sociality and the moral order, and harnessing already existing micro-field of power in order to link their governmental objectives with activities and events far distant in space and time." (1999: 18).

The expansion of neoliberal practice has also led to the rise of the new tactics in public health, whereby individuals are expected to have responsibility to care for their bodies and take on as much preventive action as possible, all while maintaining the ability to work and consume (Peterson & Lupton 1996). Critical to the globalization of public health campaigns is the assumption that individuals are now "global citizens with a global world-view" who adopt neoliberal practices of consumption (Peterson & Lupton 1996: 99). Cause marketing for breast cancer links back to this idea of personal responsibility to ensuring one's health within the new public health. If products are sold in the name of fighting cancer, then it would follow that purchasing more and more of them is considered a moral action and part of personal responsibility. In other words, the 'rational' transformation of activists to consumers is part of the interconnected global economy characterizing modern society.

In this dissertation, I show an example of where the "tenacious assumptions" (Gordon 1998) of this complex web of corporate and state interests, the conflation of health with beauty, and biomedicine and public health have been stretched too far. By ignoring the lived realities of breast cancer and the gender dimensions of daily life, as well as failing to create a sense of solidarity, the campaign has only had limited success.

This case study also illustrates the effects of increasing privatization and the transitions to a post-welfare state in Austria. Pink Ribbon Austria's goal of providing financial assistance for impoverished women with breast cancer is an example of a transfer of responsibility from the state to the private realm where consumers take up the task to help women with breast cancer in need. Anthropologists can draw from this example to interrogate the processes of privatization across welfare states and the ways it is obscuring problems like poverty, inequality, and unequal access to health resources.

I tried to push the existing scholarship further with an example of how the neoliberal underpinnings of the global breast cancer awareness campaign are failing to take hold, and how people are speaking out against it. I started with the premise that bringing the campaign to Austria was suspect for three main reasons: The situation of cancer care and survival from breast cancer in Austria is on a global- and even EU-level quite good. Secondly, a community of women with breast cancer did not spur the importation of the campaign, meaning there were likely other motives behind the global flow of the campaign. Lastly, as discussed in chapter two, the central tenets of the campaign, including speaking openly about cancer, being cheerfully optimistic and hopeful, and taking on new sociocultural identity of a 'survivor' were discordant with Austrian constructions of cancer.

In chapter three, I showed how the sexualized images, exclusivity of the events, and the questionable high operating costs of Pink Ribbon Austria are counteracting efforts to establish solidarity with women with breast cancer and to instigate real change in improving care for breast cancer. At the same time, Pink Ribbon Austria is not purporting that it will find a cure for cancer, but rather that it will be present to help women with breast cancer until a cure can be found. Figure 7.1 shows how the campaign directly states that its donations are used to 'help breast cancer patients.' Certainly there are merits to the campaign, including the fact that collects funds to help women with breast cancer. However, the methods and modes with which it achieves these goals is not entirely sound for the reasons outlined in this dissertation. In other words, the campaign could be conducted to create a better and broader impact, but for the time being it is better than nothing.

However, a bigger issue is the unnecessary grief the campaign images and messages of personal responsibility for controlling breast cancer caused. While one staff member at Pink Ribbon Austria lamented the highly sexualized nude models as the face of the campaign, she mentioned that it was the image mandated by "corporate" for that year, and she hoped that "corporate" might consider a friendlier image for the following years. The need to use the globalized image designed by marketing experts in Manhattan skyscrapers illustrates the tradeoffs when ascribing to a neoliberal paradigm of public health campaigns. In contrast to previous years, the 2014 image of the breast cancer awareness campaign featured a white father and daughter in judge's robes, an Asian grandmother, mother and daughter, a black mother with her son and daughter, and a heterosexual white couple in business clothes embracing one another (figure 7.2). It is a marked improvement from the four nude supermodels touching each other, but it is still a group of remarkably attractive, normative, wealthy (note the jewelry) people with full heads of hair. Obviously one can be poor, unattractive, or non-hetero-normative and get breast cancer too. Lastly, the use of English and promotion of the "Pink Ribbon *Family*" makes clear that the awareness campaign is coming from outside of Austria. Austrians have an ambivalent relationship to Americanization, and rightfully so (Larkey 1999; Thurnher 2004). The American version of "turbo-capitalism" was said to bring hedonism, decadence, and superficiality to Austria (Bischof 2003: 6). It could simply be that women find the American ‘survivor’ identity superficial, and I cannot blame skeptics for wanting to resist the McDonald’s-like spread of breast cancer awareness. In addition, privileging the chic, cosmopolitan, global Austrian woman who can identify with the campaign (or maybe has seen pink ribbons on trip to the U.S.) over the average Austrian woman is also likely working to create a sense of exclusion. If women with cancer are expressing that they would like to take part in these events, but that the events are simply not part of “their world,” just whose world is it? Who has a right to determine the discourse and actions surrounding breast cancer in the public realm?

Figure 7.1: Donation box at the Vienna International Airport promoting support for breast cancer patients.

In chapter four, I described how misleading notions of breast cancer risk and control over breast cancer are disseminated through informational sessions. I drew upon scholarship on the creation of the “risk role” within biomedicine and the new public health, through which control over complex diseases like breast cancer are promoted as personal responsibility. I argue that this risk role for cancer in part relates to the fact that the etiology of breast cancer is poorly understood. Using data from surveys among 137 Austrian women without breast cancer, I also showed how women are to some degree misinformed in regard to breast cancer risk and the purpose of mammography, and offered some reasons as to why women might have been misled. I furthermore drew from interviews among women with breast cancer to show that the emphasis on controlling risk within information sessions and media reports is creating unnecessary feelings of guilt for "not having done enough" to prevent cancer. Understandably, such sentiments can lead to alienation and shame. Sustaining an awareness campaign while alienating the community of suffering it seeks to aid, not only through financial donations but also through destigmatization, is one way to diminish the impact of the campaign.

Figure 7.2: The 2014 Breast Cancer Awareness Campaign poster, as seen in Zell am See near Salzburg. It reads, "Let's defeat breast cancer. We're strong together. Read our story. Tells us yours." The poster is next to a radio advertisement.

In chapters five and six, I focused on the immediate and long-term experience of having breast cancer. The interviews among women currently undergoing neoadjuvant or adjuvant therapy centered on the experiential and interpersonal aspects of having breast cancer. I strived to show that the campaign does little to speak to the lived reality of having breast cancer, especially for the many who see their illness as the result of emotional distress and the accumulation of stressful burdens in their lives. I also mentioned the multiple failed attempts in biomedical and epidemiological studies to establish a link between emotional distress, personality type, and chronic stress on breast cancer risk, although admittedly such studies are not without significant methodological hurdles. Since emotional distress is a meaningful aspect of how a woman makes sense of her disease, it is important that biomedical personnel do not automatically dismiss it (see Kleinman 1988; Kleinman & Benson 2006). However, I caution against the misuse of this practice and suggest that practitioners resist medicalizing emotional distress. In chapter six, I looked at how the perceived impact of cancer (both positive and negative) can impact physical and mental health-related quality of life in long-term breast cancer survivors. The fact that a negative perceived impact of cancer impacts both aspects of quality of life is not unique to Austria. This does however emphasize the need to bolster care and consideration for the needs of long-term cancer survivors. Furthermore, it urges those who are more biomedically inclined to understand that even in the long term, there are patterns to how people respond a cancer diagnosis; in other words, how each person comes to terms with cancer may be an individual experience, but it is likely shaped by the broader sociocultural context. The breast cancer awareness campaign could potentially aid here in giving a voice to the growing population of long-term survivors, but this has yet to be realized.

There is no doubt that this dissertation levies strong critique against the globalization of the breast cancer awareness campaign. Some of the political-economic dimensions of the corporatization of breast cancer awareness and the medicalization of women's lives warrant such critique. However, had I heard positive responses or seen what a positive impact the inclusion of the campaign has had on the lives of women with breast cancer– if I could stand behind the 'information' disseminated as an anthropologist, an epidemiologist, and a woman just as much at risk for breast cancer as most– I would have tempered this critique. My goal was not just to critique the globalization of cause marketing for breast cancer, but also to give a voice to those living with the illness. With that, many of the quotes from the women who took part in this study speak for themselves. Despite my critique, it is beneficial to try and establish a dialogue in order to improve the current situation of the campaign. The following section offers some potential inroads for bettering the experience of having cancer and revamping the campaign to meet women's needs.

Recommendations

Not surprisingly, it would be impossible to make a sweeping statement about the lived experience of breast cancer. To do so would be neglectful of the complexity of biomedical, sociocultural, and individual factors governing how a woman lives out her illness. That being said, there are some general patterns that have crystallized out of this research which could lead to improvements in the psychosocial wellbeing of those affected by the disease. Some would arguably be difficult to implement, but I still find them to be worth mentioning. To be clear, these recommendations do not attend to the startling inequalities in cancer care in a global sense. That advocates in the developed world lobby for psycho-oncologists, dieticians, and clinical study nurses in each cancer ward while those in the developing world struggle to obtain even palliative pain medication is a tragedy. For the time being, I will reserve that issue for a future research initiative.

1.) *Think critically about what kind of message 'beautifying' breast cancer and creating exclusive events in the name of awareness sends.*

I have never been diagnosed with breast cancer, but to think of seeing an image of a thin, sexy, young supermodel with voluptuous breasts and vibrant hair precisely at the time when I might be in danger of losing both of those traits of my femininity would not only be alienating, but infuriating. To beautify breast cancer with a narrowly defined trope of aesthetic beauty and sex appeal contributes to women's suffering. Furthermore, to place advertisements and products on busy shopping streets with similar advertisements for fashion or cosmetics places the campaign squarely in the superficial consumer world (figure 3.5 for the comparison to the lingerie advertisement). This may lead to temporary gains in profits, but in the long run, failure to connect with people on a personal level and/or continually putting something as serious as cancer in the realm of makeup and jewelry, makes a campaign unsustainable.

2.) *Widen the definition of advocacy and 'awareness' to include building a sense of community and solidarity.*

This goal would likely be facilitated through a deeper connection and active participation on the part of women with breast cancer as well as from the community, not by having VIPs parties for breast cancer show up in local celebrity news. While having celebrity involvement is likely necessary for initial recognition, it is important that everyone can take part in the events.

I would also like to note that I do believe that those associated with the campaign truly do want women with breast cancer to be disabused of stigma in the sense that they do not feel the need to hide their illness. I believe the sentiments of the campaign worker who wants to see women walk around in public without a wig are genuine. I doubt, however, that this goal could ever be achieved by throwing private parties with presumably healthy, attractive, and wealthy people. In response to the high-society galas, an oncologist said to me, “I think they have all these fundraisers so they can fund more fundraising parties” (keep in mind, there were no donations passed around at the one Pink Ribbon Austria gala I attended and there was no cost to the ticket). In his opinion, the galas had become so lavish and costly that they were no longer about helping women with breast cancer.

In February 2015, the newly appointed Minister of Health, Sabine Oberhauser, was diagnosed with cancer. Like Barbara Prammer (mentioned in chapter two), Oberhauser publicly came forth with her diagnosis. However, Oberhauser took her efforts to destigmatize cancer one step further by appearing in the media without a wig or headscarf after losing her hair. She reported that her inspiration actually came from watching the popular American television series *Sex in the City* (*Kurier*, February 24th, 2015). One of the main characters, Samantha, was diagnosed with breast cancer after scheduling an appointment for breast augmentation. As famous PR representative and “survivor,” Samantha holds a speech in front of hundreds of other survivors at a breast cancer fundraiser. Sweating and uncomfortable, Samantha removes her blonde wig at the podium. The women in the audience responded with wild applause and began to remove their wigs too. By constantly appearing in the media and the Ministry of Health with chemotherapy-related alopecia, Oberhauser’s message was to encourage other people with cancer to also show the signs of their illness without shame and to stay ahead of the rumors of her diagnosis. It is too early to know if Oberhauser’s bold disclosure will have ripple effects into Austrian society; however, it is highly likely that her actions are more powerful than a few beautiful and healthy *Promis* performing a waltzing ‘flashmob’ on behalf of those with cancer. Oberhauser is speaking *with* those with cancer, not for them– and her firsthand experience is a critical first step to empowering those with cancer.

In the social epidemiological portion of this work, women responded on average affirmatively to a question on if they feel a connection to other people with cancer. Although I may critique the aspect of community cancer events in the U.S. like 5K runs or bicycle rides for their emphasis on finding an elusive cure for cancer, they can have great power in building a sense of community and the feeling that one is not alone in facing a cancer diagnosis.

With that, it is important that campaigns do not discount the impact of a few hundred people from the community in favor of one or two corporate sponsors. In other words, a cancer awareness campaign should focus on community-building through engagement with local people instead of simply accepting a donation from the biggest sponsor. This is perhaps why cancer awareness campaigns in the United States have such a rich power to galvanize communities under their rallying cries. Case in point, the event coordinator of one of the biggest community cancer fundraising events for a cancer institution in the U.S. reported that she would absolutely turn down a donation from a global pharmaceutical industry, even if it doubled or tripled the top donations from a local corporate sponsor. "People would see right through it if 'pharma' ran the show. They'd stop coming to the event. It's all about building a sense of community. It's about showing them what their donations can do right here in town." She noted that out of the $4.4 million raised at the 2014 event, only $250,000 came from corporate sponsorships, most of which were grocery stores, car dealerships, and local IT companies. Hence, having thousands of people donate even little sums can have extraordinary results. More importantly, it can unite people from all backgrounds in caring about those with cancer, remembering those who have passed away, and supporting those who continue to survive.

3. *Take a harder stance against* eminence-*based medicine and conflicts of interest in health policy decision-making.*

To preface, I am mindful of the skepticism of some anthropologists and social scientists have in regard to labeling numbers and statistics as evidence, given the fact that unsubstantiated figures are often used to support private interests. I recognize this concern, but I also recognize the value statistics from unbiased sources as a means of documenting health outcomes, as well best practice within public health and biomedicine. It is a win for patients every time a biomedical practitioner or health policy maker decides in favor of rigorously tested evidence-based strategies instead of personal experience or financial interest. Biomedical practitioners, especially oncologists, hold an immense amount of social capital in Austria, which of course can be easily abused. Furthermore, the healthcare system institutes dealing with public health interventions are highly controlled by political parties and the Austrian Chamber of Medical Doctors. Clearly there are cases such as the latest evidence on mammographic screening that simply do not work in favor of radiologists' interests. The fact that radiologists win out in that debate over how to conduct mammographic screening is a potential loss for women's health. Traditional Austrian doctors or "demigods in white" use their prestige to emphatically and emotionally bring across their motives and recommendations; in comparison, the younger, evidence-based practitioners who rely on international double blind randomized control trials for their 'best practice' come across as cool and dispassionate. In public health planning meetings, like those leading to the implementation of the universal screening program, the enthusiasm of "demigods in white" for "protecting women with annual mammograms starting at age 40" seemed to be much more in women's best interest than the evidence-based practitioners arguing in favor of starting mammograms later and performing them less frequently. Evidence-based medicine should not be a trend in biomedical research; it should be part and parcel to its core. Put succinctly, it is deeply troubling that the term evidence-based medicine is not a redundancy. In other words, the practice of biomedicine should all be governed by evidence and not opinion.

One potential solution would be mandating continuing education for doctors so that they can keep up with the rapidly changing state-of-the-art in biomedicine and epidemiology. If that does not work, another option would be instituting trials with one arm for the *eminence*-based strategy and one for the evidence-based strategy. The trial could compare outcomes and cost-effectiveness of the strategies, which could then dictate health policy decision-making.

There is also a dearth of basic science research and far too much reliance on the pharmaceutical industry. In fact, Austria has one of the lowest public spending amounts for cancer research in the EU (Eckhouse & Sullivan 2006). This should be revised and more funds should be given to public health and social epidemiological research. This way, in addition to promoting better public health measures, the social and cultural factors that shape the burden of disease could be more systematically understood and addressed.

4.) *Be upfront about the limitations of mammographic screening.*

Many women think that they owe their lives to getting screened regularly for breast cancer. This is not always the truth, although the worst offenders of *eminence*-based medicine like to promote it as such. I mentioned the limited benefits and clear drawbacks of mammographic screening throughout the dissertation. To be clear, I am not against mammographic screening; I am against it being prescribed to women with no prior risk factors before the age of 50 and doctors making claims about mammograms that are not true. For instance, doctors should by all means refrain from stating that women should get a mammogram because “breast cancer caught in its early stages is curable.” A subset of breast cancers is highly treatable, but there is no cure for breast cancer. There are forms of breast cancer, particularly hormone receptor-negative breast cancers and so-called triple negative breast cancer, for which treatment is currently limited. Furthermore, the pharmaceutical industry is reluctant to invest in drug development for this patient subgroup because of the aggressiveness and “potential for poor follow-up” due to death. It essentially makes little difference if a triple negative tumor is found asymptomatically or symptomatically, and it is unfair to these women to hear that uniformly “catching tumors early can save lives.” I am not arguing against mammographic screening, but there ought to be more whistleblowing on those disseminating false information about it.

5.) *Continue to make quality-certified breast health centers the standard care and follow through with the goal of having all women with breast cancer treated in a certified center.*

To date, twenty centers in Austria are certified based on international quality standards. Many of these centers have had their certification renewed since 2014. However, many of these centers are in urban areas, leaving women in rural regions without close access to the best possible care. Worse, the cultural dimensions of doctor prestige, or “the demigods in white,” made some rural women I interviewed apprehensive to seek care in a certified center. This is problematic and can lead to unnecessary or poorer treatment. Unfortunately, such topics have not reached the public enough to empower those facing a cancer diagnosis to even know to ask to be treated in a quality-certified center.

6.) *Make applying for financial assistance easier for women with breast cancer to locate*.

There is a bureaucratic process to ensure that those who receive aid are truly in need. This is of course necessary. However, if a woman learns that financial assistance for women in need is Pink Ribbon Austria's flagship project, she may find it difficult to locate a link on the campaign's website. Currently, someone would have to know to click on a small icon in the corner of the webpage, linking them back to the Austrian Cancer Society website, where they would have to navigate it back to financial assistance. The website as a whole is dedicated to displaying the funds raised, photographs of VIP-events, pink ribbon products, and two brochures on women and cancer and breast cancer. However, if financial assistance is an important part of the campaign, it should take a more prominent place on the website. This would not only improve the accountability and trustworthiness of the organization, but would make it easier for those in need to receive aid.

7.) *Expand women's health to be more than mammograms and breast cancer.*

Women's health in Austria could use an overhaul. With all of the publicity surrounding breast cancer, it is easy to see how other health issues affecting women are overshadowed. The fact that 62% (n=85) of the sample of women ‘at-risk’ for breast cancer thought more women die of breast cancer than heart disease is not unique to Austria, but it is troubling, especially because smoking rates among Austrian women are some of the highest in the European Union (OECD Report 2014). Women smoke for different reasons and have different vulnerability to tobacco smoke (WHO 2010). Making gender-centered and ethnographically informed interventions would be an advantage before the sequelae of tobacco-related health problems take hold. This is not to say that putting emphasis on breast cancer is not important; however, to make it the overwhelming focus at the expense of other major health issues is to do a disservice to public health.

Directions in Medical Anthropology

The political economics of sociocultural representations of illness

The spread of the pink ribbon has not stopped with Europe. In fact, many public-private ‘partnerships’ have already brought the pink ribbon to sub-Saharan Africa, China, and all far corners of the earth. I write partnerships in scare quotes because the power dynamic within these connections is neither equal nor neutral. Medical anthropologists are well positioned to understand the structural dimensions behind the introduction of new sociocultural representations of breast cancer. There is a need to continue research on the subject at the intersections of the neoliberal business practices of multinational corporations, biomedical practice, and public health.

Psychologist Michael Murray traced some of the common ground between social representations of illness and narrative theory (2010, see also Winskell et al. 2011). He argues that through narrative, communities both create social representations while drawing from an existing collective one. I argue that medical anthropologists can push this further by looking at the political-economic dimensions of ownership of sociocultural representations of disease. These can include interrogating the interests and motivations behind these representations, what impact they have the illness experience, and most importantly, what they obscure in regard to the health needs of those afflicted with the illness. In this case, multinational corporations and bureaucratic offices constructed novel sociocultural representations of breast cancer in Austria while leaving the "community of suffering" it aimed to help out of the equation. In addition, anthropologists can understand the constraints in how people are able to speak about their illness and speak back to sociocultural representations of illness. This became particularly clear to me from the ways women hesitated and constantly added qualifiers to their personal narratives of illness. Thus, it is critical to understand the tensions between sociocultural representations of illness (and who is pulling the strings behind them) and the constraints behind the formation and expression of an illness narrative.

Incorporating constructions of cancer to social epidemiology

Understanding the interplay between these sociocultural representations can help guide work in social epidemiology, as was the case with the portion of this study on long-term survivorship. Anthropologists willing to work in interdisciplinary settings can make for better-designed questionnaires and interview guides for social epidemiologists looking to understand how breast cancer is experienced across social gradients and cultural beliefs. But it is not about just adding a monolithic version of culture (i.e. 'add culture and stir'); rather, anthropologists contribute concepts such as cultural models, or a "constellation of beliefs, values, and norms that pertain to a particular domain of activity," which can be empirically assessed (Dressler 2001, 2005; Kohrt, Hadley & Hrushka 2009: 230). These cultural models can influence health outcomes, change over time, and vary between contexts (Hrushka & Hadley 2008). Hence, more than cultural 'translators,' anthropologists are an integral part to building the scope and models of studying complex health issues like cancer. As the global burden of cancer rises, collaborative work between the two disciplines that incorporates macro and microsocial factors will be essential.

Merging neoliberalism, biomedicine, and public health

The edited volume *Confronting Cancer: Metaphors, Advocacy, and Anthropology* (McMullin & Weiner, eds. 2009) depicts the intersection of cultural understandings of cancer and biomedicine. McMullin and Weiner note the power dynamics at hand in "the subordination of cultural knowledges of cancer to the cultural knowledge of biomedicine" (2009:18). Medical anthropologists are well positioned to study other forms of power, such as global capitalism, that shape the experience of having cancer (see Karakasidou 2009). With that, anthropologists should continue to critically examine biomedicine's increasing partnerships with multinational corporations, including the pharmaceutical industry and the cosmetics industry, among others. The playing field within public-private partnerships is never level. Medical anthropology can attend to the overt and subtle ways in which power dynamics are enacted within the so-called 'partnerships.' Perhaps more meaningfully, the experience-near accounts of medical anthropology can document how these power dynamics impact the ways in which people learn to live and cope with cancer.

McMullin & Weiner's edited volume also drives home the point that studying cancer has the potential to teach us about difference. In this case, the homogenous branding of the pink ribbon as a means of representing breast cancer only made the differences in global breast cancer illness experiences more glaringly apparent. Anthropologists need to examine these differences, not just because they are "an intimate and valuable part of life," but because they have the power to reveal inequalities and social arrangements that could have potentially gone unnoticed (McMullin & Weiner 2009: 24). Furthermore, they can illuminate the ways that people speak back to outside forces that influence the cancer illness experience. In this case, it was not just about rejecting the sexualized images of the campaign or seeing it as a part of the "VIP-world." Instead, it was about vocalizing the profound connection women drew between their roles as women and breast cancer. Witnessing the unfolding of the global, homogenous breast cancer awareness campaign without creating an authentic sense of community or local representation was like the *Wizard of Oz's* 'Toto' pulling back the curtain on the neoliberal wizard. People simply could not buy into it. It is however important to reiterate that this was not due to lack of interest, as I heard from multiple women that they would like to have a presence at campaign-related events. They did not know how to participate, had tried and did not feel as though they were taken seriously, or simply were not permitted to take part.

Anthropologists working within public health have critiqued the tendency of public health intervention and policy planners, who have a tendency to focus on changing culture instead of tailoring the intervention to be culturally compatible (Erwin et al. 2010). The spread of the breast cancer awareness campaign through the branding of the pink ribbon is not a case of myopia within public health. It is a strategic, lucrative, unbounded tool that has been crafted by marketing masterminds to combine private interests with a public health message. Hence, the globalization and commercialization of women's health within these campaigns is a critical avenue for research within medical anthropology. It is the duty of anthropologists *in* and *of* public health to illuminate how these dynamics are playing out within program planning and implementation, and how women are affected on the ground.

Medical anthropology should look at what the overwhelming emphasis on breast cancer in North American and European countries obscures in regard to women (and men's) health. Noting similar mortality rates for prostate and breast cancer, Jeannine Coreil et al. (2001) state that the overall heightened preoccupation with breast cancer can be directly tied with the American cultural preoccupation with the female body as a sex object. The authors note further that the broader gender culture of Western nations is that women's issues, particularly breast cancer and other health issues, are viewed in a sympathetic light where women are passive victims "living out their lives at the mercy of outside influences" (Coreil, Bryant, & Henderson 2001:109). We must be critical of this notion because it portrays women to be passive and in need of outside care. This makes breast cancer a vulnerable target for cause marketing, and issues like *pinkwashing* and sexualization of breast cancer that come along with it. In other words, the male gaze and privileging of women's sexuality removes attention and resources from other forms of cancer (Bell 2014).

Masking death and social death within the neoliberal paradigm

Another major theme to consider within the neoliberal paradigm as it pertains to health is the blatant neglect of death. I mentioned briefly that the campaign is an insulting far cry from the harsh reality of premature death affecting many (particularly young) women with breast cancer. The overemphasis on self-responsibility over cancer risk when there is neither a cure nor effective therapies for many forms of cancer is one of the greatest wrongs of this latest bent in public health and biomedicine. In the Austrian context, the voices of those with metastatic breast cancer were effectively silenced within the breast cancer awareness campaign and its messages of prevention, early detection and hope. Again, anthropologists can leverage their experience-near ethnographic approaches to give a voice to this form of suffering, and all else that is hidden behind the smoke and mirrors of the neoliberal paradigm of health.

The issue of shutting out death is a different form of stigma in and of itself. In many ways, the stigmatization of breast cancer within both Austria and the United States has vastly improved within the last few decades. Based on study participants' reactions, this transformation may have been even more pronounced in Austria within the last twenty years. Nevertheless, negative social interactions following a diagnosis, the loss of friendships, and discrimination at work are all forms of stigmatization that remain a harsh reality for women with breast cancer. Arthur Kleinman's (2012) emphasis on focusing on the ontology of stigma is useful for giving more nuance to the persistence of interpersonal issues women face following a diagnosis. Shedding light on these problems can also be a means of showing the limited benefits to the widespread presence of the pink ribbon. Although Kleinman's charge was intended for studies of mental health issues, applications to a wider range of illnesses, including cancer, may prove useful. I use the stigma concept throughout this dissertation as means of accessing the exclusion some women endure, although I acknowledge its oversimplification of the lived experience of social death (i.e. avoidance, self-isolation). I tried to give attention to how women feel as though they have to hide their illnesses, including the subtle ways that having breast cancer can negatively impact regular social interactions. I also tried to move beyond stigma to show that many women who experienced emotional distress from their multiple roles as women were able to instigate meaningful changes in their lives. Thus, this work demonstrates the importance of looking at the multiple facets of social changes following a diagnosis, including what these changes may enable in a person's life.

Rethinking uncertainty in the anthropology of cancer

In January 2015, *Science* published new findings to show that genetic mutations that lead to oncogenesis, the creation of cancerous cells in the body, are to a large extent random (Tomasetti & Vogelstein 2015). Tissues that require more cell divisions to maintain homeostasis (normal function) are more likely to produce random mutations that lead to the onset of cancer. These data suggest that up to two-thirds of cancer are due to "bad luck" mutations (*ibid*.). Reactions to the article in the popular press were explosive. After so much of the 'fight' and 'hope' for the cure and the public health rhetoric of prevention, boiling the onset of cancer down to just bad luck is incomprehensible to people. Both public health officials and lay alike simply could not accept the near lack of control we have in the onset of cancer. After all, sending the message “make good choices for your breast health” is much more compelling than “accept the inevitable: it’s just bad luck.” If these findings are replicated, public health will have to critically reexamine its discourse of risk and prevention.

Although these findings are brand new, they may point to potential novel directions within the anthropology of uncertainty and the anthropology of cancer. Much of the anthropology of cancer has centered on the process of meaning-making and the search for answers behind the question, “Why me?” If “bad luck” were to becomes the dominant paradigm of understanding oncogenesis, the process of substituting meaning for a lack thereof would provide new ways of considering cancer-related suffering and how people interpret and live with their illness.

Anthropologists have outlined how culture is embedded within notions of risk, including the categories used to label risky people, contexts, or behaviors (Douglas 2013 [1992]; Lupton 2013 [1999]). Boholm (2003) outlined a broader paradigm of risk by arguing for the contextualization of risk within power dynamics, trust in science and biomedicine, relationships, and underlying cognitive mechanisms. Cancer is a particular case that requires its own line of risk research for its defiance of the boundaries between self and other and the internal and the external, as well as its highly charged cultural meanings. Anthropology is also well positioned to not only critique the persistent rhetoric of cancer as a largely preventable disease, but also the stakeholders who benefit from the promotion of these misleading messages.

Concluding Thoughts

The next era of breast cancer treatment will likely include novel technologies in genetics, pharmaceuticals, and screening. At the same time, the burden of breast cancer is predicted to increase around the world (Kaiser & Bouskill 2013; Porter 2008). Breast cancer will continue to be 'big business' and there be multiple inroads for the insertion of private interest (or 'public-private partnerships'). It will be critical to understand how biomedical constructs get construed as facts and how the web of industry, biomedicine, and the infusion of neoliberal practice on daily life compromise women's health. This dissertation showed some of the encouraging ways women with breast cancer are able to speak back against the dominant discourse of the campaign, and it is important that anthropologists ground such resistance in ways meaningful to those with cancer. Lastly, with the campaign showing no signs of stopping, we will need to critically make clear the consequences of merging business and women's health, particularly in more vulnerable populations where quality care for cancer is desperately needed.

APPENDIX

A. Ethnographic Methods

From September 2012-August 2014, I conducted 18 months of ethnographic and social epidemiological research. The study utilized mixed methods from six sources of data in order to strengthen data validation and trustworthiness (Gioia 2004). These methods also enabled me to look at breast cancer awareness from multiple vantage points. The Emory University Institutional Review Board as well as the Medical University of Vienna Ethics Commission approved the research protocol.

1.) Participant Observation in Vienna: In order to gain an in-depth description of the enactment of the breast cancer awareness campaign, I performed participant observation at local breast cancer events, in the neighborhoods of the study participants, including popular shopping areas where pink ribbons are generally found, and public gathering spaces where various advertisements and campaigns are publicized. When possible, I conversed with others, including shoppers, store clerks, and Pink Ribbon Austria event organizers.

2.) Content Analysis of the Print Media: Media representations of disease are shown to influence public perceptions of disease (Corbett & Mori 1999; Young et al. 2008). Throughout the fieldwork period, I performed a systematic, close reading of the popular press for depictions of breast cancer, including daily newspapers of varied readership (*Kronen Zeitung*, *Die Presse*, *Der Standard*), the weekly news magazine *News,* and a monthly magazine (*Woman*) for representations of the breast cancer awareness campaign.

I opportunistically searched for other forms of print media when possible. I recorded and organized relevant articles by themes including prevention, screening, stigma, et cetera.

3.) Survey on knowledge of breast cancer risk and screening: I began the first phase of research by administering a short survey (see appendix A) to 137 Austrian women without breast cancer in order to gather basic data on women's understanding of breast cancer epidemiology in Austria, perceptions of risk for the disease, familiarity with the pink ribbon, and opinions and behaviors in regard to mammographic screening. When possible, I spoke with women informally after to gather more information on perceptions of breast cancer among women without the disease. I also offered to explain the correct answers to the true or false questions on the survey at a woman's request.

4.) Participant observation and informal interviews in breast care clinic and rural regions: Participant observation at the Vienna General Hospital provided insight into patient interactions and interactions with medical personnel, and the general atmosphere of the hospital setting. My frequent presence at the hospital also helped build trust and rapport with the study participants and biomedical personnel (Schensul et al. 1999). I also engaged five oncologists and ten nurses in conversation regarding treatment for women with breast cancer and perceptions of their own constraints in providing treatment.

In addition, I spent six weeks in total in rural Alpine villages working alongside women in their homes and mountainous land. I worked for room and board, as well the opportunity to have informal conversations with women to gain insights into their lives, their work, and their views on breast cancer. I was unable to record these conversations due to their impromptu nature, but I recorded field notes as soon as possible.

4.) Narrative interviews: Illness narratives are a methodological and theoretical means of revealing the explanatory models, or reasons for one's afflictions, and also of understanding how meaning is made and communicated from the experience of having a disease (Hunt 1998; Kleinman 1988; Matheison & Stam 1995). Illness narratives are contextually, historically and linguistically shaped, and often differ from that of the biomedical view (Kleinman 1988; Garro & Mattingly 2000). They capture the inherent negotiations of illness experience and social representations of illness (Lazlo 1997), and have been shown as an effective means with which women can assert their ideological conformity or nonconformity to broader sociocultural representations of illness (Murray 2002).

With the generous help of the head study nurse, I came to the clinic during open hours. The study nurse asked patients if they would like to join the study and provided them with informational material about the purpose of the study and a consent form. The interviews were designed as semi-structured and narrative-based, meaning that I came prepared with an interview guide, but let women elaborate on particular themes they found salient and allowed them to create their own narrative, or story, of their experience. I conducted 54 interviews in total, which I organized into three age groups (ages ≤ 45, 45 ≤ 60, and 60≤).[103] Interviews lasted between 30 minutes and 4 hours, at times continuing sporadically over a few days or weeks.

A note on narrative interviews: Narratives, or how people speak to their illness, are much more than a personal story of one's illness. Instead, narratives are deeply embedded within social institutions, cultural norms, and to a large degree, sociocultural

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[103] Although I originally wanted to employ quota sampling to achieve three equal groups of fifteen women (Bernard 2014; Gravlee 2011; Pelto & Pelto 1978), recruitment of women in the youngest age group was difficult due to the fact that there are fewer women diagnosed. I then altered this structure to reflect the age structure of breast cancer risk, with 10 women interviewed in the youngest group, 18 in the middle group, and 26 in the oldest age group.

representations of an illness. It is impossible to create a narrative or make sense of an illness that is devoid of the portrayal of the condition within the greater sociocultural milieu. Gathering narratives is a window into understanding how people make sense of their lives following an illness under the constraints of their cultural worlds. Sociocultural representations of illness and structural constraints shape the experience of being ill, which in turn affects the ways that people make sense of being sick and tell it within an illness narrative. Narratives in turn are a microcosm of the meaning of being sick, personal agency, and the impact of external structures on the illness experience. Narratives are best understood in the context of the sociocultural institutions that "at once restrict the freedom of, and give shape to, indeed make possible, the creation" of a narrative (Saris 1995:55).

I transcribed the interviews and identified segments for emergent themes that pertained to the key research questions (Miles & Huberman 1994). I focused on emergent patterns to identify commonalities in the narratives of the illness experience (Ryan & Bernard 2003), while paying close attention to themes that repeat within interviews (D'Andrade 1991) and the use of metaphor within interview responses (D'Andrade 1995). I explored any potential age differences within the three age strata. The overall narrative arc of the interviews came in the form of storytelling in relation to the development of cancer and asking women to situate cancer in the contexts of their lives.

5.) Analysis of social support: In the US, the breast cancer awareness campaign and its creation of a common identity of women with breast cancer have created social identities and spaces with which women with breast cancer build a sense of camaraderie and support (Bouskill 2012; Coreil et al. 2004). This aspect of the research explored how women reached out to others throughout their illness experience, whether or not women found support in other women with breast cancer, and how some hid their illness from particular people. I developed a social support map (see appendix B) as both an elicitation technique and as a means to understand the types of relationships involved in social support and the frequency of these connections. This method adapts the idea of weighted ties, or adding value—such as frequency— to links in social network in a social network analysis (Knoke & Yang 2008; Valente 2010; Wasserman & Faust 1994). This method also allowed me to draw correlations between women's experiences of stigmatization and their explanatory models for breast cancer and differences in social support.

6.) Survey collection among long-term breast cancer survivors:[104] In May 2014, I sent out three surveys to a total of 230 long-term survivors who were treated for their first breast cancer diagnosis, on average, 13 years ago in the Breast Clinic at the Vienna General Hospital. The response rate was 52% (n=152). The three surveys were as follows: 1.) The "Impact of Cancer Scale, version 2" (Crespi et al. 2008; Zebrack et al. 2006, 2008). The Impact of Cancer Scale was developed upon recognizing that people living with cancer experience negative as well as positive changes in their lives following a diagnosis often years after an initial diagnosis; 2.) the Short Form-36 scale (Hays et al. 1993),

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[104] Throughout this analysis, I purposefully resist calling those with cancer 'survivors.' It is my place as an anthropologist to critique these labels, not to assign them. The study of long-term survivorship is the only portion of the research where I do use this label mostly to conform with the literature.

which is a standard self-report instrument for eliciting physical and mental quality of life; and 3.) a generic survey to gather sociodemographic, clinical, and behavioral factors (more detailed information on these scales can be found in chapter six). These surveys can be found in the appendix C-E. Data collected from these surveys resulted in the formation of linear regression models to show the correlation between the positive and negative impacts of cancer and physical and mental health-related quality of life.

Limitations: There are a series of limitations within this study. Notably absent are women with immigrant backgrounds living in Austria who cannot speak German well enough to participate in an interview. Due to my own language barriers, I omitted a section of women from the study who also have valuable contributions to understanding experiences of breast cancer in Austria. I also could not locate any specific statistics on breast cancer incidence and mortality rates among women from immigrant backgrounds. I regret this limitation as well because it is clear that the breast cancer awareness campaign makes little to no overt effort to appeal to Austria's growing immigrant population.

The sample group for the social epidemiological portion of this study is by epidemiological standards small and not entirely representative (these issues are discussed in detail in chapter six). It is however intended to be an exploratory study and not readily generalizable. One issue with this portion of the research is the inability to compare demographic and medical information on all women invited to join to the study versus those who responded. Unfortunately, a database containing the information of all women invited to participate in the study was lost in a computer crash, making it impossible to draw conclusions about the respondents versus non-respondents.

One potential limitation is the fact that recruitment for semi-structured, narrative interviews took place within an urban, quality-certified, teaching hospital where many women also took part in clinical trials. This may have biased the study in the sense that these women are more apt to adhere to (i.e. comply with) with biomedical protocols. As mentioned, access to treatment in a certified breast clinic varies greatly between urban and rural hospitals. However, based on my conversations with women from across the country, the only main difference caused by this selection was the high level of patient satisfaction women felt with their doctors, nurses and hospital staff.

I was not permitted to ask certain questions in semi-structured, narrative interviews. These included direct questions regarding stage of cancer and other clinical factors. While women often offered this information directly or indirectly within the interview, the overwhelming majority of women had stage I or II breast cancer at the time of the interview. It is expected that their interview responses only reflected one time point, and that metastatic breast cancer is a vastly different experience.

A clear limitation is that all but five interviews took place at only one time point. This does not speak to the vicissitudes of experiencing breast cancer. I also did not systematically analyze data from the three women who developed metastatic breast cancer in the sample of 55 women currently undergoing treatment. To date, one has passed away, another is currently in the hospital, and the third by coincidence is a good friend I met outside of this research. I have also contacted other women with metastatic breast cancer, but the interviews were unstructured. Death is a subject that I do not systematically analyze within this work. Part of the issue is not being able to gather much data on it beyond brief e-mails, telephone conversations or text messages women sent to say that they had relapsed and were coming to terms with the end of their lives. The hardest issue for women with metastatic breast cancer appears to be teetering on good health while knowing that it is only temporary. As for my good friend, she and I speak often about her struggles of wanting to live while also wanting to accept the inevitability of a premature death. She is a carrier of the BRCA1 mutation and experienced rapid metastasis throughout her body. I cannot emotionally dissociate myself enough from our conversations to write objectively about this experience. I can definitively say that to compare her body, withered away from chemotherapy and cut across with scars, to the bodies shown in the breast cancer awareness movement in Austria is a heinous insult. Breast reconstruction at the end of a woman's life brings no quality of life, and it is equally troubling to her when doctors assume she would like to go through the difficult procedure. I have watched her numerous times struggle to find the words to say to her loved ones that she is learning to accept her life how it is and hopes that they can too. *None* of these issues are discussed in the campaign, including its events, its informational sessions, or its brochures. Metastatic breast cancer is appallingly absent from public portrayals of cancer, but it remains a merciless reality for too many women.

B. Survey of breast cancer risk and mammographic screening (English version)

Demographic information:

1. How old are you? ______
   a. 18-29
   b. 30-39
   c. 40-49
   d. 50-59
   e. 60-69
   f. 70+

2. What is your highest level of education? ______
   a. No high school
   b. Completed advanced high school
   c. Secondary school
   d. Professional school
   e. University degree

3. What is your postal code?____

4. (Yes/No) Do you have a family member or close friend who has/had breast cancer?______

Please answer the following questions to the best of your ability:

5. (True/False) Studies show that mammograms can reduce the mortality rate from breast cancer for women under the age of 45. ______

6. (True/False) There are more 60-year old women with breast cancer than 45-year old women with breast cancer. ______

7. (True/False) Early detection reduces the number of women with breast cancer. In other words, mammographic screening prevents the development of breast cancer. ______

8. (True/False) More women in Austria die of breast cancer than heart disease. ______

9. (True/False) The mortality rate of breast cancer has gone down in the last twenty years. ______

10. Please fill in the blanks: On average, ______ out of every ______ Austrian women will develop cancer before she turns ______ years of age.

11. List as many risks for breast cancer as you can: ____

Your opinion:

12. (True/False) It is common sense to get a mammogram every year. ______

13. (True/False) If every women over 45 would get a mammogram, breast cancer could be defeated. ______

14. What does the pink ribbon stand for? ____

15. Please choose one of the following options: ______
    a. I go to get a mammogram at least ever 1 to 2 years.
    b. I am planning to go regularly to get a mammogram every 1 to 2 years after I turn 45.
    c. I am older than 45, and I get mammograms, but not regularly.
    d. I could go to get screened, but I don't think it's important.
    e. I am not planning to get screened for breast cancer when I am older than 45.
    f. I am not sure if I will go to get screened.
    g. I will not get screened for breast cancer.

C. Survey of breast cancer risk and mammographic screening (German version)

Fragebogen „Wahrnehmungen von Brustkrebs“

Grundlegende Information:

1. In welcher Altersgruppe sind Sie? ______
   a. 18-29
   b. 30-39
   c. 40-49
   d. 50-59
   e. 60-69
   f. 70+

2. Ihr Bildungsgrad: ______
   a. keine Matura
   b. Matura
   c. Hauptschulabschluss
   d. Höhere Berufsbildende-Schule
   e. Studium

3. In welcher Stadt wohnen Sie? Wenn Sie in Wien wohnen, in welchem Bezirk wohnen Sie?____

4. (Ja/Nein) Haben Sie Mitglieder im engen Familienkreis oder Freundinnen, die bei denen Brustkrebs diagnostiziert wurde?______

Beantworten Sie bitte die folgenden Fragen:

5. (Richtig/Falsch) Studien belegen, dass Früherkennung von Brustkrebs durch Mammographie für Frauen zwischen 40 bis 45 Jahren Sterblichkeitsraten reduzieren kann.______

6. (R/F) Es gibt eine höhere Anzahl an brustkrebserkrankten Frauen im Alter von 65 Jahre als im Alter von 40 Jahre. ______

7. (R/F) Früherkennung bzw. Mammographie reduziert die Anzahl an Brustkrebsdiagnosen. In anderen Worten, Früherkennung verhindert die Entstehung von Brustkrebs. ______

8. (R/F) In Österreich sterben mehr Frauen an Brustkrebs als an Herzkreislauferkrankungen. ______

9. (R/F) In den letzten 20 Jahren ist die Sterblichkeit an Brustkrebs in Österreich zurückgegangen. ______

10. Bitte füllen Sie die folgenden Lücken aus: In Österreich erkrankt 1 von ______ Frauen an Brustkrebs vor der Erreichung des ______ Lebensjahres.

11. Zählen Sie so viel Brustkrebs-Risiken wie möglich auf:
____
____
____

Ihre Meinung zu:

12. (R/F) Regelmäßig zur Früherkennung zu gehen ist selbstverständlich. ______

13. (R/F) Wenn jede Frau über 45 regelmäßig zur Früherkennung ginge, könnte Brustkrebs besiegt werden. ______

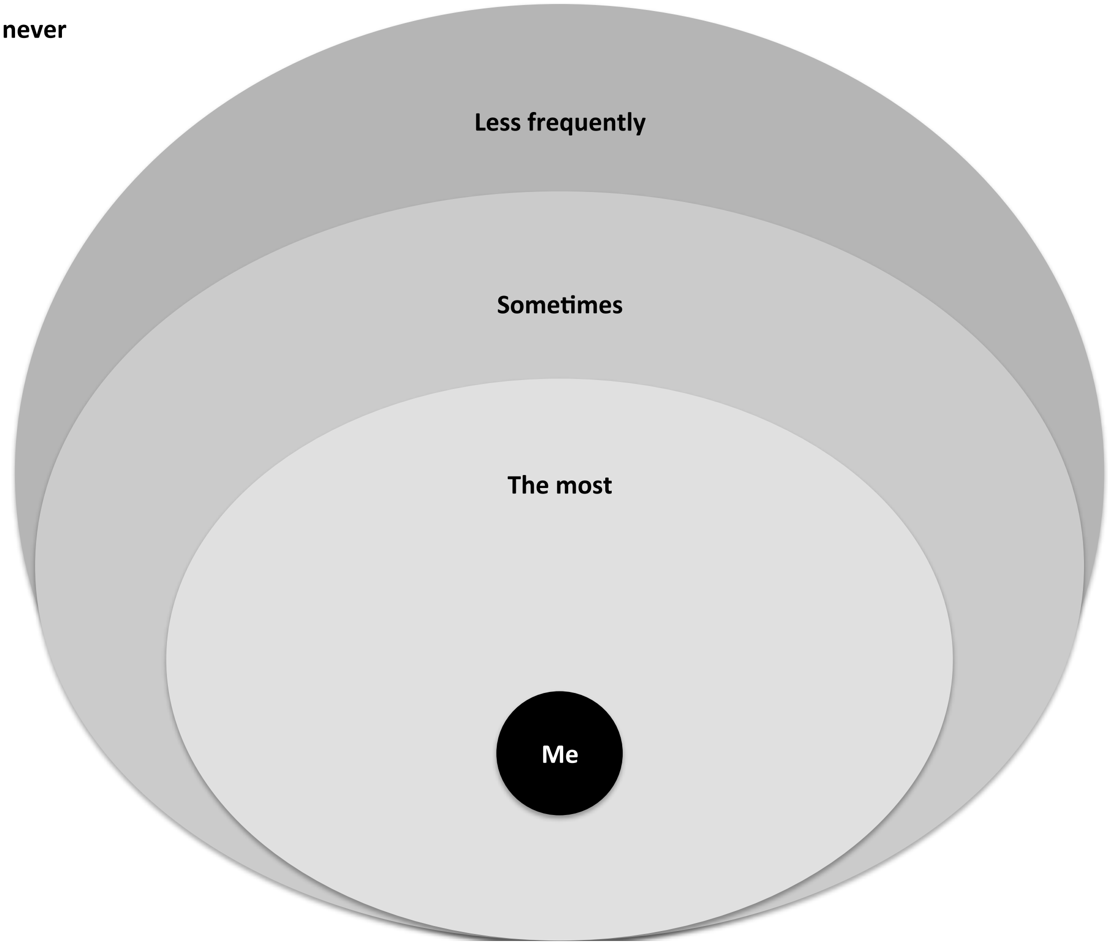
14. Was bedeutet das Pink Ribbon (deutsch „Rosa Schleife“)?
____
____
____

15. Bitte wählen Sie auf Sie zutreffende Option: ______
    a. Ich gehe regelmäßig zur Früherkennung (alle 1 bis 2 Jahre)
    b. Ich plane ab 45, regelmäßig zur Früherkennung (alle 1 bis 2 Jahre) zu gehen.
    c. Ich bin über 45 Jahre alt, und ich gehe zur Früherkennung, aber nicht regelmäßig.
    d. Ich könnte schon zur Früherkennung gehen, aber ich halte es nicht für nötig.
    e. Ich plane nicht, regelmäßig zur Früherkennung zu gehen.
    f. Ich bin nicht sicher, ob ich zur Früherkennung gehen möchte.
    g. Ich ziehe es vor, nicht zur Früherkennung zu gehen.

Vielen Dank!

D. Social support map

never



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E. Impact of Cancer version 2 Scale (English Version)

This tool is provided courtesy of Brad Zebrack, PhD, University of Southern California School of Social Work.

Impact of Cancer Scale Tool

EMPLOYMENT

1. Are you fully retired from paid employment?

_____ 1 Yes ***go to NEXT PAGE***

_____ 2 No

2. Were you employed and earning income at some time during the last 12 months?

_____ 1 Yes _____ 2 No ***go to NEXT PAGE***

Please circle the number for each statement below that best describes how much you agree or disagree with the statement.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
3. I am concerned about not being able to work if I were to become ill again……………………	1	2	3	4	5
4. Concerns about losing health insurance keep me in the job I have now……………………..	1	2	3	4	5
5. I worry about being forced to retire or quit work before I am ready……………………….	1	2	3	4	5

LIFE OUTLOOK

We are interested in knowing about your personal views or perspectives on life. Given your life **as it is now**, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
5. Having had cancer makes me feel unsure about my future………………………………	1	2	3	4	5
6. I worry about my future……………………....	1	2	3	4	5
9. I feel like time in my life is running out……..	1	2	3	4	5

YOUR BODY AND YOUR HEALTH

We are interested to know how having had cancer **NOW** affects your body and your health, if at all.

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
1. I do not take my body for granted since the cancer……………………………………...	1	2	3	4	5
2. Having had cancer has made me more concerned about my health………………….	1	2	3	4	5
3. I am more aware of physical problems or changes in my body since having had cancer..	1	2	3	4	5
5. I worry about my health……………………..	1	2	3	4	5
8. New symptoms (aches, pains, getting sick or the flu) make me worry about the cancer coming back………………………………….	1	2	3	4	5
10. I am concerned that my energy has not returned to what it was before I had cancer….	1	2	3	4	5
11. I am bothered that my body cannot do what it could before having had cancer……………...	1	2	3	4	5
12. I worry about how my body looks…………...	1	2	3	4	5

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13. I feel disfigured………………………………	1	2	3	4	5
14. I sometimes wear clothing to cover up parts of my body I don't want others to see……….	1	2	3	4	5
15. Having had cancer has made me take better care of myself (my health)…………………..	1	2	3	4	5

FEELINGS ABOUT CANCER

Given your life as it is **NOW**, how do you feel about having had cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1. I consider myself to be a cancer survivor……	1	2	3	4	5
2. I feel a sense of pride or accomplishment from surviving cancer………………………..	1	2	3	4	5
3. I learned something about myself because of having had cancer……………………………	1	2	3	4	5
6. I feel that I am a role model to other people with cancer…………………………………...	1	2	3	4	5
8. Having had cancer has made me feel old……	1	2	3	4	5
9. I feel guilty today for not having been available to my family when I had cancer…...	1	2	3	4	5

MEANING OF CANCER

Given your life as it is now, how much do you agree or disagree with each of these statements about cancer?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
3. Having had cancer turned into a reason to make changes in my life……………………..	1	2	3	4	5
4. Because of cancer I have become better about expressing what I want………………………	1	2	3	4	5
5. Because of cancer I have more confidence in myself……………………………………..	1	2	3	4	5
6. Having had cancer has given me direction in life……………………………………………	1	2	3	4	5
7. I feel like cancer runs my life………………..	1	2	3	4	5
8. I view having had cancer as a private experience……………………………………	1	2	3	4	5
9. I am constantly reminded that I had cancer….	1	2	3	4	5

ACTIVITIES AND RELATIONSHIPS

This section includes questions about your social activities and about important relationships in your life.

Given your life as it is now, how much do you agree or disagree with each of the following statements? ***(Circle the number for each statement that best describes how much you agree or disagree with the statement.)***

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
2. I feel a special bond with people with cancer..	1	2	3	4	5
3. Because I had cancer I am more understanding of what other people may feel when they are seriously ill…………………...	1	2	3	4	5
4. Having had cancer has made me more willing to help others………………………………...	1	2	3	4	5
7. Having had cancer has made me feel alone…	1	2	3	4	5
8. Having had cancer has made me feel like some people (friends, family, co-workers) do not understand me……………………………	1	2	3	4	5
10. Uncertainty about my future affects my decisions to make plans (examples: work, recreation/travel, get married, get involved in relationships, have a family, go to school)…..	1	2	3	4	5
11. Having had cancer keeps me from doing activities I enjoy (examples: travel, socializing, recreation, time with family)……	1	2	3	4	5
13. On-going cancer-related or treatment-related symptoms (for example bladder or bowel control, lymphedema, hair loss, scars, infertility, premature menopause, lack of energy, impotence/sexual problems, aches, pain or physical discomfort) interfere with my life………………………………………..	1	2	3	4	5

Circle the number for each statement that best describes how much you agree or disagree with the statement.

14. Are you currently married, living together as married, or in a significant relationship?

_____ 1 Yes *go to **QUESTION 19 on NEXT PAGE***

_____ 2 No

Given your life as it is now, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
15. Uncertainties about my health or my future have made me delay getting married or getting involved in a serious relationship……	1	2	3	4	5
16. I wonder how to tell a potential spouse, partner, boyfriend, or girlfriend that I have had cancer……………………………………	1	2	3	4	5
17. I am concerned about how to tell a spouse, partner, boyfriend, or girlfriend that I may not be able to have children………………….	1	2	3	4	5
18. I worry about not having a spouse, partner, boyfriend, or girlfriend………………………	1	2	3	4	5

STOP HERE

Please answer the following questions ONLY if you are currently married, living together as married, or in a significant relationship. Otherwise, please stop.

Given your life as it is now, how much do you agree or disagree with each of the following statements?

Please circle the number for each statement that best describes how much you agree or disagree with the statement.

	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
19. I am open and willing to discuss my cancer with my spouse/partner………………………	1	2	3	4	5
20. My spouse/partner is open and willing to discuss my cancer with me…………………..	1	2	3	4	5
21. Uncertainty about my health has created problems in my relationship with my spouse/partner………………………………..	1	2	3	4	5
22. I worry about my spouse/partner leaving me if I were to become ill again…………………	1	2	3	4	5

F. Impact of Cancer Scale (v2) (German Version)

This tool is provided courtesy of Brad Zebrack, PhD, University of Southern California School of Social Work.

Ihr Leben nach einer Krebserkrankung

BESCHÄFTIGUNG

3. Sind Sie bereits in Pension?

_____ 1 Ja ***gehen Sie zur FRAGE 6***

_____ 2 Nein

4. Waren Sie in den letzten 12 Monaten angestellt bzw. haben Sie ein Gehalt bekommen?

_____ 1 Ja

_____ 2 Nein ***gehen Sie zur FRAGE 6***

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
3. Ich bin besorgt, nicht weiter arbeiten zu können, falls ich wieder krank werden sollte………………	1	2	3	4	5
4. Ich bin immer noch berufstätig, weil ich besorgt bin, ansonsten finanzielle Einbußen hinnehmen zu müssen ………………………………………….	1	2	3	4	5
5. Ich mache mir Sorgen, in Frühpension gehen zu müssen …………………………………………	1	2	3	4	5

LEBENSAUFFASSUNG

Wir sind an Ihren persönlichen Ansichten bzw. Ihren Lebensperspektiven interessiert. Wie weit sind Sie mit den folgenden Aussagen einverstanden?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
6. Meine Krebserkrankung hat bewirkt, dass ich die Zukunft als ungewiss empfinde…………………..	1	2	3	4	5
7. Ich mache mir Sorgen um die Zukunft………………………………………….	1	2	3	4	5
8. Ich habe das Gefühl, dass die Zeit davonläuft……………………..................................	1	2	3	4	5

KÖRPER UND GESUNDHEIT

Wir möchten wissen, ob und in welchen Maß Ihre Krebserkrankung Ihren Körper und Ihre Gesundheit beeinflusst.

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
9. Seitdem ich mit meiner Krebsdiagnose konfrontiert wurde, halte ich meinen Körper so wie er ist nicht mehr für selbstverständlich………………………………………..	1	2	3	4	5
10. Die Erfahrung meiner Krebserkrankung hat dazu geführt, dass ich sensibeler mit meiner Gesundheit umgehe………...	1	2	3	4	5
11. Ich gehe bewusster mit körperlichen Problemen und physischen Veränderungen um...	1	2	3	4	5
12. Ich mache mir Sorgen um meine Gesundheit …….....	1	2	3	4	5
13. Ich mache mir Sorgen, dass der Krebs wieder kommen könnte………………………………………....	1	2	3	4	5
14. Wenn etwas mit meinem Körper nicht stimmt, bin ich besorgt, dass es wieder Krebs sein könnte …………….	1	2	3	4	5
15. Meine Krebserkrankung bewirkt, dass ich mich in Bezug auf meine Gesundheit unsicher fühle…………..	1	2	3	4	5
16. Ich bin beunruhigt, weil ich nicht die selbe Energie wie vor meiner Krebsdiagnose habe………….................	1	2	3	4	5
17. Es stört mich, dass mein Körper nicht die selbe Leistungsfähigkeit wie früher hat……………..........	1	2	3	4	5
18. Mein körperliches Erscheinungsbild beunruhigt mich………..	1	2	3	4	5

19. Ich fühle mich entstellt………………………	1	2	3	4	5
20. Ich wähle Kleidung manchmal so, dass Teile meines Körpers von Anderen nicht wahrgenommen werden können.…..……...................	1	2	3	4	5
21. Meine Krebserkrankung hat dazu geführt, dass ich mehr auf mich und meine Gesundheit schaue……………………………………………	1	2	3	4	5

KREBSWAHRNEHMUNGEN

Was empfinden Sie heute bezüglich Ihrer Krebserkrankung?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
22. Ich betrachte mich selbst als Krebsüberlebende…	1	2	3	4	5
23. Ich bin stolz auf mich bzw. ich habe ein Gefühl der Erfüllung, weil ich Krebs überlebt habe………..	1	2	3	4	5
24. Meine Krebserkrankung hat dazu geführt, dass ich mehr über mich selbst gelernt habe………………..	1	2	3	4	5
25. Ich sehe mich als Vorbild für andere an Krebs erkrankten Menschen……………………….…...	1	2	3	4	5
26. Ich fühle mich wegen meiner Krebserkrankung alt Aufgrund meiner Krebserkrankung gealtert…………………………………………...	1	2	3	4	5

27. Ich habe heute ein schlechtes Gewissen, dass ich während meiner Behandlung nicht immer für meine Familie da war…………………………………...	1	2	3	4	5
28. Ich sehe meine Krebsdiagnose als Privatsache an………..	1	2	3	4	5
29. Ich werde ständig daran erinnert, dass ich eine Krebserkrankung hatte……………………………	1	2	3	4	5

BEDEUTUNG VON KREBS

Wie weit sind Sie mit den folgenden Aussagen zu Krebs einverstanden?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
30. Meine Krebserkrankung hat dazu geführt, dass ich mein Leben verändert habe……………………..	1	2	3	4	5
31. Meine Krebserkrankung hat dazu geführt, dass ich jetzt meine Wünsche bzw. Bedürfnisse besser ausdrücken kann……………………………………	1	2	3	4	5
32. Meine Krebserkrankung hat mir geholfen, mehr Selbstbewusstsein zu entwickeln.…………………..	1	2	3	4	5
33. Seit meiner Diagnose habe ich eine Neuorientierung im Leben erfahren…...……………	1	2	3	4	5
34. Meine Krebserkrankung kontrolliert mein Leben.	1	2	3	4	5
35. Ich habe das Gefühl, dass ich auf Grund mehr Kontrolle über mein Leben habe............................	1	2	3	4	5

AKTIVITÄTEN und BEZIEHUNGEN

Dieser Teil des Fragebogens besteht aus Fragen über Ihre sozialen Aktivitäten und wichtige Beziehungen in Ihrem Leben. Wie weit sind Sie mit den folgenden Aussagen über Krebs einverstanden?

Bitte bewerten Sie die folgenden Aussagen anhand dieser Bewertungsskala und kreisen Sie die zutreffende Zahl ein.

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
36. Ich empfinde eine besondere Verbundenheit mit anderen an Krebs erkrankten Menschen.................	1	2	3	4	5
37. Auf Grund meiner Krebserkrankung habe ich mehr Mitgefühl mit schwer erkrankten Menschen entwickelt.…………………..................................	1	2	3	4	5
38. Die Krebserkrankung hat meine Bereitschaft, anderen zu helfen, erhöht…………………………...	1	2	3	4	5
39. Ich habe mich auf Grund meiner Krebserkrankung allein gelassen gefühlt…………..	1	2	3	4	5
40. Auf Grund meiner Krebserkrankung fühle ich mich von manchen Menschen (Freunde/innen, Familie, Kollegen/innen) nicht immer verstanden…………………………………………	1	2	3	4	5
41. Permanente Nebenwirkungen verursacht durch meine Behandlung (wie z.B. Narben, Unfruchtbarkeit, Energieverlust, Lymphödem, Sexualprobleme, Schmerzen) beeinflussen mein Leben.………………………………………….	1	2	3	4	5

42. Meine Unsicherheit über die Zukunft beeinflusst meine Entscheidungen und Pläne (wie z.B. Karriere, reisen, heiraten, Beziehungen, Familie, studieren)……………………………………….	1	2	3	4	5

43. Meine Krebserkrankung hat mich in meinen Aktivitäten gebremst (wie z.B.: reisen, Hobbys, Zeit mit Freunde/innen, Zeit mit der Familie)……………………………………	1	2	3	4	5

44. Sind Sie verheiratet oder in einer langfristigen Beziehung?

_____ 1 Ja *gehen Sie zur* ***FRAGE 48 auf der nächsten Seite***

_____ 2 Nein

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft zu**
45. Meine Unsicherheit über meine Gesundheit bzw. Zukunft hat meine Entscheidung zu heiraten bzw. eine Beziehung einzugehen verzögert……	1	2	3	4	5
46. Ich überlege mir, wie ich einem/einer potenziellen Partner/in erzählen kann, dass ich Krebs hatte…………………………………	1	2	3	4	5
47. Ich bin besorgt, dass ich keinen/keine Partner/in finden werde……………………	1	2	3	4	5

ENDE. VIELEN DANK!

Bitte beantworten Sie diese Fragen NUR wenn Sie verheiratet sind, oder in einer langfristigen Beziehung leben. Wenn nicht, haben Sie schon den Fragebogen komplett ausgefüllt. Vielen Dank für Ihre Hilfe!

	trifft nicht zu	**trifft eher nicht zu**	**weder-noch**	**trifft eher zu**	**trifft**
48. Ich spreche offen und frei mit meinem/meiner Partner/in über meine Krebserkrankung……………	1	2	3	4	5
49. Mein/meine Partner/in ist bereit, mit mir über meine Krebserkrankung zu sprechen……………..	1	2	3	4	5
50. Meine Unsicherheit bezüglich meiner Gesundheit war bereits ein Problem in meiner Beziehung…...	1	2	3	4	5
51. Ich bin besorgt, dass mein Partner/meine Partnerin mich verlassen würde, wenn ich wieder mit einer Krebsdiagnose konfrontiert wäre………	1	2	3	4	5

ENDE. VIELEN DANK!

G. Demographic Questionnaire (English version)

1. When were you born? (Month/Year **only**):______

2. What is the highest level of education you have attained?: ______
   a. No high school diploma
   b. High school diploma
   c. Secondary modern school qualification
   d. Professional degree
   e. University/college degree

3. What is your zip code?________________

4. Do you have a spouse or a longtime companion? (Yes/No)_____

5. Do you have children? (Yes/No)______
   If yes, how many?
      Daughter(s)______

      Son(s)_______

6. If you have children, are your children of adult age? (Yes/No)________

7. What is your height and weight? Height_________ Weight__________

8. Employment status:__________
   a. Full-time employment
   b. Part-time employment
   c. Unemployed
   d. Retired

9. Is your current employment status your **desired** employment status? (For example, If you work part time, would you rather work full time?) (Yes/No)_________

10. Which best describes your level of stress?
    a. I am stressed out every day
    b. I am stressed out often, but not every day
    c. I am rarely stressed out
    d. I am never stressed out

11. Which best describes your alcohol consumption
    a. I do not drink alcohol
    b. I only drink sporadically
    c. 1 drink per day
    d. 2+ drinks per day

12. Who do you live with?______

  a. I live alone
  b. with an adult/with adults
  c. with a child/children
  d. with a child/children and an adult/adults

13. What is your monthly salary (for you alone, not you and your spouse)?_______
  a. Less than €1000/Month
  b. Between €1001 and €2000/Month
  c. Over €2001/Month

14. If you have a spouse, what is your combined monthly salary?_______
  a. Less than €1000/Month
  b. Between €1001 and €2000/Month
  c. Over €2001/Month

15. When were you diagnosed with breast cancer (year)?__________

16. Which forms of therapy for breast cancer did you receive?

  a. Chemotherapy (Yes/No) _____ (If yes, how long?)__________
  b. Radiation (Yes/No)_____ (If yes, how long?)__________
  c. Anti-hormonal therapy (Yes/No)_____ (If yes, how long?)_________

17. Do you attend therapy or psychotherapy? (Yes/No)_________

18. Do you attend a self-help group? (Yes/No)_________

19. Do you use any complementary or alternative medical therapies? (Yes/No)
    If so, list them here (Examples include taking mistletoe extract, traditional Chinese medicine, tai chi, chi gong, meditation)____
    ____
    ____
    ____

20. Are you of the opinion that stress or a difficult emotional phase in your life played a role in the onset of your breast cancer? (Yes/No)_______

21. Do you exercise regularly (at least two times per week? (Yes/No)_________

THANK YOU FOR YOUR PARTICIPATION!

H. Demographic Questionnaire (German version)

1. Ihr Geburtsdatum (**nur** Monat/Jahr):___/ ___

2. Ihr Bildungsgrad: __________
   a. keine Matura
   b. Matura
   c. Hauptschulabschluss
   d. Höhere Berufsbildende-Schule
   e. Studium

3. Was ist Ihre Postleitzahl?__________

4. Haben Sie einen Ehegatten bzw. einen Lebensgefährten/in? (Ja/Nein)_____

5. Haben Sie ein Kind bzw. Kinder? (Ja/Nein) __________

   Wenn ja, wie viele?
   Tochter/Töchter__________

   Sohn/Söhne__________

   Wenn Sie Kinder haben, sind alle Ihre Kinder
   schon älter als 18? (Ja/Nein) __________

6. Ihre Größe und Gewicht: Größe (cm)_________ Gewicht (kg)__________

7. Ihre Berufstätigkeit:__________
   a. Vollzeit
   b. Teilzeit
   c. Arbeitslos
   d. in Pension

8. Wenn Sie berufstätig sind, ist Ihr derzeitiges Beschäftigungsausmaß von Ihnen gewünscht? (zum Beispiel: Beantworten Sie bitte mit „nein“ wenn Sie Teilzeit arbeiten, aber lieber Vollzeit arbeiten möchten, oder andersrum) (Ja/Nein) _______

9. Ihr Wohnsituation: __________
    a. Ich wohne alleine
    b. mit einem/r Erwachsener/e bzw. mit Erwachsenen
    c. mit Kind/ern
    d. mit Kind/ern und einem/r Erwachsener/e bzw. mit Erwachsenen

10. Ihr Nettoeinkommen (Nur Sie): __________
    a. Unter €1000/Monat
    b. Zwischen €1001 und €2000/Monat
    c. Über €2001/Monat

11. Ihr gesamtes Familiennettoeinkommen:__________
    a. Unter €1000/Monat
    b. Zwischen €1001 und €2000/Monat
    c. Über €2001/Monat

12. Ihr Alkoholkonsum: __________
    a. nie
    b. sporadisch
    c. regelmäßig (1-2 pro Woche)
    d. jeden Tag

13. Ihr subjektiver Stressfaktor:__________
    a. täglich Stress
    b. öfter Stress
    c. selten Stress
    d. nie Stress

14. In welchem/n Jahr/en haben Sie Diagnose Brustkrebs bekommen?_____________

15. Welche Behandlung haben Sie bekommen? (Ja/Nein)
    a. Chemotherapie _____ (wenn ja, wie lange?)__________

    b. Strahlentherapie_____ (wenn ja, wie lange?)__________

    c. Antihormontherapie_____ (wenn ja, wie lange?)_________

    d. Andere Behandlungen (z.B.: Antikörper, Kinase-Hemmer, usw.)___________ (wenn ja, wie lange?)_________

16. Nehmen Sie etwas aus den zusätzlichen medizinnahen Bereichen in Anspruch? (wie z.B. Chi Gong, Tai Chi, Traditionelle Chinesische Medizin, Meditation, Misteltherapie, Yoga, Nahrungsergänzungsmittel, autogenes Training, usw.)

    (Ja/Nein)___________

    Wenn Ja, welche?

    ____

    ____

    ____

17. Gehen Sie zu einer Selbsthilfegruppe? (Ja/Nein)______

18. Gehen Sie zu Psychotherapie? (Ja/Nein)_______

19. Sind Sie der Meinung, dass Stress bzw. eine schwierige emotionelle Phase einen Faktor der Auslösung Ihres Brustkrebses war? (Ja/Nein)_______

20. Machen Sie regelmäßig (mindestens 2 mal pro Woche) Sport bzw. körperliche Bewegung? (Ja/nein)_________

VIELEN DANK FÜR IHRE TEILNAHME!

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