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LIFE WITH, AFTER, OR BEYOND CANCER:
BREAST CANCER SURVIVORSHIP AND THE NEW NORMAL

by

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ABSTRACT OF THE DISSERTATION

Life with, after, or beyond cancer:
breast cancer survivorship and the new normal

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I examine how women “move on,” or are unable to, after a diagnosis of breast cancer. I interviewed 80 survivors of various types and stages of breast cancer to explore the relationship between how breast cancer survivors think about cancer and how they manage the daily consequences of this disease, including its effects on identity. My main objective was to examine the cognitive strategies and social practices survivors employ for living with (a history of having had) cancer. Cancer experience is undoubtedly shaped by factors like disease stage and type, treatments received, time since diagnosis and treatment, age, and social location. But many of my participants, across categories, described bracketing some aspects of their experience while holding onto a certain degree of ontological insecurity as they redefined their lives after, with, or beyond cancer. Drawing on ontological insecurity enabled them to remain attuned to their selves: they used cancer to help them redraw

boundaries in their lives and focus attention on their selves in ways they were not doing previously. While self-regulatory health practices, feminist ideologies/the women's health movement, and environmental awareness overlap in breast cancer survivorship to produce activated patients and actualized subjectivities, my participants also discussed how the existential and medical uncertainties of their experiences led them to create new spaces for meaning in their lives. However, while many of my participants wanted to use cancer as a catalyst for self-growth or change across life domains, certainly not all of them were able to do so. Survivorship programs are critical in this regard. They can help survivors harness the uncertainty they feel instead of allowing it to become paralyzing or debilitating. Many survivors need help framing ontological insecurity as a resource to employ, not something to move beyond; but, moreover, they need spaces in which they can acknowledge these uncertainties as part of their new realities.

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Dedication

To Janet Hemler

and Mara Trager

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INTRODUCTION

Living in survivorship

Heather: If you had seen me like, when I stopped treatment, like, it was bad. I was like—you would see me, and you'd be like, "Oh, she's so well-adjusted." [chuckling] And like, internally, I was like—psychologically, it was just really hard, and it was not the physical—none of the physical was an issue for me. None of it. It was fear. Fear of dying. I've always been afraid of death my whole life, which is ironic that I got hit with some life-threatening illness. [nervous laughter] Really ironic. [Pause.] Fear of like, having to go through it again. Fear of [lowering voice] leaving my kids. Fear—like, I feel like, before cancer, I had—I still have a great life. But before cancer—great life. Loved it, happy, well adjusted—I thought. [laughter]

Me: [laughter]

Heather: Great kids, great husband. Like, I had—it was like the full picture. And just really felt like, blindsided. Then, once you are diagnosed, and you have kids, and you're going through treatment—I just think you have to—like, for me, that's what you're focused on. So, you focus on the physical, right? . . . And then when all the treatment is over—can I curse on your tape?

Me: Yeah, absolutely.

Heather: When all the treatments are over, you sit there and you're like: Holy shit. What just happened?

—Heather, 45 years old, survivor of stage III breast cancer.

Breast cancer is a “critical event” (Giddens 1991) that, for many women, causes a “biographical rupture”—a tear in one’s taken-for-granted assumptions about life that destabilizes a person’s sense of self and life narrative (Bury 1982). This type of disruption can affect the core of a person’s self, what Giddens (1991) terms “ontological security,” one’s basic trust in a shared framework of reality. Diagnosis of breast cancer, which often occurs through routine mammogram, without symptoms, is often a shock, displacing

a woman from her normal life into a new liminal position between health and illness, life and death, and old self and new self (see Little et al. 1998).

Although a person is redefined as a “cancer survivor”¹ from the moment of diagnosis (NCI 2009), she may not begin to understand what this means, to her health or sense of self, until she enters a more “extended” or “permanent” phase of living with, after, or beyond² cancer (see Mullan 1985). For most survivors, only after active treatment has ended, or, in the case of metastatic cancer, treatment has reached a stasis, can they, as Heather describes above, begin to ask, “What just happened?”

For survivors who do reach this point, time and space open to the practical, existential, and psychosocial questions “bracketed” during the early phases of treatment (Giddens 1991). Making sense of cancer—what is cancer, why did I get it, and what does this mean?—is important for most people (Davis et. al 2000; Fife 2005; Jim et. al 2006; Ville and Khlat 2007; Kernan and Lepore 2009). But these questions largely do not have solid answers. For those who seek this kind of meaning, their quest may be continuous, as meanings shift over time and with new information (Davis et. al 2000). Other kinds of questions start to compete for attention: “What do I do now?” “Am I

¹ “One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life” (National Cancer Institute 2009).

² See MDAnderson’s website for how they describe people diagnosed with cancer. The words used to describe cancer are part of what is sociologically interesting about cancer: it is at once chronic and discrete, which make its status fuzzy and the language used to describe one’s cancer status awkward. <http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/survivorship/index.html>

going to be OK?” “Will cancer come back?” “Will life ever ‘return to normal’?” Survivors try to manage the anxiety and uncertainty inherent in these questions, and intrinsic to their disease, to make their existence feel less liminal, more concrete.

Breast cancer survivors, as anyone, cannot live in liminal positions for long without negative mental health consequences (Burke 1996; also see Ebaugh 1988), which is why meaning-making and narrative reconstruction are so important (G. Williams 1984, Bury 1991; S. Williams 2000; also see Swidler 2001). People are “activists” on behalf of their own mental well-being; they “purposefully engage in problem-solving and/or actively reconstructing the meaning of their life experiences to sustain their sense of self-worth and alleviate tension or anxiety” (Thoits 1995: 58). They employ cognitive strategies for making sense of various types of dissonance within the self (DiMaggio, 1997; Zerubavel, 1991; Markus, 1977). Breast cancer survivors employ particular techniques to help make life feel “normal”—even if they acknowledge that, after cancer, life is not the same. Survivors often create a “new normal” so that their lives are not lived in a liminal, anxiety-producing space between health and illness, life and death, old self and new self. They try to move beyond these binaries into a new experience of being (see Thomas-MacLean 2004; Frank 2001).

This dissertation is about how breast cancer survivors create their “new normal” in living with cancer or a history of having had cancer. It is about how they think about cancer in relation to their selves, re-formulating their

identities, redefining their selves, and rethinking life's meaning. For this project, I interviewed 80 women, survivors of different stages and types of breast cancer, of different lengths of time since diagnosis, and of different ethnic groups, ages, and socioeconomic backgrounds (I describe my research methodology fully in Appendix 1). While I set out trying to understand how survivors experienced the medical disruptions in their lives and how they came to conceptualize themselves via chronic disease, I soon discovered that these topics were subject to question: Do breast cancer survivors experience cancer and the medical world as disruptive? Do they think about cancer as a chronic disease? How do they think about cancer? What changes to their lives, if any, did they attribute to cancer?

Survivors talked about the strategies and techniques they used for returning to life “as normal” or creating a “new normal” amid differing levels of uncertainty, insecurity, and health effects. Some were well aware of the cognitive “tricks” they played on themselves, while, for others, these strategies were more integral to who they were and how they thought about their life in relation to illness. Most of the survivors I interviewed re-conceptualized their selves and futures in relation to cancer to some degree; the parameters of their existence had changed, practically and philosophically, as their bodies and minds had been altered by medical interventions. In this dissertation, I examine the sociological processes involved in how survivors do the work of redefining themselves and the terms of their existence after their cancer diagnosis. I describe how survivors “move on” in life after, with, or beyond

cancer—depending on how they define the cancer experience—attending to survivors’ expectations for themselves and larger cultural imperatives for using the cancer experience as an opportunity for self-development.

In this introduction, I review the “context” a breast cancer survivor finds herself in upon being thrust into the world of cancer: the construction of breast cancer as a particular kind of life event, the growth of breast cancer survivorship and the “survivor” identity, the rise of health models that encourage self-regulation and surveillance, and the profound destabilization of body and self via modern medicine. These areas are important backdrops to the chapters that follow. I present them here in order to describe the social phenomenon of breast cancer survivorship from multiple angles. The culture and collective identity that have arisen around breast cancer mark it as a distinct type of experience, even as it shares attributes with other types of traumas (other illnesses but also other unexpected and life-altering events) and normal experiences (like aging). Breast cancer survivorship is important as a phenomenon precisely because of its similarities to other types of events and its differences: breast cancer is a prominent collective illness identity, a “cause,” a source of strength and empowerment, perhaps even a culture; but it is also a potentially deadly disease. Breast cancer survivorship provides an opportunity for women to engage with “the self,” but this engagement depends on grappling with mortality, uncertainty, and insecurity. Many survivors walk a fine line living in the now and holding thoughts of recurrence or their own mortality in the backs of their minds. This does not mean that they experience

life as liminal; they enact cognitive strategies to engage in particular forms of consciousness, harnessing some of the ontological insecurity to help them move forward. Survivors tried to make life “normal” while making use of the shifts in perspective they experienced, shifts resulting from the ruptures in life assumptions and ontological security they experienced through cancer.

Breast cancer as a “critical event”

The larger question driving this dissertation is about how people experience ruptures to personhood and recreate themselves from those experiences, about how, or to what extent, they are able to reclaim feelings of trust and security in the world. Breast cancer often produces ontological, experiential and existential shifts in personhood—however other types of events may produce similar shifts. To some extent, the kind of “critical event” (Giddens 1991) that provokes these ontological, experiential and existential shifts is arbitrary, dependent upon particular circumstances of a person’s life. Many kinds of life experiences can cause ruptures to one’s basic assumptions (Janoff-Bulman 1992; Kauffman 2002) or provoke “moral shocks” that produce a new consciousness and direct one to take new actions (Jasper 1997). People are largely unable to predict and hence prepare for negative outcomes (Cerulo 2006), even if the statistics and odds of certain events happening, like cancer, are well known. Individuals are often blindsided by unanticipated events, the unexpectedness aiding in the event’s ability to produce disruption.

Moreover, events are not necessarily positive or negative in their own rights. Events that are disruptive or negative for some people may be non-

eventful or positive for others depending on contextual factors (Thoits 1995, 2013; Baum et al 2005). Thoits (2003) has found evidence that undesirable events or problems in highly salient identity areas are more likely to be *interpreted* as failures or major losses than events that occur in non-salient areas. “Negative” events in high-salience areas are, as Simon claims, perceived to be “highly threatening, and psychologically harmful because they disrupt a valued aspect of the self” (1997: 258). Stress researchers tend to focus on negative events more than positive ones as the impact of these events tends to be greater on health than that of positive events (Wheaton et al., 2013: 303), and much of the research on cancer, until fairly recently, has focused on the negative effects of the experience. Yet, despite the cultural fear and stigma surrounding cancer, its impact on the body, and the literature describing cancer’s deleterious effects on self esteem, some survivors described their cancer as not significant or special, overshadowed by other demands or framed in alternate ways (see Williams 2000, Lawton 2003, and Sinding and Wiernikowski 2008). Other survivors told me that cancer was, if not “the best thing that ever happened” to them, then a catalyst for positive change or a strength-building experience. Importantly, these descriptions of cancer are retrospective and embedded within a cultural context that emphasizes the silver linings and growth potential of negative events (Bell 2012; Kaiser 2008; Deimling 2007; Cerulo 2006; ; Sinding and Gray 2005; Ehrenreich 2001). But, clearly, even an event like cancer is shaped by how a person defines it and incorporates it into his or her life narrative within a particular socio-historical

context (Hubbard et. al, 2010; Williams 2000; Stryker 1981; Williams 1984; Leventhal et al. 1980; Schutz 1967).

While people do have some agency or variability in terms of how they define what happens to them—what definition they attribute to a situation (Thomas and Thomas 1928)—some events are less malleable in their social meanings than others, restricting the variability of individual-level meanings we assign to them. Serious illnesses, and cancers in particular, have strong cultural definitions and significance. Cancer, once the “Big C,” the disease about which people dare not speak at dinner parties, has become more treatable, manageable, and less stigmatized—now even framed in breast cancer survivor circles as a potentially positive event for self-growth (Bell 2012; Willig 2011; Kaiser 2008; Deimling 2007; Kromm et. al 2007; Wilkinson & Kitzinger 2000; Doan et al. 1993). The social movements and fundraising efforts around cancer have catapulted awareness and framed understandings of breast cancer in particular ways (King 2006, Klawiter 2008; Sulik 2011). But breast cancer is marked by a schism between its public face of pink ribbons and heroism and its private experience of anxiety, uncertainty and invasive treatments. This division also seems to create more of a rift between survivors of early stage breast cancer with good prognoses and those with metastatic or more aggressive types of breast cancer (Vilhauer 2010). Some criticize breast cancer culture for infantilizing women (Ehrenreich in particular bemoans the teddy bears and crayons in care-packages, 2001), covering over their fears, and promoting a dominant discourse of survivorship

that many women cannot or do not want to uphold (Ehrenreich 2001; Sinding and Gray 2005; Willig 2011, Sulik 2011). The “pinkwashing” of breast cancer, a term coined by Breast Cancer Action (“Before You Pink” n.d.; also see Sulik 2011: 370), has attempted to raise public consciousness of breast cancer and normalize the experience to some degree; but this kind of normalization has depended on women wearing wigs and prostheses or undergoing invasive reconstructive surgeries in order to look “normal” to the rest of society (Kaiser 2008; Ehlers 2012). Being normal has continued to mean that women look “healthy,” i.e., not suffering from cancer.

Pinkwashing has not seemed to allay fears of cancer, even if it has managed to increase public awareness and decrease stigma to some extent (Clarke & Everest 2006; Schover 2004; Knapp-Oliver & Moyer 2009). In general, outsiders to cancer tend to blend all forms of cancer into one archetype, and they may stigmatize cancer more than people who have it (Anagnostopoulos and Spanea 2005; Chapple et. al 2004; Fife & Wright 2000; Buick and Petrie 2002; Katz et. al 1987). Fear may also be promoted by the construction of breast cancer as an “epidemic,” even though the majority of newly diagnosed cases are pre-cancerous or early stage due to changes in screening conventions (Aronowitz 2008; Thorne and Murray 2000; Lantz & Booth 1998). Treatments have improved, the number of survivors has increased, and breast cancer has become a common event (one out of eight women will be diagnosed with invasive breast cancer in her lifetime). Breast cancer campaigns have turned the disease into a heroic enterprise, a cause

adopted by corporate philanthropic marketing (King 2006). But the experience has not become normalized to such an extent that the disease has become completely integrated into the social fabric (Kaiser 2008, Leopold 1999).

Survivorship is tricky. Survivors and support groups may want to normalize survivorship as a phase of life, but normalizing cancer would actually decrease the need for survivor identities. Survivorship exists because of its ontology as a medical condition that contains risk, uncertainty, and the shadow of recurrence or death. The very real threat of the disease destabilizes normality. The threat that lies within survivorship may lay dormant at times, but it is renewed at different moments according to social and medical cues.

This, perhaps, is the most defining element of breast cancer. Beyond the brutality and side effects of treatments, breast cancer forces survivors to live with risks and uncertainties in an intimate way. Although some risk factors and the mechanisms of how cancer works are known, what precisely “causes” an individual’s cancer and what can “cure” it are not. Risk factors, like being female and having an early beginning to menstruation and late entry into menopause, are not factors women can control. They are just part of being women. Not having children or having children later in life, other risk factors, are not usually choices women make in regard to their perceived cancer risk. And even more traditionally understood risk factors, like inheriting a genetic mutation, may be unknown to the individual or not considered definitive. BRCA 1 and 2 mutations, for instance, only cause five to ten per cent of breast cancers. Of women with these mutations, 55-65% of women with BRCA 1

and 45% of those with BRCA 2 are predicted to have breast cancer by age 70 (NCI 2015). Survivors know that other cancer-related genetic mutations, molecular agents, and chemical compounds have yet to be discovered. They also know that there are many different kinds of breast cancer and that every person's breast cancer acts uniquely to them: some early-stage cancers can be deadly while later staged cancers can be managed. Doctors are forthcoming that they do not know which early-stage cancers will be deadly and which ones will not, and my participants reported that their doctors told them they could not explain why they, specifically, got cancer. The unpredictability of cancer conflicts with the cultural esteem accorded to science, and, while scientists' knowledge may be more advanced than current treatments for cancer (Mukherjee 2010), cancer's evasiveness can also deflate the trust and authority that patients concede to the experts. The particular type of unknowability and unpredictability of cancer produced in tandem with cultural fears surrounding cancer can create existential anxiety in a way other chronic illnesses and other types of experiences may not. Survivors negotiate a delicate terrain, bracketing risks to a certain degree, living in a space of defined and undefined uncertainties, in order to proceed in life (Giddens 1991). Some scholars have defined cancer's "exceptionalism" in terms of its production of (continued) "death salience" (Little & Sayers 2004).

Being a "survivor"

Before breast cancer culture adopted "survivor," the term was perhaps most strongly associated with the Holocaust. Stein (2011, 2015) describes how

the “second generation” pushed their parents to tell their stories in public, driven by cultural shifts arising out of progressive movements of the 1960s and 1970s, which helped to produce the collective Holocaust survivor identity. Progressive movements connected to feminism and therapeutic/self-help culture, particularly around issues like child abuse, incest, domestic violence, and rape, shaped the cultural dialogue about victims’ rights. Telling—“reclaiming”—one’s story became an important part of these social movements, transforming a victim into an empowered survivor. These movements employed the term “survivor” to designate personal strength in overcoming trauma (see Stein 2011; also King 2006, Sulik 2011). Support groups, health manuals, self-help books, and memoirs for and by breast cancer survivors emerged from this context (see Leopold (1999) and Gardner (2006) regarding the influence of media on survivor identities), helping forward survivorship identities, as did new forms of “biosociality” (Rabinow 2005) and shared treatment experiences. Klawiter (2008) also notes cancer patients had to enter a new regime of biomedicalization in order to be able to establish a collective identity, as past medical regimes isolated cancer patients and discouraged the construction of illness identities.

Breast cancer activists and advocates, especially the National Coalition for Cancer Survivorship (NCCS), a survivor-led advocacy organization, built on the foundations and meanings of “survivor” established by these other progressive movements. Dr. Fitzhugh Mullan, instrumental in establishing the NCCS (Kaiser 2008), first used “survivor” in relation to cancer in his 1985

article “Seasons of Survival,” published in the *New England Journal of Medicine* (Kolata 2004). Mullen distinguished between “acute,” “extended,” and “permanent” survival to demarcate different health concerns but also the different psychosocial needs of people within these “seasons” (Mullan 1985). As more people were living longer after diagnosis and treatment, a need to define these different periods emerged. Today, survivors no longer think of breast cancer as an imminent death sentence, but they also commonly recite the aphorism that they will be considered cured of cancer when they die of other causes.

The NCCS chose the term “survivor” to help with these psychosocial needs and to define life after treatment as different than the patient status. According to an article published in the *Journal of the National Cancer Institute*, “The NCCS put forth a definition of cancer ‘survivor’ in 1986 at a time when cancer was a disease that people needed to learn how to fight. The word, [NCCS President Ellen] Stovall said, was designed to empower patients to make decisions about their care and to push for better research and treatment” (Twombly 2004). Notably, Stovall describes that people “needed to learn how to fight”—in the late 1980s, people were not yet “empowered” by cancer but were still its victims—pairing empowerment with the ability to “push for better research and treatment,” a call to political action. However, over the course of the 1980s, this kind of language was appropriated by mainstream breast cancer organizations that promoted individual-level empowerment rather than pursuing activist-oriented goals (King 2006, Sulik

2011). Cancer survivors emerged, learning how to be empowered through their disease, becoming advocates but largely not political activists (Leopold 1999) (I discuss this more deeply in Chapter 2).

The roots of “survivor” within experiences of trauma and victimhood frame cancer in particular ways, perhaps encouraging the personalization of empowerment through cancer survivorship. The clinical description of “survivor” can be traced back to at least the 1960s, where “survivor syndrome” depicts the survivor of trauma as a psychologically disturbed entity (see Bell and Ristovski-Slijepcevic 2013). While “survivorship” connotes strength and heroism, it also rests upon conceptualizations of trauma and psychological dysfunction. These oppositional meanings exist within survivorship today and continue to contribute to the cultural schemas about cancer: the breast cancer survivor is both flawed and triumphant. Breast cancer may no longer be stigmatized, but it is “approached with both fear and optimism” (Kaiser 2008: 80; Clarke 1999). The emphasis on positivity within cancer survivorship is connected to these imperatives to triumph over victimhood status but also to triumph over personal flaws.

Cancer survivorship both benefits from and becomes defined through its implicit association with other types of survivors. On the one hand, application of the term “survivor” to so many different types of experiences generalizes trauma, conflating these different types of traumas into the archetypal survivor identity (see Fassin and Rechtman 2009). The result is that “survivor” becomes someone who overcomes, who fights—and this does not

map directly onto the experience of all cancer survivors. On the other hand, survivor movements have focused public attention on the experiences of sufferers, defining the actions perpetrated against them as a type of violence. These movements have provided a narrative and positive identity for sufferers, enabling individuals to transcend victimhood and morally stigmatized social statuses (there is a long history of women being blamed for their cancers): individuals no longer need to hide what has happened to them or feel ashamed and implicated in the experience; they can be triumphant and agentic (Park et. al 2009). The potential to create alliances with other identities perceived structurally and psychologically similar has helped breast cancer advance as a movement and identity. Rallying around the term gave breast cancer activists a way to raise public awareness and politicize women's experiences of breast cancer, even if activism and advocacy have become split over time. Importantly, this kind of social context is critical for illnesses to become embraced as collective identities (see Solomon 2012; Conrad and Barker 2010; Barker 2002).

Adoption of survivor terminology is not without contention. The term has come to be applied in medical and community domains to anyone who has been diagnosed with cancer (in some circles, their loved ones)—from the moment of diagnosis. Battle metaphors in cancer may influence this thinking, but I think it is also an attempt to be inclusive of those with terminal prognoses. One is said to battle cancer moment by moment, and hence survive cancer moment by moment; one begins to survive the disease the moment one

is diagnosed (NCI 2009). This is not completely logical, as people live for differing periods of time with cancer before knowing that they have it. This definition, therefore, considers the psychological battle with cancer part of survivorship.

Within the survivor community, survivors themselves have mixed feelings about the term. Some feel “survivor” does not describe what happens during active treatment: the term makes their role in receiving treatment sound too “active.” They feel that “survivor” should really be reserved for those who have finished treatment or are in remission. Others feel this term diminishes the experiences of those who will not and do not survive, as those people also “fought” but were not able to survive cancer. Others want to leave cancer behind completely, resenting being forced into an identity related to cancer. And yet others think the term is limiting, preferring to call themselves “strivers” or “thrivers,” as they have moved “beyond” cancer (see Kaiser 2008). Bell and Svetlana Ristovski-Slijepcevic (2013) note the contentiousness of the term for survivors and medical practitioners alike in its assumption that survivors experience cancer as a trauma, and the same kind of trauma at that. Many survivors told me they dislike the term but continue to use it as there is nothing better in circulation. The majority of individuals who have had cancer do identify to some degree with “survivor,” even if they have a contentious relationship with the term (Zebrack 2000; Deimling et. al 2007; Park et. al 2009; Helgeson 2011; Jagielski et al. 2012). Many carve out their own definitions within the dominant images and understandings (Kaiser

2008).

Cancer survivorship as a continuum

Despite problems with the term “survivor” (Khan et. al 2012; Kolata 2004), there is clearly a need to define and describe the period of life experienced by people after cancer diagnosis (Feuerstein 2007).

“Survivorship,” as a stage of life, an identity, and a health status is a relatively recent phenomenon, produced in part by medical advances in treatment, but earlier and increased detection has also expanded the survivorship pool. The number of cancer survivors will outpace new cases of cancer by 2050 (Aronowitz 2008; Hewitt et al. 2006; Kolata 2009a & b), such that new medical and social structures are needed to adequately care for and incorporate this category of people (NCI 2007).

Cancer survivorship mandates life-long membership: it encompasses all phases of treatment—diagnosis, active treatment (surgery, chemotherapy, radiation), follow-up care/monitoring (often with adjuvant chemotherapeutic or hormonal drugs)—and all phases of the disease (no further evidence of disease, metastasis, remission, recurrence, long- and late-term effects from treatment, and new cancer). Survivors may shift or maintain multiple positions in this continuum (see Figure 1, below). Survivors will also experience non-cancer health events through the course of their survivorship, each influencing how they think about cancer, illness, and their selves.

In such a way, breast cancer is both discrete and continuous, perhaps a “blended stressor” (see Wheaton et al. 2013). Survivors may think of the

disease as an acute occurrence but the experience of cancer as chronic and continuous. Diagnosis and treatment are particular moments of crisis within breast cancer *survivorship*, standing out to survivors as hot events. But, to the medical community, breast cancer itself is chronic condition (Hewitt et al. 2003; Hewitt et al. 2006; Maus et al. 2009; Phillips and Currow 2010), and “survivorship” is a life-long endeavor that strings together cancer-related events into a continuum. Within this continuum, the different “events” of breast cancer may not be so easily delimited. Even though a recurrence may happen ten years later, it is still a “recurrence,” another happening of the original cancer, marked by shared genetic material. Effects from treatment may not transpire for a decade, but they were put in motion at the time of treatment. How survivors and medical practitioners think about these occurrences as events or extensions of one event influences how they are experienced, how the actual biological happenings are interpreted, and how doctors and patients interact. As survivors are never considered “cured”—the best a survivor can hope for is to be “NED” or “no evidence of disease”—the lines demarcating cancer are often blurry. Cancer sets a survivor on a new life path but retains its potential to shock the survivor anew with different-but-related health events over the course of one’s survivorship.

As survivorship encompasses multiple experiences and stages of experience, the language used to describe cancer experiences becomes strained. MDAnderson (2015), one of the top NCI-designated cancer centers in the country, uses terms like living “with,” “through,” or “beyond” cancer to

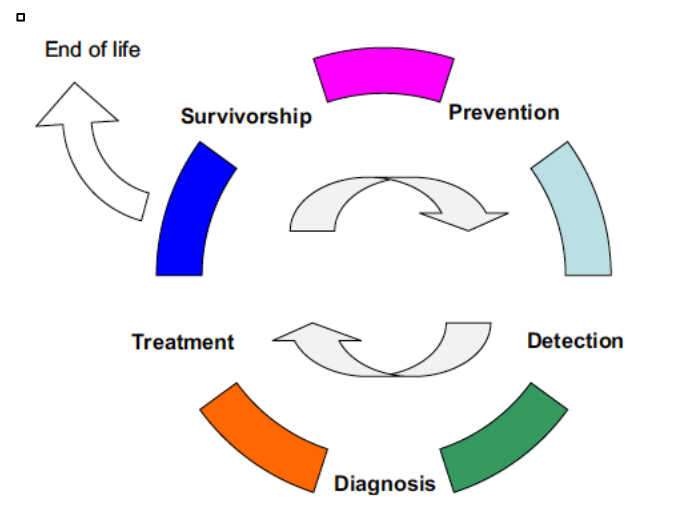
demarcate different periods of survivorship, echoing Mullen's (1985) original "acute," "extended," and "permanent" periods of survival. These terms feel less medical, perhaps in attempt to take into consideration survivors' experiences of illness and allow them to adapt these terms to different time frames. Living "with" cancer can connote different experiences: those newly diagnosed, currently receiving treatment, or those with metastatic cancer. But survivors may feel they live "with" the experience of cancer but not the disease, or they may feel they still have cancer cells in their bodies, and hence will always be living with cancer. Living "through" cancer has been used to describe the period after active treatment, during which survivors receive follow-up care; but follow-up care can continue for the rest of a survivor's life. In many cancers, the first five years are considered critical to recurrence, so that survivors often feel that if they can get "through" the first five years, they can feel relief. "Beyond" cancer may mean living in long-term survivorship, although survivors may feel they are psychologically beyond cancer after treatment ends.

The field of cancer prevention and control conceptualizes each occurrence, and perhaps even pre-cancer occurrence, as part of one illness career, as shown in the figure below. This figure depicts endless cycling through all stages of survivorship until death. It recognizes that living "with," "through" and "beyond" cancer are themselves temporary states. This cycle might be better drawn to look like a spiral rather than a closed circle: a survivor of one cancer may reenter the prevention phase once treatment for

her primary cancer is over, but she will be at a radically different place medically and phenomenologically than she was before cancer—and she may inhabit different positions simultaneously if being treated for different cancers or illness effects at the same time.

Figure 1: Rowland and Bellizzi's

“Cancer control continuum (revisited)” (2008: 192).



But what this graphic does well is show that one can never reenter the non-cancer population. While medical researchers may conceptualize the “cancer continuum” as pictured above, survivors may think about new cancers and treatment effects as related or isolated conditions, incorporating them into one totalizing illness career or embarking on new illness careers with new occurrences or symptoms. Illness conceptualizations matter for identity, influencing coping strategies and health outcomes (Leventhal et al. 1980; Leventhal et al. 2001; Fife 2005). Researchers find that people employ a variety of coping techniques to normalize cancer, distance themselves from it, or understand themselves anew in relation to it (Charmaz 1991, 1995; Miller

1995; Bury 1991), all of which may influence psychological and health-related outcomes. For instance, if a survivor experiences cancer and its sequelae as distinct entities, she may not think of cancer as a chronic disease and thus may not envision herself within this cycle of cancer survivorship, which may have consequences for health behaviors.

This figure also raises the question of if there actually is a “non-cancer” population: considering the expansion of boundaries around the “at risk” population, the “non-cancer” population might be better renamed the “pre-cancer” population (see Aronowitz 2008). The “at risk” population has grown in breast cancer through expanded clinical criteria, earlier screening (screening debates continue in regard to when women should begin having mammograms and over the efficacy of breast self-exams) and the rise of preventative or prophylactic treatments (albeit these percentages are small), the “prevention” part of this cycle might need to be drawn larger to illustrate the magnitude of this period; survivors themselves devote an inordinate amount of attention and energy during survivorship to prevention practices (Bell 2010). And, indeed, recent findings about cancer’s “randomness”—although the research did not include breast or prostate cancers—makes it seem as though everyone really is “at-risk” (Tomasetti & Vogelstein 2015; Couzin-Frankel 2015). Not being able to precisely link risk factors to one’s own lives, or perhaps not being able to answer questions about what causes cancer beyond the biomedical explanation, fuels perceptions of risk. Even though there are set risk criteria

for breast cancer, most survivors are quick to point to themselves or others as examples that defy those criteria.

Frank's (2009) formulation of "remission society" and Jain's (2007) "living in prognosis" are poignant in regard to survivors' conceptions of risk and experiences of self within the breast cancer continuum. Frank (2009) conceptualized living in a "remission society" in which people are always in a state of post-illness but never "cured," a society in which medicine has the potential to colonize the self. Sickness and health are still conceptual dichotomies if not dichotomous experiences; people live with permanent visa status, always pre-sick. More specific to cancer survivors, Jain (2007:77) describes, instead of living in remission, living "in prognosis," experiencing a "simultaneous sense of life and death." She describes how the lives of survivors are plagued by counterfactuals, "lived in time that folds around inevitability" (2007: 90). Because prognosis is an abstract statistical probability that threatens the meaning of the present, survivors look back at previous phases through counterfactuals, feeling morally responsible for cancer and recurrences. Much health information is directed at them in survivorship for how to lead a healthy lifestyle and prevent cancer (Bell 2010, 2012; Willig 2011). But survivors also begin to perceive their bodies through the lens of cancer, looking forward toward worsening states: many survivors attribute new aches and pains to cancer first, instead of other causes (Hudson et al. 2012), antithetical to the way in which many are diagnosed. Moving into this continuum, therefore, presents multiple challenges for identity, both in

terms of the types of challenges presented and the phenomenological time at which these challenges present themselves (also see Charmaz 1991).

One last point I want to make about cancer continuum graphic above is that, while the size of each phase within the continuum obviously cannot be drawn to scale—the detection period can last much longer, for instance, than actual treatment, or vice-versa—each stage is not given equal attention by the medical community or the community of survivors. Despite conceptualizing breast cancer as a continuum and acknowledging the complex ways in which breast cancer experiences defy linear time and biological models, most of the focus in survivorship is on the early stages, the entry phases into this continuum. While it is true that survivors do not reenter the non-cancer population, if there actually is a non-cancer population, it is also true that they are expected to act as if they are cured while outside medical doors. But, importantly, more medical and lay attention is focused on early-stage survivors and the early phases of the continuum. Because numbers of early stage breast cancer survivors continue to rise, survivorship services tend to focus on the needs of these survivors, most of whom have fairly good prognoses. The survivorship movement and medical community have been criticized for ignoring metastatic survivors and for undermining women's health by directing funding toward awareness or screening instead of research for a cure (see Sulik 2012, King 2008). Breast cancer support groups, advertised for all breast cancer survivors, can exclude metastatic survivors: their needs are different from the larger numbers of early stage survivors so

that groups are not relevant to them, but, also, group organizers do not want metastatic survivors to scare early stage survivors or make them feel that their experiences are invalid by comparison (see Vilhauer 2010). Even though survivorship is conceptualized as a life-long endeavor, and breast cancer a chronic condition, cancer may be experienced more as a dichotomy than a continuum in reality.

Survivorship of Breast Cancer

Breast cancer comprises the largest segment of the cancer survivor population. It receives more NCI funding than any other type of tumor (NCI 2013). It also receives more philanthropic donations than the top three killer diseases combined when considering the most popular foundations (Belluz 2014). Breast is most common cancer for women and is the second cause of cancer deaths for women. It is the third leading cause of death for women overall, after heart disease and lung cancer. The median age of diagnosis is 61, and the median age of death is 68. While white women have the highest rate of breast cancer, African American women have the highest mortality rate from breast cancer (Gerend and Pai 2008; NCI 2015; ACS 2013). Despite the picture presented by these statistics, though, breast cancer is not one, unilateral disease, but a complex multitude of diseases, perhaps close to 200 types (Jain 2009). For the uninitiated, breast cancer is generally perceived as one cohesive disease. This is partly encouraged by cancer organizations. Finer distinctions are often sacrificed in order to construct a unified breast cancer identity, community, and political health campaign. This unified conception of breast

cancer may actually be harmful in the long run since it contributes to cultural fears of breast cancer and leaves women ill-prepared for how complicated breast cancer is.

Cancer outsiders may be most familiar with breast cancer stages, if they are familiar with any distinctions within breast cancer, although celebrities like Angelina Jolie have recently injected more nuanced discussions of breast cancer risks and genetic predispositions into the public forum. Breast cancer is classified from stage 0, comprised of ductal or lobular carcinomas in situ, which are, respectively, precancerous or abnormal clusters of cells enclosed in the milk ducts or lobules, to stage IV, metastatic breast cancer, breast cancer that has spread to other parts of the body. Stages I-IV are considered invasive breast cancers because these cancers have broken out of their original enclosed structures, like ducts or lobules, into breast tissue, and staging is determined by the TNM system: tumor size (T), presence in lymph nodes (N), and spread to distant parts of the body (M). There are multiple codes of T, N, and M that represent different tumor sizes, number of affected lymph nodes, and metastatic presence, such that permutations and combinations of different Ts, Ns, and Ms represent different understandings of a cancer's development. Yet, this staging system itself says nothing about a tumor's characteristics or molecular make-up, which are more important in assessing how fast a tumor grows, how likely a tumor is to spread, and how likely a tumor is to respond to particular treatments (Cianfrocca & Gradishar 2009).

Major differences in breast cancer tumors classification center on receptor status. Tumors that are receptive to the hormones estrogen or progesterone are called ER/PR positive or negative. Tumors that contain gene mutations that overproduce a protein called human epidermal growth factor receptor 2 are labeled HER2+ (Her-2-positive). These classifications have become shorthand within the survivor community for how aggressive or slow a tumor might be: hormone-receptive cancers tend to be the more run-of-the-mill cancers; they are the easiest to treat and the slowest growing because they rely on hormones. Survivors tell me that if you had to choose a type of breast cancer, you would want to choose this one. HER2+ (Her-2-positive) cancers, on the other hand, tend to be more aggressive and less responsive to hormonal therapies. “Triple-negative” cancers are also considered aggressive, as they do not respond to treatments targeting estrogen, progestin, or HER2 and are fast-growing.

In addition to these tumor characteristics, breast cancer survivors may also carry mutations in BRCA 1 and 2 genes, which indicate increased lifetime risk for breast, ovarian, and other types of cancers. Young people are more likely to have cancers caused by BRCA mutations. Inflammatory breast cancer, another type of invasive cancer that is extremely aggressive, is also more likely to occur in younger women. Younger women who have breast cancer are more likely to have a more aggressive type of breast cancer, as are African American women. These two types of women are thought to have denser breast tissue, which may make cancer more difficult to find on

mammograms, but they also have higher rates of these aggressive types of tumors (Young Survival Coalition 2015). (To be clear, higher mortality rates among African American women are not solely related to their higher likelihood of getting aggressive cancers; many scholars have documented the social causes of this health disparity. See, for instance, Blackman and Masi 2006 and Gerend and Pai 2008.)

Different types of breast cancer and related gene mutations have different recommendations for treatment and adjuvant drug regimens and thus different potential side and late effects. Each cancer is ascribed a different risk-level for recurrence based on classifications like stage, type, grade (how closely the tumor's cells resemble normal tissue cells), receptor status, and the like. Yet despite all of the intricacy in classifying breast cancers, there is surprising generalization across breast cancer within medicine as well as in the public's imagination. Treatment follows strict protocols based on classifications rather than personal biological profiles; in other words, treatments are not (yet) personalized to the survivor but to a system of classification, some of which I have outlined here (see Baird and Caldas 2013). Moreover, even though some breast cancers may resemble other types of cancers, like ovarian (Burgess & Puhalla 2014), endometrial (Kolata 2013) or prostate (Tabár et. al 2014), more than other breast cancers, cancers are still lumped into classification by original tumor site. Thus, despite the multitude of differences between breast cancers, treatments of breast cancer are remarkably limited, and medical experiences remarkable similar—which plays

a role in producing similarities between survivor experiences and collective identity.

Moreover, medical classification schemes are influenced by cultural ideas of the body as much as they are by genetics and biology, and the focus on the breast as a discrete body part has in part informed medical history with regard to breast cancer. Beyond the paternalism in medicine, part of the intriguing history of breast cancer involves professional spats between surgeons and oncologists. While surgeons are often demeaned as butchers, surgery was originally esteemed within breast cancer as the most “complete” and direct treatment. Although recognizing that cancer could spread in the blood or lymphatic system, surgeons benefited from the “early detection” public health campaign because, if cancer could be said to be localized to the breast, and if the breast could be seen as a distinct and external body part, then they could convince women that removing the breast—if caught in time—was curative (see Aronowitz 2001, 2007, 2008).

Early Halstead mastectomies removed more than what is commonly associated with the breast—muscle and back tissue, leaving women drastically disfigured—but Halstead’s rationale was that the more breast tissue and lymph nodes removed, the less likely cancer would be to return. This thinking about breast cancer is enticing but flawed. If cancer cells have already spread to the blood stream or lymphatic system, which today’s medical advances still cannot completely determine at time of surgery, then mastectomy would do little good if those cells grow elsewhere; if cancer cells have not spread, also

somewhat unknowable (surgeons look for “clean margins,” but this practice does not always rule out recurrence), then a lumpectomy would suffice (Mukherjee 2011). Either way, removing the entire breast does little to prevent recurrence.

Theory now holds that recurrence may be based more on the molecular make-up of the cancer than the stage or type of breast cancer. Mastectomy, however, is still selected by women anxious to “get it all” despite reassurance by studies that find lumpectomy as successful as mastectomy for the above reasons. Prophylactic and double-mastectomy is also on the rise (Tuttle et. al 2007; Tuttle et. al 2009; Hawley et. al 2014), illustrating the continued success of early detection campaigns and their extension to the “at-risk” population. These understandings, though, are based on perceiving the breast as a discrete body part and of cancer as a site-specific organism. These understandings may be mostly “true,” but they also have had repercussions for how doctors and patients perceive breast cancer, how they design studies, and treatments are conceptualized. As I mentioned above, some breast cancers are more similar to other types of cancer than to other breast cancers, which complicates understandings of cancer and the body, and removing the breast does not mean breast cancer will not occur on the chest wall or reoccur in other parts of the body, even if it does reduce perceptions of risk.

Cultural ideas about women, the body, and women’s bodies in particular also undergird experiences and understandings of breast cancer. The breast, if not the predominant way women are identified as “women” in our

society (see Friedman 2011, 2013), is obviously a highly sexualized, objectified body part. Breast cancer campaigns originally had to overcome the stigma of discussing both cancer and the breast in public (Mukherjee 2010). Mothers continue to fight to breastfeed in public, showing how difficult it still is for the general public to think about the breast outside of this paradigm. Against this backdrop of breast culture, doctors are trained to view the breast as just another body part, and to think of bodies as distinct from patients. Perhaps these contradictory lenses—the cultural emphasis on fetishizing and idolizing the breast and the medical emphasis on the clinical body—causes medicine to present somewhat contradictory messages to survivors about the breast: the breast is at once something that can be removed without much fanfare and something necessary to rebuild or reconstruct for women to maintain a sense of wholeness and sexuality.

Clashes with doctors over treatments are often a result of conflicting frameworks through which doctors and survivors perceive disease and the body. Survivors note that their oncologists and particularly their surgeons are not known for their emotional attentiveness or ability to perceive the patient as a holistic entity; surgeons are famous for their “crude” and jarring comments to survivors about the body (many survivors told me their surgeons advised them to “just cut it off,” which they found offensive). Medical processes demand that people distance themselves from their bodies, contrary to the way most people experience themselves. As such, women are left to cope with the

emotional, embodied components of breast cancer on their own or within other forums.

The body is a social construct as much as it a personalized filter for experiencing the world: “bodies are socially constituted, always situated in culture and the outcome of individual practices directed towards the body” (Entwistle 2000: 11). Survivors are caught between medical and lay discourses, practices, and experiences of the body. Breast cancer is disruptive for many women because of what treatment does to the body and the ways in which the world of medicine compromises their relationships to their bodies, altering their understandings of their selves. Chemotherapy makes women lose their hair and turns their nail beds black. Mastectomy removes a breast. Lumpectomy can be disfiguring. Lymph node removal can cause lymphodema, a massive swelling of the arm that requires wearing a tight arm sleeve at all times. Medications make women gain weight. Treatments can force women into early menopause and decrease libido and sexual response. Some women have persistent neuropathy in fingers and toes, further decreasing quality of life. Treatment is an onslaught on the body, not just the breast: as survivors note, borrowing a phrase from renowned breast surgeon and cancer advocate Dr. Susan Love, mainstream treatment options are limited to “slash, burn, and poison” (Bolotin 1997). Many survivors struggle with body image, gender identity, and sexuality, some for long periods of time after treatment (Kornblith et. al 2003; Fobair et. al 2006).

Feelings of detachment from the body and discrepancies between one's ideal self and present self after cancer make "moving on" after cancer more difficult for some survivors than others. For instance, those who internalized traditional gender roles and attitudes and held a more "objectified" body consciousness reported greater body image disturbance and quality of life after treatment than others (Boquien et. al 2013). Younger survivors may have distinct body image, sexuality, and quality of life issues because of their age (Avis et. al 2004; Howard-Anderson et. al 2012). Some studies find that women have more difficult psychosocial adjustments after mastectomy, although this may also be because of an interaction with age (Fobair 2006; Avis et. al 2004; Yurek et. al 2000). In my own study, I found younger survivors were more likely to opt for reconstructive surgery, suggesting they were more susceptible to negative body image and feelings of stigma after cancer surgery. They felt they were too young to not look "normal," and joked that their permanently perky new breasts were a silver lining to cancer. On the other hand, several older women remarked that losing their breasts was not essential to their identity; they felt their breasts were no longer central to their sexuality, and some said that their breasts had already done their most important job, nursing their babies, a long ago (indeed, breast feeding may also change women's feelings about their breasts, too). Survivors may use different frames—like childrearing—to think about their breasts (Langellier and Sullivan 1998). And survivors may contextualize losing a breast or enduring these brutal physical transformations in relation to the risk of losing

one's life (Meyerowitz 1981), such that losing a breast becomes a necessary and welcome sacrifice if they feel it will save their life. In addition, some women choose mastectomy because it eliminates the need for mammography, sparing them the anxiety of future screening. Not all survivors center their "feminine" identities on their breasts; some survivors feel that their breasts are essential to their sense of self and sexuality, and others do not (see Langellier and Sullivan 1998). But one's relationship to her breasts does influence decision-making and adaptation to treatment choices, whether that means choosing mastectomy over lumpectomy, or electing for reconstructive surgery (and what kind of reconstructive surgery) or not.

Cancer intervenes in women's conceptualizations of their bodies beyond their experiences of treatment and the medical world. The physicality of cancer, or lack thereof, is significant for how women conceptualize the disease and their body. Women who can feel their breast lump may develop an understanding of the lump as both self and other, and this may help them adjust to cancer as an illness. Morris (1999: 193) discusses how women often "dialogue" with their lumps, perceiving the lump as both "me" and "not me," which helps them negotiate risks and maintain feelings of empowerment. In my own interviews, women have described how odd it was living with their lumps, attending and not attending to them at particular times, coming up with alternate terms for them, or revisiting experiences they had had with the new knowledge that their lump was present at those times. Other survivors who could not feel their lump and were diagnosed through a routine screening had

a more abstract relationship to breast cancer. Some survivors talked about how they felt betrayed by their bodies or their breasts in producing cancer. One survivor felt that her breast had turned on her, refusing to look at that breast in the shower. Another survivor was bitter that her body could not grow a baby but could grow cancer. Because cancer was invisible, non-palpable and symptom-less, they did not have an embodied way to understand the disease.

Not feeling any symptoms of cancer, one's experience of undergoing invasive treatments may be even more disruptive. One survivor said she felt fine when she had cancer; it was only when she was treated that she felt sick (also see Leopold on cancer's invisibility, 1999). The treatment of cancer forced these survivors to experience the illness whereas they felt detached from the actual disease. Medical technologies can create a sense of "fragmented body" when tests show and reveal the body in ways people cannot experience for themselves. Even though some women may appreciate these views into the body, medical testing often raises more uncertainty and questioning, further destabilizing their relationships with their own bodies (see Griffiths et. al 2010). Serious illness, in general, may cause people to think about their bodies more instrumentally, although this detachment is often accompanied by feelings of loss (see Charmaz 1985, 2002). But the feelings of loss that women report, and the difficulties with sexuality and body image that follow treatment, are particularly salient because of the how the body is assailed in this type of cancer, entwined with cultural and personal conceptions of womanhood and sexuality (Emilee & Perz 2010).

Life with, after, or beyond cancer

In this research, I set out to explore about how people “move on,” reconstructing their selves and lives, after a disruptive event. I wanted to understand how our cognitive processes and social practices, guided by cultural understandings, work together to recreate ontological security—or if that is even possible. I wanted to understand how people who had a projected life path or idea of future self might work with those conceptualizations in rethinking their life after biographical rupture. I assumed that, in order to proceed with life, one would need to “repair” or cover over these ruptures to some degree, that the practical, psychosocial and existential questions provoked by a diagnosis of breast cancer would have to be addressed for one to function according to social norms of personhood. Re-conceptualizing one’s identity and rebuilding the mental scaffolding necessary to feel “safe” are complex psychological processes but, after all, they are social ones, as well. Redefining one’s self, reimagining one’s future, and reinterpreting one’s mission and meaning in life do not happen in a vacuum; they are guided by cultural understandings of what constitutes a self, a future, and a meaningful life.

Some survivors I interviewed said breast cancer was not a rupturing event for them, while most said it changed their lives completely. Many survivors told me they did not “go back to normal” but learned to live according to a “new normal.” I realize that “new normal” is jargon that survivors pick up from support groups. The term “new normal” has appeared

in multiple contexts since I began this research: TV shows, economic assessments, reactions to climate change. But the term, much like the “survivor” term, has currency for survivors: it enables them to envision themselves in a new phase of life, one that is not liminal, defined by life or death, and one that enables them to capture loss and hope at the same time.

Some survivors told me that, as much as they wish life could go “back to normal,” they also do not wish this. Over the course of developing their “new normal,” they began to see the shock of breast cancer, which jarred them out of ontological security and into a state of hyperawareness, as a positive event: it empowered them, in a way. Many people have written about people’s capacity for resilience, their ability to bounce back from or see the silver linings in negative experiences (Taylor, for instance, 1989). Some cancer survivors did tell me about the positive lessons they learned through their cancer experiences. But the “new normal” many cancer survivors embraced was not necessarily one that restored ontological security; in many ways, it was a new normal that embraced ontological *insecurity*—a normal in which they accepted the shadow of a second diagnosis or recurrence hanging off to the side of their lives. This understanding gave many survivors the power to take control over their lives in ways they could not do previously in their lives.

Of course, not all survivors do this. But most survivors put the pieces of their lives and selves together, just not “back” into their original shapes or configurations. Metaphors about “going back to normal” or “putting it behind them” largely do not fit their experiences. Many survivors treasure what they

have learned about themselves through the cancer experience. Their “new normal” mimics the routines of their old lives but incorporates their new understandings about life and its uncertainties. Many attribute cancer with giving them the right or permission to live consciously and make decisions about where to lay their attentions and efforts; the experience clarified the meanings in their lives. For some, this was positive, but others floundered under the weight of this moral imperative.

Chapter Outline

In this opening chapter, I have outlined breast cancer survivorship—what it is, how it came to be, and the contours of what it means for individuals inhabiting it. As I have discussed, breast cancer is a disruptive experience for most women because the body is attacked, the self is taken out of familiar contexts, and the mind has to deal with a breakdown of ontological security and subsequent influx of existential quandaries. The visibility and success of breast cancer survivorship has enabled and forced women to sculpt modern sick identities in distinct ways. The remainder of this dissertation looks at particular components of processes of rupture and “new normalization” more deeply.

Chapter 2

Breast cancer consciousness and empowerment

In this chapter, I provide a historical overview of breast cancer survivor culture and weigh in on debates surrounding “the new paradigm of health”—health as part of the modern project of self. With the rise of the women’s

health movement and breast cancer survivorship, women have become more involved in their own care. But they are also subject to particular regimes involving self and health. Some scholars critique the self-surveillance and regulation that these kinds of movements promote. Others document the benefits of “post-traumatic growth” for survivors. Ironically, amidst the pressures of modern life, cancer may enable survivors to push back against social conscriptions as much as it subjects them to new ones: women feel empowered and emboldened by cancer to say “no” to overwhelming social roles and to focus their attention on their selves—yet survivorship encourages conformity to narratives and actions of self development.

Chapter 3

Cancer’s impact on the self: identity ruptures and strategies of repair

Many sociologists have written about the biographical disruptions that major and chronic illnesses create in people’s lives. Drawing on these discussions, I examine the relationships between survivors’ perceptions of cancer’s disruption, their “identity reactions” to different levels of disruption or lack thereof, and variation in styles of incorporating cancer into self-concept that result from these two domains. I conceptualize biographical disruption as occurring on a scale of severity across time: disruption occurs not just during crisis moments of diagnosis and treatment; cancer has potential to be biographically disruptive at different points and in different ways across the illness career. Perceptions of disruption shape how survivors build or change identities in “reaction” to breast cancer. Some survivors create new identities

or project “imagined identities” into the future to help them cope with identities they have lost. Others enact various strategies to enable them to continue past identities into the future. Some experience identity foreclosure, in which they feel they cannot continue valued identities. For some, loss becomes stasis: they do not recover from losing identities and cannot create new ones to take their place. How survivors experience disruption and identity change leads them to negotiate how they want to incorporate cancer into their lives with the “facts” of their disease: some integrate cancer into their larger self-concept, some compartmentalize cancer into domains, times, and spaces, and some reject or eject cancer from their lives. These interlocking domains—perceptions of biographical disruption, identity reactions, and incorporation styles—shape how survivors move forward “with,” “after” or “beyond” cancer, which I discuss in the next chapter.

Chapter 4

Life in the “new normal”

The literature on cancer survivorship well documents the pressure survivors face from loved ones and others to “move on” or for “things to go back to normal.” Survivors in my study, following the strategies for incorporating cancer into self-concept discussed in chapter two, chose various ways of constructing normality following cancer. Most felt that “going back” to normal was not an option. They constructed a “new normal.” However, what this “new normal” means to survivors is subject to variation based on the limitations survivors experienced following cancer. In this chapter, I discuss

the cognitive strategies and social practices survivors employed in constructing normality and making use of cancer as a catalyst for self-development. Most survivors experienced poignant shifts in their perspectives on life following cancer, contracting and expanding symbolic boundaries around the self in order to take control over meaning construction in their lives. Many attempted to harness the ontological insecurity they felt in order to make significant changes to their lives and selves. Those with physical and cognitive disabilities resulting from treatment and lack of social support were less able to frame and take advantage of cancer as an “opportunity” for growth, while those who did not consider cancer disruptive also did not perceive cancer as this kind of opportunity. The cancer survivor who perceives cancer as moderately disruptive and who is not mired in attending to physical, mental, or psychosocial constraints is the one best able to take advantage of survivorship imperatives for refashioning the self.

Chapter 5

Perceptions of cancer: what is it, why did I get it, and can I be cured?

The medical establishment now describes breast cancer as a chronic disease, however I find that not all survivors conceptualize their cancer as such. Early-stage cancer survivors largely perceive cancer as something that cannot be cured but that is also not chronic. They employ multiple techniques for sustaining the apparent incongruity between these terms. Metastatic survivors, on the other hand, do experience their cancer as chronic, but they hold differing definitions of what chronic means based on their experiences of

their disease. How survivors think about cancer in these terms—cured/curable/not cured, discrete or chronic—are strategies for managing uncertainty and ambiguity. As the medical community cannot offer explanations for cancer that survivors find definitive and satisfying, and because their use of terms for cancer often do not match survivor's experiences, survivors build their own meanings on top of medical definitions for these terms. In this chapter, I also discuss survivors' theories of cancer causality, as establishing a working theory of cause aids survivors in making sense of cancer's origin and course, encouraging them to employ particular strategies for managing cancer. Survivors' understandings of these cancer terms and hypotheses about its causes are important to defining their situations: these understandings provide the conceptual frameworks that undergird the strategies and practices I describe in chapters three and four for incorporating cancer into self-concept and constructing normality following cancer.

Conclusion

In the chapters above, I discuss how survivors carve out space in their lives for breast cancer, but also how breast cancer can provide an opportunity for self development. To conclude, I revisit the techniques and strategies survivors use to create their new normal, but I also discuss the pressures they feel to use cancer as an opportunity for self-development. I discuss the potential for other kinds of events to lead to the same outcomes but also what might be specific about breast cancer at this cultural moment for tapping into

imperatives surrounding the self. These moral and cultural imperatives may create deeper inequalities, as using cancer as a catalyst for self-development is only possible for women with the resources and skills to do so. Those who cannot use cancer for self-affirmation are subject to self-blame for their failures, but they may also experience worse social-psychological outcomes by virtue of being in this new position of strain. Importantly, dominant breast cancer culture issues these imperatives but often prevents survivors from harnessing ontological security.

Appendices

Appendix A: Methodology

Appendix B: Interview Schedule

CHAPTER TWO

Breast cancer consciousness and empowerment

Culturally, breast cancer is not treated like any other disease, or like any other cancer: market forces have forged a culture of survivorship (King 2006, Sulik 2011). Membership in the survivor community comes with obligations: to be strong, to fight, to thrive. Today's dominant survivorship culture is not about activism but advocacy: it is a movement organized around individual-level empowerment. The dominant message of survivorship is to better oneself: the emphasis within breast cancer culture is on thriving, making the most of one's life. The harm in this, critics maintain, is that survivorship becomes another type of sick role to play, complete with feeling rules (Sulik 2011).

In this chapter, I discuss the socio-historical trends that have coalesced to create "breast cancer survivorship" as a cultural phenomenon, expanding upon the discussion of the breast cancer survivor identity I provided in the introduction. While there are tensions and dilemmas present within the breast cancer culture of today, particularly in terms of defining oneself through or against dominant scripts of survivorship, national trends shape the local breast cancer identities survivors are able to enact. The emphasis on empowerment within survivorship is difficult to resist as breast cancer has become fashioned as an opportunity for growth and self-improvement. Women can resist or redefine these scripts, but they have to contend with them.

My purpose in this chapter is two-fold: to explain how the emphasis on empowerment has been shaped by the breast cancer movement and other social trends, and to then discuss the implications of empowerment imperatives on breast cancer survivors. Women's participation in breast cancer campaigns has always been organized around messages of empowerment. Women became involved in health movements in order to disseminate potentially life-saving information and messages about taking control of one's health. However these messages have coalesced with other social movements to direct this kind of empowerment inward, toward the self, rather than outward, toward activism. Early breast cancer campaigns encouraged a "do not delay" message that put the onus on managing breast cancer on women; this message became the "early detection" message we receive today. This message has become an organizational frame for breast cancer involvement, but it focuses women's attention and efforts on cancer education and awareness. Importantly, early detection is not prevention nor is it a cure. It may be the best line of attack we currently have for managing the effects of cancer, but the early detection message defines women's participation as advocacy and not as activism for investigation into theories and causes of cancer.

Public health campaigns encouraging education, awareness, and advocacy merge with today's pink-ribbon culture—and other important social trends I discuss below—to promote empowerment within individual women. While pink-ribbon culture is ostensibly about honoring those women who

have died, the culture places more emphasis on those who live, asking women not to “survive” cancer but to “thrive” after cancer. Imperatives to thrive, to be empowered, and to kick cancer’s butt can disservice survivors. Survivors need a space where they can confront mortality and learn to harness the ontological insecurity they feel in order to adjust to life with cancer. The dominant breast cancer culture may block survivors’ abilities to do this by saturating survivorship with messages about overcoming vulnerabilities and suppressing death, detaching survivorship from the realities of cancer.

The evolution of breast cancer survivorship

Scholars think about the modern breast cancer movement in three periods: early 20th century, in which women were mobilized around messages of early detection, working within the established ideas and social relationships of the time; the 1960s-70s, during which the convergence of feminism, the women’s health movement, and the rise of therapeutic/self-help culture spurred women to become active patients, to create support and activist groups, and to challenge medical and social protocols; and the end of the 20th century, during which the breast cancer survivorship identity was crystallized and then appropriated by corporate cause-marketing. Below, I give an overview of breast cancer history, attempting to explain how medical treatments and social trends have produced particular breast cancer subjectivities and imperatives for survivors. My purpose here is to explain current-day breast cancer culture and provide the context in which my interview participants experience breast cancer.

The narrative that emerges through these events is one of gradual and controlled “empowerment” as women learn to navigate social and medical channels. Scholars argue that women in the first half of the 20th century participated in cancer education and outreach efforts that supported established systems of medicine and gender, race, and class. They gained experience with grassroots campaigns within these organizations, but they pushed the party line in order to participate. The more activist 1970s enabled women to challenge existing structures. The women’s health movement was a response to the medicalization of women’s experiences and male control of their bodies, but this movement did not focus on breast cancer until fairly late. The movement did give women the tools to ask questions of their doctors and challenge their subordination in the doctor-patient relationship.

The activism of the 1970s was offset by a more conservative feminism, as well. Progressive and conservative conflicts in the emerging breast cancer movement are shown through organizations’ adaptations of AIDS activism. The success of the AIDS movement in the 1980s was a model for the breast cancer movement, but breast cancer organizations split in terms of strategies they were willing to adopt (Ericksen 2008; King 2006). The Susan G. Komen® foundation’s ability to harness cause-related marketing and corporate philanthropy catapulted breast cancer culture, but at cost to the visibility of more activist and progressive breast cancer groups. The dominance of Komen and its media control continues to shape breast cancer

survivorship and the types of survivor identities promoted into the 21st century.

Early 20th century: beginnings of the modern breast cancer social movement

The burgeoning cancer movement was jumpstarted in reaction to the 1914 Cancer Report, the first report of its kind, solicited of the US Census Bureau by the newly formed American Society for Cancer Control (ASCC). The ASCC was a voluntary organization of gynecologists, surgeons and actuaries, formed explicitly to increase public knowledge about cancer. This report was the first of its kind, publishing time-series data on cancer mortality. Despite decades of Halsted mastectomies, a surgery that removed all breast tissue, axillary lymph nodes, and chest wall muscle, the breast cancer mortality rate almost quadrupled between 1900 and 1914. Another report ten years later showed that mortality rates had continued to rise through 1920 (as they would throughout the century). Overall, deaths from breast cancer rose 71% among 50-59 year olds between 1900-1920, while other cancers increased 36% (Leopold 1999: 157-8). Increases in incidents and mortality would continue for decades, into the 1990s.

The overarching message the ASCC took from these reports was that women were not seeking treatment in time (Leopold 1999: 157-158). They embarked on a public education campaign about the symptoms of cancer, proposing early detection as a form of cancer control. This rationale stemmed from and protected their belief in the curative potential of surgery for cancer, particularly breast cancer (Lerner 2000: 32), and in the theory of cancer as a

localized disease. The ASCC was mostly comprised of surgeons, given the surgical professional dominance in the early century. The Halsted mastectomy rested on the assumption that cancer could be cured if removed before spreading to other parts of the body, which depended on women recognizing the symptoms and coming forth to see doctors as early as possible. (The flaw in Halsted's theory was that if a patient's cancer was truly localized, then the invasiveness of his surgery was not necessary. Yet, he believed that the more "meticulous" the surgery, the better chance of survival, even though statistics did not support his claims. Mukherjee (2010: 69-70) describes "radicalism" as a psychological obsession of surgeons, for whom delivering the most perfect and difficult surgery was catamount to actually curing cancer.) This rationale placed the onus on women for preventing breast cancer, implicitly blaming them for lack of adherence to medical guidelines—because of ignorance, laziness, or complacency in recognizing the symptoms of cancer.

The ASCC's public health campaigns promoted a message of "do not delay" (see Aronowitz, 2007, for a thorough history). They published pamphlets, advertisements, and worked with popular women's magazines to publish articles about early cancer detection, conflating early detection with prevention. Prevention—and cure—was related to theory of "natural" progression of cancer. The Halsted mastectomy was thought to leave as little chance for recurrence as possible, as it removed all breast tissue and connected muscle, but it also left women weak, disabled, and deformed. Campaigns focused on women's fears, but, importantly, they highlighted individual

women's responsibility for good health outcomes. Early detection gave women hope that they could live if they submitted themselves to invasive, radical surgery. Women were taught that they were responsible for confronting this disease, but they were also taught that it could be confronted (Gardner 2006: 72). These messages minimized doctors' role in cancer control, as women who were not cured were thought to have submitted "too late" and women presenting with "benign" symptoms felt they had "prevented" cancer. Aronowitz (2007: 162) argues that because more women complied with the public health messaging, the ratio of deaths to number of cases decreased, creating the impression that survival rates had increased. These increases, then, supported the message that early detection saved women, keeping the delay message in circulation throughout the 20th century, even though mortality rates remained relatively consistent. The early detection message is still prevalent today, although debate rages about its efficacy. Women continue to feel responsible for their late-stage cancers and for educating other women about early detection, especially after the advent of mammography, when screening becomes synonymous with prevention.

Because of the direct message about women's responsibility, the ASCC drew hoards of female volunteers, mostly white and middle class. Women were prepped for their role in cancer control after involvement in the "science of motherhood" and tuberculosis education campaigns, in which they made use of their female networks (Gardner 2006: 18-19). Affluent women in particular became prominent in cancer education, although their wealthy

husbands were the ones who served on the boards of cancer-related organizations. The Women's Field Army (WFA), an affiliate of the ASCC and the General Federation of Women's Clubs (GFWC), was largely responsible for spreading information about cancer to women. A hybrid of feminine gentility and "military" structure, the army capitalized upon existing networks of women and women's clubs, giving groups and individuals within them autonomy in outreach campaigns, although the ASCC demanded each branch of the WFA gain the approval of local medical societies.

The importance of the WFA was that it designed programs exclusively for women on cancer. Over two million women joined the WFA in thirty nine states from 1936-1945. The GFWA, a group that actively promoted cancer awareness by delivering information to members about state health organizations and financial appropriations for research and treatment, supported the WFA's goals by offering financial assistance to women and access to diagnostic centers. The messaging was created by medical and health professionals, harnessed by the ASCC, and delivered by individual women through their participation in the WFA. They distributed 668,000 copies of the ASCC-created "What every woman should know about cancer." Women did not challenge medical authority or doctrines but adopted the conventional ideas and language crafted for them by the ASCC. Their role was not to threaten male authority but to pass on information to women (Gardner 2006: Ch. 2). Embedded within a system of male medical expertise, women nonetheless gained experience by participating in cancer control. Harnessing

existing networks of women would facilitate later survivorship organizations and identities, but working within traditional structures and deferring to medical knowledge production on cancer shaped the types of cancer survivorship identities that emerged. Garner (2006: 83) claims that women accepted this arrangement so that they could participate in creating a public health movement, which empowered many white, middle-class housewives.

Post-WWII, cancer activity took a different approach. While the public in general was confident about technology and science, the years surrounding WWII saw a drop in cancer research. Incident and mortality rates of cancer had been steadily increasing since the turn of the century; the success of the “do not delay” public health campaign increased incidences but did not decrease mortality. And breast cancer at this point was not given special consideration in scientific research (Leopold 1999: 177, 246-7); in fact, the budget for breast cancer was strikingly low given its mortality rate, although part of this reflected the mass exodus of staff into war-related research (Patterson 1987: 171). The NCI’s total budget in 1945 was \$500,000. In 1943, The March of Dimes raised \$15 million. The ASCC raised \$102,000. When Mary Lasker, prominent New York socialite and wife of an advertising executive, took over the ASCC in 1944, she was appalled that the organization did not have the funds to support research and considered even \$500,000 an “[un]suitable sum for an advertising campaign for toothpaste” (Ross 1987: 35). She changed the ASCC to the American Cancer Society, replaced the medical board with experts in financial management and public relations. She

used her husband's contacts to wage a massive public relations campaign to goad the government into designating funding for cancer research (Gardner 2006: 95). By 1945, the ACS had become the principal non-government funding agency for cancer research in the country. Their educational mission, however, still focused on early detection, and films and articles produced throughout the 1940s continued to convey this message. Lasker's PR-coup set a precedent for how to market breast cancer, foreshadowing Nancy Brinker's marriage of breast cancer to corporate philanthropy in the 1980s.

Despite the public health campaigns and reinvention of the ASCC as a fundraising machine, breast cancer was not largely distinguished from other forms of cancer until the 1970s, when high-profile women, like Betty Ford, made their breast cancer public (Leopold 1999). The NCI only began listing breast cancer as a separate disease in annual reports in 1965 (Leopold 1999: 113). The predominant theory was that cancer was cancer: breast cancer, leukemia, lymphoma were all types of cancer that operated according to the same basic rules, so that a cure for one would be transferrable to all (Mukherjee 2010). Treatments were generic, not specific (Leopold 1999: 113). This way of thinking permeated science and culture. All the major associations were devoted to cancer, not singling out breast cancer, and they often categorizing "women's cancers" together in their educational efforts. Early campaigns even lent themselves to the connotation of cancer as a woman's disease as women were thought to be more susceptible to cancer (Leopold 1999: 278). The ASCC's/ACS's public health campaigns and

women's role in cancer education did not give rise to collective identities in relation to breast cancer as these efforts were focused on prevention, on being healthy. Participants were healthy women; sick cancer patients were not part of early awareness campaigns except as examples and vignettes in pamphlets, and they were usually stigmatized for their lack of vigilance (see Leopold 1999 and Gardner 2006).

Cancer patients and survivors of cancer were largely not visible in daily life. Klawiter (2008) describes the early 1900s as the "regime of medicalization," dominated by cancer survivors' adherence to a sick role which isolated patients from each other. Reach to Recovery (RTR) continued in this vein even though it was ostensibly an outreach program. Founded in 1954 by Terese Lasser, a cancer survivor herself (although the "survivor" identity was not yet in commission), RTR was an organization that encouraged women who had had mastectomies to visit other women recovering from surgery in the hospital to teach them how to wear prostheses and encourage them to return to "normal" life. Women were not meant to remain in touch after this meeting. In a sense, RTR is a forerunner to the "Look Good, Feel Better" program of the 1990s, which donates cosmetics and beauty lessons to cancer survivors. Both programs were designed to help women transition into a post-cancer life: RTR delivered the message that concealing mastectomies would help women resume their regular social roles, which would be psychologically beneficial for them. It encouraged invisibility of the disease while, at the same time, bringing breast cancer survivors out

into the open, at least insofar as they divulged their status to others going through the same experience. RTR was not an effort aimed at forming a collective identity: it encouraged hiding that identity in order to be normal. But, it fostered knowledge that other women who had mastectomies and survived breast cancer were out in the world, if only concealed.

Klawiter argues that even through RTR was an “anti-identity movement” (2008: 121), it nonetheless laid the foundation for a collective identity by establishing an informal network of women who could discuss problems related to mastectomy. Media messaging in the 1950s also started to discuss breast cancer surgery more overtly, and cancer educational materials had begun to address the consequences of breast cancer treatment. Gardner argues that around this time American women began to recognize that a community of women with breast cancer existed. These hidden communities were informal and apolitical. Individuals did not identify themselves according to their illness, but tried to move past it. Breast cancer survivor identities and the survivorship movement do not fully emerge until the feminist and the self-help movements crystallize in the 1970s and 1980s, transforming cancer “patients” first into “victims” and then into “survivors.”

70s activism, 80s appropriations

Klawiter (2008) defines the 1970s and 1980s as the “regime of biomedicalization,” in which such new forms of biosociality (Rabinow 2005) as shared experiences of risk, screening, diagnosis, treatment, and rehabilitation paved the way for the formation of a new collective health

identity. If the early century represented a “regime of medicalization,” in which cancer moved from the home into the hospital, and in which adherence to the sick role prevented collective identity formation, then the social and medical trends of the 1970s helped “illness identities” emerge from these shared experiences (Charmaz 1991, Barker 2002). The illness identities women with breast cancer had access to at this point were ones of suffering and invisibility: they were “cancer patients” and then, with punitive new treatments and consciousness raising, “cancer victims.” Radical mastectomy was still common throughout the 1970s, but proponents of breast conservation surgery, chemotherapy, and radiation were mounting. The harsh chemotherapies of the 1980s transformed breast cancer into a prolonged and brutal public battle: women looked sick, losing their hair, becoming emaciated, having their skin turn grey and their nails black. Unlike with radical mastectomies, cancer patients going through chemotherapy could not conceal their cancer status in public. Intense treatments and stigma created strong bonds between cancer patients, bonds forged through collective suffering.

Early survivorship groups were modeled on the “rap session”—a spillover from consciousness raising groups of the 1970s. As oncology units did not address the psychosocial needs of survivors, survivors created groups based on common feelings and experiences, spaces for them to share their experiential knowledge of medical protocols and bureaucracy as well as to express fear and suffering. The rise of the feminist health movement and self-

help culture helped women tap into anger about illness, describing themselves as victims of cancer rather than blaming themselves for its occurrence.

Women's belief in early detection and in their personal responsibility for their health—produced in part through “do not delay” public health campaigns of the ACS—produced feelings of shame and self-blame (Leopold 1999: 172-3). Becoming a “survivor”—a term employed in the 1980s by an advocacy organization—was not only about surviving breast cancer and its toxic treatments, but about overcoming these feelings of self-blame and victimhood, as well.

The women's health movement did not, at first, take on breast cancer as an issue. They were focused on birth control, abortion rights, and the medicalization of women's experiences. But their challenge to the paternalism of medicine and medicalization was not lost on women with breast cancer. The 1971 publication of *Our Bodies, Ourselves*, while largely not about breast cancer, did provoke questions about treatment and was instrumental in raising women's consciousness about their rights and responsibilities within the doctor-patient relationship. The first edition described medical knowledge on cancer as incomplete and highlighted the risks of treatment: “The most important thing to remember is that breast cancer is still not very well understood, that probably no treatment is clearly the best one, and that your feelings about losing a breast or receiving radiation or taking general anesthesia are all important considerations in making any decision” (Boston Women's Health Collective 1971: 265 cited in Gardner 2006: 206). Later

editions included more information on breast and cervical cancers, promoted breast self-exam, discussed doctors' responsibilities, and presented medical studies that challenged the necessity of radical mastectomies. (Respected surgeons Drs. Oliver Cope, George Crile, Jr., who later became Rachel Carson's doctor, and William Nolan, who published his findings in *McCalls* and the *Radcliffe Quarterly* after being blocked out of major medical journals, actively challenged radical mastectomy, although Dr. Bernard Fischer's clinical studies comparing radical mastectomy to lumpectomy with chemotherapy and radiation, published in 1985, changed the practice.) The 1976 edition encouraged women to share their experiences with others, learn more about medical procedures, and use the RTR program. Gardner (2006) argues that women had always been invested in cancer awareness, so that cancer, within women's circles, was never "silent," but that they had not challenged medical authority until the 1970s and 1980s, when the women's health movement, feminism, and other social movements and trends converged.

Leopold (1999) claims that feminists became interested in breast cancer as an issue after they had had breast cancer themselves. Their insider knowledge was helpful for three reasons: they learned the limits of medical knowledge and the unpredictability of the disease first hand, they felt empowered by survival, and they did not feel a need to revere their doctors anymore—they had already received their "best and worst" (p. 250). She claims this galvanized women into action. Frank (2003) makes a similar

argument about how experiences of cancer thrust women into advocacy and activist positions. For Rose Kushner, this may have been the case. Kushner, an experienced medical journalist and feminist, was diagnosed with breast cancer in 1974, the same year as Betty Ford. She quickly researched breast cancer and refused to have a “one-step” procedure, in which a woman would go into surgery for a biopsy and receive a radical mastectomy while still under anesthesia if her pathology indicated malignancy. Kushner convinced her surgeon to perform a biopsy only because he was convinced it would be negative (Lerner 2001: 177). Eighteen doctors rejected her request for a modified mastectomy before she found one. After her experience, Kushner devoted her work to ending the one-step procedure and challenging the efficacy of the radical mastectomy and aggressive chemotherapies. Kushner’s research and activism, efforts culminating in several publications on breast cancer, earned her a position as the first lay member of an NIH scientific committee, evaluating treatment options for breast cancer, and later President Carter’s National Cancer Advisory Board. She also cofounded NABCO, the National Alliance of Breast Cancer Organizations, whose mission was “to educate both patients and clinicians about good breast health, provide the latest breast cancer information, and foster community support,” (CancerNetwork 2001) and was a task force member of the ACS.

Adding to Kushner’s feminist critique of the medical establishment, Susan Sontag and Audre Lorde critiqued the social aspects of suffering and stigmatization associated with cancer. Sontag’s *Illness as Metaphor* (2001

[1977]) describes how the social meanings attached to cancer and AIDS define and describe the experiences of sufferers, foreshadowing Arthur Kleinman's (1988) distinction between illness and disease. Sontag called for a liberation of disease from illness metaphors, as if stripping the biological disease of its cultural associations would annihilate the stigma attached to disease. She understood that social meanings construct how a disease is perceived and stigmatized, but she did not go so far as to articulate that these social meanings actually construct the disease itself (Scheper-Hughes and Locke 1986). Nevertheless, her larger point was to illustrate the ways social meanings of disease add to suffering. In a similar vein, Lorde's *The Cancer Journals* (1997 [1980]) criticized cultural conventions that relied upon women's subordination. She refused to wear a breast prosthesis, arguing that doing so reinforced heteronormative femininity and rendered breast cancer invisible, masking women's suffering in order to support the status quo. This critique hit the core mission of organizations like Reach to Recovery, which encouraged women to look normal and return to their normal lives after cancer.

Yet, Leopold argues, the rise of breast cancer consciousness was not within the progressive feminist movement, but with Betty Ford (1999: 249). Ford's disclosure helped women forge an imagined community of other survivors. Her cancer inspired approximately 55,000 people to write her, many sharing their personal breast cancer experiences and offering advice for post-operative care, showing the emergence of an illness identity (Gardner 2006: 191). Her encouragement to women to have breast exams and mammograms,

which she had not done, resulted in the “Betty Ford bump”—an increase of breast cancer incidence of approximately 15 per cent (Lerner 2014). While feminists, and Rose Kushner, in particular, were dismayed by Ford’s deference to her doctors and her husband—her choice of the “one-step” procedure and military hospital instead of an NCI-designated cancer center were particularly egregious to Kushner—other women were emboldened by her. The distinction between the feminist positions of Ford and Kushner mark a division in breast cancer culture between the more activist-oriented strain of the cancer community and mainstream breast cancer culture. Ford continued the line of breast cancer advocates supporting the expert systems already in place, trusting doctors and the government to deliver the gold standards for women’s treatment. Kushner and others presented a more activist route, challenging the politics behind breast cancer research and treatment, advocating for women’s decision-making as part of the medical team.

Throughout the 1970s, breast cancer became more defined as a distinct cultural concern and a medical problem. Leopold (1999: Ch. 7) argues that as public recognition of breast cancer grew, breast cancer itself, ironically, became more invisible. The 1972 Breast Cancer Detection Demonstration Project brought mammography and breast self-exams into common use, further increasing *breast* cancer awareness while also defining an “at risk” population. Mammography caught small cancers and pre-cancers, so that more women had no visible symptoms of the disease when diagnosed. Leopold argues, “diagnosis is no longer a confirmation of illness but an advanced

warning of disease” (1999: 227) by which she means that women no longer suffered a long illness period with lesions and other symptoms *before* diagnosis; they were only “sick” *after* diagnosis—and usually from treatment, not cancer. Catching cancer early meant women felt more discrepancy between the disease state and treatment for it: the disease was painless and unnoticed while treatment was toxic and traumatic. This shift in experience of cancer contributed to burgeoning breast cancer identities as did the growing numbers of women diagnosed. Even though cancer mortality rates did not decline until the 1990s (and even then, not by much), the increases in numbers diagnosed and discussion of the disease in newspapers, magazines, and popular TV shows created a growing sense of breast cancer as both commonplace but formidable. If individual women were still stigmatized for contracting the disease, the disease itself became less stigmatized as it gained “respectability” as a medical entity (Leopold 1999: Ch. 7).

In the 1970s and 1980s, breast cancer becomes a “medical problem,” a legitimate and discrete scientific enterprise with its own screening practices, clinical trials, and statistics. Women had claimed an active role in their treatment and in health advocacy, laying the foundations for illness identities, but breast cancer had to first be legitimized as a distinct disease, with distinct medical protocols, before growing numbers of patients could collectivize as “breast cancer survivors.” Breast cancer patients also needed a message of empowerment to *want* to rally around the collective identity. The punitive treatments of the era made women feel as if they had lost their identities and

senses of self (Charmaz 1983). Being a “survivor” offered many a message of hope and strength. Breast cancer activists and advocates, especially the National Coalition for Cancer Survivorship (NCCS), a survivor-led advocacy organization, employed this term specifically to empower cancer survivors after treatment.

The political consciousness that emerged in the 1960s-1970s created the potential for activist survivorship identities to emerge, but the 1970s-1980s’ focus on “expressive individualism” (see Cowie 2010) shifted attention within breast cancer to self-empowerment. For instance, women’s magazines, running information-based stories on cancer since the 1930s, took a more personal turn in the 1980s. Ann Gillian and other celebrities reinforced breast cancer as a personal narrative. The trend toward “public observation of personal trauma” via memoirs and self-help books also helped shape the perception of cancer as an individual, personal act (Leopold 1999: 254). Rather than transforming breast cancer awareness into political consciousness, these stories couched breast cancer within predictable narratives of personal exploration, faith, and strength (ibid), a direct line to the pink-ribbon culture criticized by Gayle Sulik (*Pink Ribbon Blues*, 2011), Samantha King (*Pink Ribbons, Inc.*, 2006), and Barbara Ehrenreich (“Welcome to Cancerland,” 2001, and *Bright-sided*, 2011) for excluding narratives of hardship, death, and dying. Cancer survivors emerged, learning how to be empowered through their disease, becoming advocates but largely not political activists.

Support groups may have funneled women's anger toward self-empowerment rather than activism, as well. This movement toward "the self"—toward narratives of personal exploration and strength—is a product of 1970s therapeutic/self-help culture (Stein 2011, 2014). Despite the decades of public health campaigns, women at this point in time still received most of their knowledge from the experiences of others in their social networks, which, Leopold (1999) claims, caused them to engage with breast cancer on an emotional level and not a political one. The advent of aggressive chemotherapies might also have turned women's focus inward, on the self, rather than outward, on the politics of medical science. High-dose chemotherapy and bone marrow transplants emerged in the 1980s. These treatments were devastating and had long-term effects. Some women may have been too consumed by treatment effects to be able to forge activist identities during treatment. Surviving these therapies left women grateful to be alive as breast cancer mortality was still rising during the 1980s and into the 1990s. Harsh treatments brought women together, largely not to fight for different kinds of treatments or protest medicalization, but to find hope and comfort in togetherness—and then to claim triumph in living. The kinds of personal narratives dominant in the 1980s and 1990s may have raised awareness of the effects of treatments and helped to forge a collective identity, which helped destigmatize cancer and give women a voice, but they largely worked to depoliticized breast cancer, as well. Environmental and medically-oriented breast cancer activist organizations exist, but they are marginalized in

terms of publicity, fundraising power, and survivor identification. The backlash against progressive feminism and the rise of identity politics and neoliberalism in the 1980s and 1990s, the harsh treatments employed in the “War against Cancer,” the cooptation of consciousness-raising by the self-help and positivity movements, amongst other social trends, coalesced to redirect survivors’ attention toward self-empowerment and advocacy rather than cancer activism.

The dominance of “pink-ribbon culture”

The division between political activism and self-focused advocacy represents different “cultures of action” (Klawiter 2008) within the breast cancer movement. Klawiter uses this term as a heuristic to define different motivations, actions, and philosophies present within particular local contexts, but national organizations often set the tone for their constituents as much as they are influenced by them. Within breast cancer, one particular organization embodies the dominant “culture of action” today: Susan G. Komen[®]. Nancy Brinker formed Komen in homage to her sister, Susan G. Komen, in 1984. Brinker, married to a wealthy business tycoon, capitalized on her social connections and ability to craft breast cancer into a marketable cause, turning Komen into the largest private source of breast cancer funding in the US. Notably, Betty Ford was Komen’s honored guest at one of their first fundraising events. Komen, like Ford, is not about challenging the medical community or overarching patriarchal structures but working within them.

Komen's strength has been in appealing to corporate sponsors to raise money for a variety of purposes: education, screening, advocacy, and research. Komen has been criticized for not spending enough on research, and, within the money they do spend, for focusing on research that does not directly relate to a *cure*. Most of the research they fund can be classified as prevention or early detection. Even with the support they do give to diverse programs, Komen is best known for rallying survivors around messages of self-empowerment, aligning themselves closely with National Breast Cancer Awareness Month and the pink ribbon. Race for the Cure[®], their signature event, is ostensibly about remembering those who have died of breast cancer, but it has become more about creating an opportunity to feel empowered (and promoting pink merchandise). Komen's successful fundraising campaigns and its alliance with corporate partners has ushered in an era of "cause-related marketing" (King 2006): non-controversial and non-confrontational, breast cancer is the perfect corporate cause (Belkin 1996). Komen does not follow the "extreme" strategies of ACT UP, as other activist breast cancer organizations, like Breast Cancer Action, do (see Klawiter 2008); nor does it frame breast cancer through women's rights (in fact, Komen sparked controversy in 2102 for attempting to withdraw funding from Planned Parenthood's mammography program). Their website, with links to educational material, is overwhelming geared toward fundraising and Race for the Cure[®]. It also links to its own shopping website where shoppers can buy pink-ribboned merchandise to show their "support for the cause," another

point of contention for those who claim breast cancer activism has been coopted by consumerism.

The National Breast Cancer Coalition (NBCC), created in 1991, is a product of the more progressive strain of breast cancer consciousness. It is an activist organization, aimed at lobbying for legislative efforts and yielding influence over cancer research agenda. Its message is not to educate or prevent cancer through screening, but to influence breast cancer policy and “eradicate” breast cancer (Gardner 2006: 217). Instead of an annual race, they sponsor Project LEAD[®] (Leadership, Education and Advocacy Development), a program that trains activists in the science of breast cancer so that they can participate in breast cancer research. Dr. Susan Love, one of the founders of the NBCC and the author of *The Breast Book*, the bible for breast cancer survivors, wrote with colleagues in *Ms.* magazine that the early detection campaign, one of Komen’s main funding allocations, fosters false hope and security for women. Furthermore, she argues that early detection has delayed investigation of other potential cancer causes, and has helped create a culture in which women learn to fear their bodies (Gardner 2008: 219).

The NBCC, a coalition of 600 organizations, importantly does not include Komen. Komen was invited to initial meetings, but declined to join. Klawiter tells how one prominent local activist described the initial meeting as an uncomfortable affair with the “Komen ladies” in their pearls on one side of the table, pitted against the “feminists and lesbians” on the other side (2008: 139). As types, the NBCC represents the activist wing of the breast cancer

movement on the national stage, arising out of challenges to the status quo, the evolution of the women's health movement, and AIDS activism, embracing diversity, while Komen represents the conservative wing, working with the establishment and the elite, and promoting traditional ideas of femininity and conservative politics (King 2006). The polarization of these two groups also “represents an ideological split in the national breast cancer movement about what constitutes beneficial content for breast cancer awareness and organizational activities and appropriate sources of breast cancer funding” (Sulik 2011: 52).

There was a middle ground on the national stage. NABCO, the organization co-founded by Ruth Kushner and run by Amy Langer, was an organization of grassroots community organizations based on outreach to and for survivors. However, they dismantled in 2004, claiming the breast cancer field had become too crowded and that the funding climate did not support their labor-intensive programs. Sulik (2011) claims grassroots-type efforts simply can no longer compete in a culture where advocacy is a consumer lifestyle; pink-ribbon culture depends on the “persistent presence of mass media that diverts attention to what people can do,” i.e., donate money or buy particular products, which “limit[s] other avenues for support and divert[s] attention from deep analysis of the social and cultural forces that prevent eradication of breast cancer” (p. 63). Even though congressional staffers rated NBCC one of the top 25 influential health policy groups in the country

(Heaney 2003; Visco 2005), in terms of public visibility, Komen reigns supreme.

I highlight the distinction between the types of activism and advocacy that have emerged within breast cancer culture for the potential they have to shape the kinds of demands and moral imperatives survivors feel as they enter survivorship. Activism has been cannibalized by cause-related marketing, perverted to such a degree that the efforts of organizations of NBCC and Komen are not compatible. Sulik claims that even though there is “ongoing resistance from within the movement [to pink-ribbon culture], mass dissemination [has] diluted and homogenized breast cancer advocacy and the culture it produced” (2011: 30). Individual women can and do find ways to craft identities from different cultures of action (Frank 2003, Kaiser 2008), but Sulik (2011: 29) argues that the “culture of survivorship” that emerges through local organizations and group dynamics becomes “packaged” for mass distribution through national marketing campaigns like Komen’s (Sulik 2011). As such, the alliance of advocacy with commercial industry “pinkwashed” (Breast Cancer Action n.d.) breast cancer culture.

The dominance of Komen’s position in the field and its promotion of the “She-Ro” breast cancer identity associated with optimism and empowerment as *the* survivor identity are undeniable (Sulik 2011). In the current climate, activism has become about awareness and donating money to “the cause”—but neither of these activities produces research directed toward a cure. Funding, cancer education, and cancer awareness are necessary but

they are not activist-oriented projects if they are not directed toward social and medical change. Komen's brand of advocacy props up the gender and medical structures that are already in place, perhaps succeeding in putting breast cancer on every American's mental map, but not radically altering the landscape so that we can think differently about breast cancer. Moreover, the type of survivor identity they promote has repercussions for survivors. To be a survivor, according to Nancy Brinker, a survivor herself, is to be "living proof of the unbelievable strength and courage each of us possesses. Every breast cancer survivor is a reminder that the only limits in life are the ones we place on ourselves" (Brinker n.d). While pink-ribbon culture is not responsible for creating the cultural imperatives around selfhood, pink-ribbon culture is responsible for how these imperatives have become part of breast cancer survivorship as a collective enterprise.

The rise and dominance of pink-ribbon culture and the self-empowered survivor continue on into the 21st century. If anything, imperatives to thrive beyond cancer have only become more extreme. Improvements to treatments in the 21st century—or at least in medications to modify the effects of treatments—mean that women are not as sick with chemotherapy and thus more able to claim survivorship identities while going through treatment. The harsh treatments that consumed the personal narratives of the 1980s have given way to the self-focused "She-Ro" narratives of the more recent decades. At the same time, the rise of preventive cancer medicine, in sync with the expansion of risk categories, puts more "healthy" women in cancer-like

positions: prophylactic mastectomies and use of adjuvant therapies like tamoxifen, while not common, are on the rise in “at risk” or “pre-cancer” populations. Narratives now move beyond simply surviving cancer but “thriving”—using the experience to become someone better than one was before.

The 21st century breast cancer culture has seen an explosion of organizations, online communities and chat rooms, blogs, conferences, and survivor retreats. Classes are organized for survivors around “Reinventing Your Life” and “Mind, Body, Spirit.” Survivors go on retreats and white-water rafting excursions with other survivors, even making pilgrimages to other countries to share cancer knowledge. Wellness becomes one’s life mission. Kris Carr, a young New York actress-photographer, embodies the new survivorship. In 2003 at age 31, she produced “Crazy, Sexy Cancer: looking for a cure but finding a life,” a documentary about living with her rare but slow-growing stage-IV cancer. The documentary details her use of alternative treatments, clean eating, and juice diets. She is now a best-selling author, wellness advisor, and motivational speaker. Young survivors follow her lead, promoting “edgier” identities, rejecting pink ribbon commercialism, but promoting the “thrivers” mentality (the names “Fuck Cancer” and the “Stupid Cancer”/“I’m Too Young For This! Cancer Foundation” (“i[2]y”) say it all). Komen’s Race for the Cure[®] is as popular as ever, and other organizations follow this model, holding their own races or gala events, while others promote more internal, wellness-oriented messages centered on yoga,

meditation, and focusing on nourishing one's soul and body. Both strains, however, promote the self and empowerment. In both, surviving cancer is not to be taken lightly: it is to be used as an experience to take hold of one's life—to make the most of the self and to offer no excuses for doing so.

What does it mean to be “empowered”?

The proliferation of breast cancer websites, chat rooms, blogs, and community organizations has given women more access to resources, social networks, knowledge and skills—important in supporting the activated patient/medical consumer/empowered survivor that women today are supposed to be. But access to this knowledge has also, as Klawiter argues, produced an “unwelcomed awareness” of the amount of uncertainty involved in treatment and medical procedures, the “lack of consensus” within the medical establishment, and the “primitive” state of the field (2008: 126-7). Their new identities as survivors, defined by strength and empowerment, also rest upon the knowledge of uncertainty and risk involved in medicine, of one's closeness to mortality. Today's emphasis on empowerment and positivity comes out of the history I outlined above, but, importantly, it is also always a reaction to death, even if thoughts about death are actively submerged. The hyper-vigilance and “She-Ro” versions of empowerment that have emerged may be reactions to the increased “death salience” of cancer (Little & Sayers 2004): the more access lay populations have to science, the more skepticism and lack of faith they seem to have in expert systems (Rose 2007). With this lack of faith comes fear and sometimes distrust. Survivors may react to these

heightened fears by overcompensating, becoming the She-Ro or zen master, in attempt to empower themselves.

How death, as a subject, is dealt with within survivor circles is complicated. “Survivorship” is about living. “Thriving” is about making the most of one’s life. Survivors want to “move on,” and they want to support other survivors, but witnessing others die from breast cancer sets them back in their efforts. The early-stage survivors I interviewed had mixed feelings about attending support groups for this reason; metastatic survivors felt ostracized from breast cancer culture because of this. The larger breast culture—à la Komen—glosses over death even as it attempts to commemorate those who have died. The focus is on joy and personal empowerment over cancer, not collective empowerment over cancer, because cancer cannot be overcome. The meaning of survivorship within dominant breast cancer culture and other recent victims groups is detached from death in a way it never could be for people surviving the Holocaust or even AIDS (“people with AIDS,” is the term employed within the AIDS movement, tellingly, not “AIDS survivor”). Even though the modern breast cancer movement began as a reaction to rising mortality rates, women’s roles were historically focused on prevention and concealing cancer (more activist breast cancer organizations, like Breast Cancer Action and Breast Cancer Fund, do bring death out into the open, but these groups are not mainstream. See Klawiter 2008).

The conflict between the larger breast cancer culture and the individual experience of breast cancer, though, is jarring: as activated patient/medical

consumers pull back the veil of medical expertise, they confront risk of death more directly than their predecessors did (full disclosure of one's prognosis was something the women's health movement helped achieve; even Rachel Carson was not told the full extent of her cancer, in the 1960s (Leopold 1999)). Yet, even though this knowledge is part of the cancer experience, the larger breast cancer culture, with its emphasis on thriving, asks survivors to suppress those fears and uncertainties in service to living. Certainly protest against death fuels survivor identities and survivor culture; but, to critics like Sulik (2011), King (2006), and Ehrenreich (2001, 2010), the lack of space within breast cancer culture to engage one's mortality and support those who are dying produces an exclusionary movement of superficial empowerment. Survivorship groups originally wanted to move cancer away from its association with death and give women hope and security. With its emphasis on being strong, staying positive, and kicking cancer's butt, however, today's dominant survivorship culture (as epitomized by Komen) proposes to empower women while having the unintended consequences of preventing introspection and deliberative self-examination.

The "optimism bias" within messages of empowerment

Breast cancer culture's emphasis on empowerment and growth, on being strong, staying positive, and kicking cancer's butt, derives from the larger culture's "optimism bias" or "positive asymmetry" (see Cerulo 2006) as much as it does from the ways in which "survivorship" and particular survivor identities evolved. The sick role pressures those suffering to do so within

bounds: to make the best of it, not be a burden on caregivers, stay upbeat, not be difficult. Survivors describe having to carry the emotional burdens of their family and friends, to reassure *them*.

But “positivity” also has a peculiar history within the science of cancer, as well. As people began living longer with cancer, researchers’ interest in patients’ “psychological adjustment” to cancer was piqued. Most often, “healthy” adjustment to cancer is defined as having a positive outlook on life, feelings of personal mastery over illness, and a positive self-concept “after” cancer. Wilkinson and Kitzinger (2000) trace this line of inquiry back to the work of Steven Greer and colleagues; Greer et al.’s findings (1979) helped promote the theory that psychological adjustment to cancer shapes disease progression. Self-help books of the 1980s ran with this “fact,” telling women that if they think positively, they can influence the biology of cancer (see Wilkinson and Kitzinger 1993). And, in fact, many of my participants espoused perspectives akin to this theory: a few thought their mental state would affect their cancer, but more latched onto the idea that stress shapes cancer, either via the immune system or some other mechanism. Certainly, most survivors in my study thought “being positive” was a better option than “being negative.” Other researchers have found survivors’ internalization of these messages have actually led to more fear and self-blame; survivors felt they were responsible for their disease states because they were not being positive enough (Wilkinson and Kitzinger 2000; Ehrenreich 2010).

There is a colonizing force behind imperatives to be well adjusted and empowered after cancer, especially when the cancer experience does not easily map on to how adjustment is defined by the research (having a fighting spirit, or positive outlook on the future, feelings of mastery, positive self-appraisals, and the like; see Zebrack 2000). One of my participants, whom I introduce in the next chapter, Rachel, was more upset by her oncologists' suggestion that she take anti-depressants than she was about her prognosis; she felt that framing her legitimate sadness, her right to mourn her lost life, as mental disorder stripped her of her sense of dignity and personhood more than her cancer had. Medicalization of "natural" emotions and experiences is at play here, but, in combination with scientific perspectives that reify positive emotions as healthier and more beneficial, the construction of illness as a moral problem is hidden behind a veneer of scientific respectability (see Horwitz 2012; Wilkinson and Kitzinger 2000). The "sick role" of the past has yielded to the "survivorship role" of the present, a role defined by "feeling rules" centered on being positive and feeling empowered (Sulik 2011). Even if survivors are supposed to process feelings of anger, fear, dissatisfaction, and anxiety in relation to cancer, these feelings are not legitimized as acceptable emotional states in their own rights; "negative" emotions—which may be critical positions not depressive emotions—are considered phases to pass through in order to reach a more "positive" way of being. Adjustment is employed uncritically with regard to conceptions of normality (i.e., questioning what normality actually means and what is required of cancer

survivors to return to normal life) and is often decontextualized from both their individual lives and a culture that implores survivors to make positive use of the experiences that happen to them (Wilkinson and Kitzinger, 2000).

“True” empowerment versus “false” positivity

Audre Lorde’s *The Cancer Journals* are interesting to revisit in terms of the tension between “authentic” empowerment, what might also be termed “post-traumatic growth” (Tedeschi and Calhoun 2004) and positivity as a colonizing force. Writing in 1980, Lorde was privy to the rising emphasis on positivity within oncology and the social world, although she was not a witness to pink-ribbon culture in its full expression. Reach to Recovery (RTR) was still instructing women on how to wear prostheses when she had her mastectomy, and she was admonished several times for not wearing one: one nurse was concerned about her mental state, another was concerned about the message she was sending to other women. RTR was a practical application of the theory that positive adjustment to cancer meant returning to life as normal—and returning to life as normal meant looking normal. She felt the prosthesis enabled women to live a lie: by wearing one, they could avoid confrontation of the social and existential issues that she felt were important to critically engaging with this experience. Lorde distinguishes the “superficial farce” of being positive from using breast cancer as a type self-affirmation:

It was very important to me, after my mastectomy, to develop and encourage my own internal sense of power. . . . At all times, it felt crucial to me that I make a conscious commitment to survival. It is physically important for me to be loving my life rather than to be mourning my breast. . . . But a clear distinction must be made between this affirmation of self and the superficial farce of “looking on the

bright side of things” (Lorde, 1997 [1980]: 75-6).

Samantha King, author of *Pink Ribbons, Inc.*, highlights this passage from Lorde to show the movement’s growing “tyranny of cheerfulness” (2006: 101-5). For me, what is interesting is that Lorde frames empowerment as a conscious decision to focus on life. Perceiving breast cancer as a type of experience that leads to empowerment is a radically different position than just viewing cancer as an illness or a disease—but she makes a distinction between “real” empowerment and false consciousness: survivorship cannot be empowering if it does not promote deep engagement with the self, which, often, means confronting death, insecurity, uncertainty, and fear—not to “conquer” or “overcome” them, but to accept them as part of the survivor identity. Without active engagement with these “negative” emotional states, survivorship becomes hollow, just another “rite of passage” (Ehrenreich 2001: 49). Narrowing one’s self to focus on only joy and positivity can be a way of *disengaging* with both the self and the outside world rather than working for a deeper “affirmation of self.”

Although breast cancer, like other pivotal experiences, can catalyze personal transformations, and many of my participants discussed how it did just that for them, critics of the modern breast cancer movement describe how the dominant discourse of survivorship directs the ways in which these “transformations” take place. King (2006), Sulik (2011), Ehrenreich (2001, 2012), and many others, criticize the tyranny of cheerfulness and breast cancer survivorship’s dominant consumer-oriented advocacy for obfuscating the pain

and suffering of breast cancer survivors, including the many who do not survive, and for perhaps being reproducing the “cancer industrial complex” by “normalizing cancer, prettying it up, even presenting it, perversely, as a positive and enviable experience” (Ehrenreich 2001: 52-3).

Breast cancer survivorship today, by individualizing empowerment and glossing over other women’s deaths, divorces the personal from the political. Dominant breast cancer culture may obstruct the self-reflection that promotes empowerment. The 5Ks and “3-days” are not designed to help women “look death in the face” (Lorde 1980: 47); they are public events to commemorate an identity built on denying death. As public events, they are ways to produce and maintain a collective identity controlled by the organizers—Komen, Avon, etc.—who need to convey a convincing narrative of overcoming cancer in order for their funders to benefit from the cause-marketing of breast cancer. Their message is about bravery, strength, kicking cancer’s butt—a glorification of empowerment over an enemy (which, for other women and maybe even participants at a later time, cannot be vanquished) rather than a way for survivors to confront death. Commemorating life, as Lorde says, is a *decision*; but there are few if any public spaces in which survivors can deliberate on and discuss death as part of the collective identity. Survivorship, as a culture, loses something in its inability to embrace death.

The stories of two survivors I interviewed can describe what that “something” is. Ruth has had stage IV breast cancer for almost 10 years. She was invited by her social worker to attend a mixed-stage group, but she is

frustrated that the group is not open to discussions about mortality:

Ruth: You can eradicate every disease in the world but you still gotta die. That's, uh, I guess a metaphysical question that I don't know if anybody wants to answer.

Me: Do people in group talk about the metaphysical?

Ruth: No. No, and I wish they would. I really wish they would. . . . I would like to—I would like to have more philosophical conversations, more [long pause], more intellectual conversations. I would really love to have that. I wish I could have that. Um, for what—?

Me: Why do you think that doesn't happen in group? Are people—they don't want to address this issue?

Ruth: Well, I think, I think part of it, and this is one of the reasons why I didn't really want to go to group—to this particular group—in the first place, this particular group is not necessarily for stage IV metastatics. . . . There's a lot of first-time [cancer survivors there], stage I, stage II, in treatment, um, leaving treatment . . . there are survivors who have nothing [in terms of cancer]. There's some women who come in who are survivors and they just come, to be there kind of—to just be [part of the group]. But there's nobody for [that kind of discussion]. I don't know why, and I think [the social worker] knows I'm like itching, you know, biting at the bit, because I want to have a more intelligent conversation and for whatever reason, I don't know what it is [they can't]. I would have to ask [the social worker] why. I don't know why.

Ruth wants to have this discussion with other women who have ostensibly gone through, or are going through, the same experience she is. She thinks the problem is that early stage survivors do not want to or cannot talk about the more “metaphysical” questions. I do not think those survivors actually do “face death” in the same way Ruth does, which enables them to be empowered in the way mainstream breast cancer survivorship intends. Ruth says that some of the survivors just come to be there—to be part of the group, or to be with their friends, or to feel the love and support—to be advocates and to participate in the survivor identity. But their inability, or the group's inability,

to have an intellectual discussion about their status as survivors and a metaphysical discussion about dying leaves Ruth feeling disempowered. She may not know why she needs to have this discussion (“Um, for what--?”), but she senses that having those kinds of discussions are important to survivorship.

Kara is a good contrast to Ruth. Kara may be a “blunter,” someone who does better with less health-related information and less engagement with medical aspects of disease (Miller 1986): even though she identifies as a “survivor,” and even hoped to become a volunteer at her hospital so she could help people “going through what I did” (strangely, the hospital turned her down; they did not want survivors working in the chemotherapy room), Kara does not think about cancer in relation to her self. She wants to make survivorship part of her life as an identity, but she divorces cancer from survivorship:

Me: I mean, do you think a lot about cancer still? Or do you try to—?

Kara: I don't really, no, no. I mean, I'm doing the 3-day. I've been training a lot. Obviously, I will be a resource for other people. My friend . . . her older sister is opting to do a bilateral mastectomy. She's never been diagnosed. . . . And so—she just actually sent me a message yesterday and asked if she could call me and talk reconstruction. I will always talk to anybody who wants to talk about it, for those kinds of reasons. You know? But like, just in daily life, I'm done. You know, I don't want to talk about it anymore.

. . . .

I'm proud of [being a survivor]. I did what I had to do. I'm looking forward to the 3 day. I haven't done it yet—it's a 60-mile walk. You walk 20 miles a day for 3 days, in the freezing—you know, the cold-weather gear. I hear that on Sunday, there's a closing ceremony. There's something special for survivors. And yeah—I'm looking forward to that. . . . And just increasing awareness and you know.

Kara is done talking about cancer, except for in circumstances where the talk is focused on information, where it is helpful and productive (“those kinds of reasons”). She is proud of being a survivor, which, to her, means she is done with the disease and can move on to living. Her focus on the 3-day is about doing something to affirm her identity; she is excited about the special recognition given to survivors in the closing ceremony. Increasing cancer awareness seems to be secondary—she tacks that explanation on after telling me what is in it for her—to the empowerment participation in the event can yield.

Ruth is one of only a handful of survivors who talked to me explicitly about death. She has metastatic cancer; her mortality is something she has had to accept. She knows she is going to die of cancer. Kara, stage I, did not want to talk about *cancer*, never mind death. To her, the interview was about being a survivor, which, for her, is about leaving cancer behind. As survivorship culture is really for early stage survivors, death does not have to, and usually does not, enter the conversation. But, without its association with death, why would early stage breast cancer need to be anything but a disease like diabetes? Survivorship, as a collective identity, has become about empowerment in part because it is culturally crafted as an opportunity for empowerment. Chemotherapy, mastectomy, reconstruction—these are all extremely difficult experiences. But they become “empowering” because survivorship needs them to be. They are individual “battles” in a “war” that cannot be won. The focus on individual empowerment gives the illusion that

advancements are happening. (See Sulik, 2011, and Hauser and Schwartz, 2015, for the power of war metaphors in cancer).

There is a feeling within critiques of mainstream breast cancer survivorship that the collective illness identity *should* be a politicized one: emerging out a tradition of consciousness-raising, the next logical step to breast cancer consciousness is direct action. Death, after all, pushed Nancy Brinker to form Komen. Injustice within medicine pushed Rose Kushner to act. The fact the current breast cancer culture is not activist-oriented is problematic in terms of what exactly the identity is for and what empowerment has come to mean. Lorde describes the importance of using breast cancer as an opportunity for “self scrutiny and an evaluation of our lives,” opening us to the “genuine conditions of our lives,” leading us to become “less willing to tolerate those conditions unaltered” (Lorde 1980: 59). For Lorde, the journey into the self propels one back outward, toward social change. Mainstream breast cancer culture blunts a “politicized collective health identity” (Brown et al. 2004) because it limits self-work to a particular space and time. Survivors struggle psychologically and existentially while in treatment and thereafter, but they are expected to move on, having kicked cancer’s butt. By promoting this rhetoric of vanquishing one’s enemy, survivors are not given a space within the dominant culture to develop the vulnerability they feel, which, cancer researchers show, often accompanies benefit-finding and feelings of personal growth (see Bower et al. 2005, Park et al. 2011; Helgelson 2011).

From my interviews, maintaining those feelings of vulnerability is critical to establishing a new normal in which survivors can use breast cancer to truly mobilize the self. Vulnerability means carrying existential uncertainty forward with them, as part of their identity. Messages about strength coming from broader breast cancer culture presume vulnerability can be overcome. Those who feel no vulnerability from cancer do not go on the same kind of “rewarding and strengthening journey toward a deeper self.” If existential issues are not raised or are blunted, then change does not occur. Survivors who say that life has gone back to normal or that life is no different than it was before—those who do not experience cancer as disruptive or who prevent cancer from being disruptive—cannot use breast cancer as a catalyst for growth.

“Survivorship” may offer survivors a way to resolve conflicts about the liminality between health and illness, but it also does so by offering particular social scripts. While there is room for personal nuance in adopting or forming an identity as a cancer survivor (Willig 2001; Frank 2003; Sinding and Grey 2005; Kaiser 2008), one’s illness career is informed by generalized medical protocols and dominant cultural discourses about survivorship; however, survivors do not just reproduce the narratives and identities defined. Engaging with the ontological insecurity of survivorship may enable individuals to promote self-enhancing agendas rather than become immobilized by the uncertainties of their prognosis or by blunting them through constraining feeling rules of positivity (Sulik 2011).

CHAPTER THREE

Cancer's impact on the self: identity ruptures and strategies of repair

Researchers have been confounded in trying to explain why some people identify as “cancer survivors” while others do not (Helgeson 2011; Park et al. 2009; Kaiser 2008), and why some survivors join or become active in community cancer organizations or support groups while others do not (Michalec 2005; Chavez 2014; Han et al. 2012). Identification as a “cancer survivor” does not seem to be linked to position in the illness career nor treatment type, stage of disease, or time since treatment (Helgeson 2011; Kaiser 2008; Jageilski et. al 2012), as one might expect. The majority of individuals diagnosed with breast cancer positively identify with cancer survivorship and “cancer survivor” (Park et al. 2009; Deimling et. al 2007; Jagielski 2012), independent of demographic or cancer characteristics, although this may be because “survivor” is the optimal term available for their status (as opposed to “victim,” “patient,” “person who has had cancer,” “thrivor”). Survivorship may also be a social fact by this point, such that survivors do not question its application to them (Khan et. al 2011). The majority of my sample accepted “survivor,” for better or worse.

Some studies suggest that identification as a “cancer survivor” may depend on perceived ability to fit within the dominant discourse of survivorship or in one’s ability to finesse the definition to fit one’s own experience (Henderson et. al 2003, Clarke & Everest 2006, Kromm et. al 2007, Deimling et. al 2007, Kaiser 2008, King 2008, Willig 2011; Jagielski et.

al 2012). Sinding and Gray (2004) and Willig (2011) note the potential for survivorship culture to marginalize particular survivors and demand conformity, even while acknowledging space for discursive struggle or local meanings to emerge. Kaiser (2008) found that of survivors adapted only particular aspects of dominant survivorship discourse into their identities. Those who rejected the identity did so because they could not fit themselves within dominant narratives nor could they adapt the discourse to fit them—importantly, some felt they did not suffer enough or endure the required treatments to be considered survivors. These findings suggest that a large majority of survivors define themselves in relation to dominant narratives, others are more “flexible” in adapting dominant definitions to their own experiences (see Zerabuvél 1991), and still others reject the identity or find it irrelevant to their lives. What might make particular survivors more able than others to “craft” their own survivorship identities is left to question (Kaiser 2008). Behind identification as a survivor, though, are larger questions about what cancer does to identity and how survivors incorporate cancer—as a health status, collective identity, and personal illness identity—into their lives.

Subtle social and psychological characteristics may mark the differences in how survivors respond to cancer. Cancer’s perceived disruptiveness may be the most critical variable influencing how one incorporates cancer into identity. Individuals who perceived cancer as part of continuous hardship were less likely to find cancer relevant as an illness identity; cancer was not singled out as a discrete illness experience (Williams

2000; Hubbard et. al 2010). Older people or those with other chronic illnesses may incorporate cancer into other frameworks, like the “aging body,” for instance (see Pound et. al 1998; Faircloth et. al 2004; Richardson et. al 2006; Sinding and Wiernikowski 2008; Kaiser 2008). Younger survivors, on the other hand, may experience cancer as more disruptive than older survivors because cancer is not common for their age group (Avis et. al 2004; Partridge et. al 2004; Howard-Anderson et. al 2012). In addition, they may be more likely to hold a survivor identity central to their self-conceptions because of the “greater incongruence between the experience of a life-threatening illness and a young age” (Helgeson 2011: 522; also see Park et. al 2011). These findings highlighting “incongruence” reaffirm theories of biographical disruption (Bury 1982). Importantly, Helgeson (2011) found that those who most strongly identified as a survivor were not those with the worst prognoses or illness-related problems but those who considered cancer “the most stressful thing that had ever happened to them” (Helgelson 2011: 522).

It is understandable why studies have not been able to predict why some people make cancer more central to their lives than others. Multiple aspects of the cancer experience may define the adaptation strategies survivors use in “moving on” with, after, or beyond cancer. Survivors’ appraisals of cancer and their experiences of treatment may shape whether and how disruptive they interpret cancer to be—and whether that disruptiveness is perceived as a negative experience or fashioned into a positive one. Perceptions of cancer’s disruptiveness may then influence their illness

experience and formation of identities around cancer—not only “cancer survivor” identities, but also other present and future identities. Cancer’s disruptiveness and its influence on identity may also shape how survivors incorporate cancer into or reject it from their lives. Survivors may embrace or distance themselves from survivorship as a movement, illness identity, or health status—or some or all of these—which can help explain, ultimately, how they incorporate cancer into their lives and identify as survivors. But identifying as a “survivor” does not occur by itself; how cancer influences other identities is also important to how one perceives oneself in relation to cancer.

In this chapter, I posit a relationship between perceptions of cancer as a biographical disruption, types of identities built as reactions to or resulting from one’s experience of cancer, and survivors’ overarching cognitive strategy for thinking about cancer in relation to the self. I build upon other prominent models of illness appraisals in order to contextualize how survivors respond to cancer. I theorize beyond these models that how survivors perceive cancer’s disruption on specific identities influences how they develop strategies for “moving on” with, after, or beyond cancer. These models do not describe how particular identities surrounding illness emerge, which I flesh out in my discussion. The relationship between perceptions of disruption, identity reactions to or formations resulting from cancer, and cognitive adaptation strategies can speak to whether and how individuals form cancer identities and what type of survivor identities they claim.

Illness appraisal models and their implications for identity

Two important models for explaining the psychosocial context in which health beliefs and behaviors arise are Leventhal et. al's (1980) Common Sense Model of Illness Representations (CSM), and Miller et. al's (1996; and Miller and Diefenbach 1998) Cognitive-Social Health Information Processing model (C-SHIP). The CSM describes a “parallel processing” model in which cognitions and emotions both influence appraisals of illness and health behaviors. Cancer is often a “hot cognition” because of how intricately emotions and cognitions are fused together (Diefenbach n.d.); and, indeed, cognition and emotion are never completely isolated processes, emotion usually informing cognition except when cognition can override emotion in deliberative self-regulatory practices. The CSM separates cognition and emotion into two paths to describe the differences in “emotional” perceptions and beliefs about illness versus “cognitions” about the known medical facts about the disease and these effects on illness representations, coping strategies, coping appraisals, and health outcomes; this process then loops back to influence the original illness “stimuli”—the cultural, biological, and biographical information that provides the context for illness concepts (Leventhal et. al 2011; Leventhal et. al 1980; also see Hagger and Orbell for a more recent review 2002).

The C-SHIP model complicates the original CSM model by adding five “cognitive-affective mediating units” that are “activated [or inhibited] by new or changing cancer threat information and treatment options” (Miller and

Defienbach 1988: 221). These units are: “cancer-related encodings and constructs,” which seem to be a part of the “illness stimuli” that Leventhal et al. discuss; “beliefs and expectations,” which include illness representations but also personality traits like optimism and beliefs about one’s self-efficacy; “goals and values” related to one’s health and one’s responsibility for one’s health; “affect and emotions,” like anxiety and worrying; and “self-regulatory competencies and skills,” which partially maps onto Leventhal et. al’s coping strategies and assessments (Diefenbach, n.d.; Miller & Diefenbach 1988). C-SHIP, in some ways, fleshes out some of the variables that frame the cognitive and emotional assessments that CSM describes. While CSM presents a higher-level, cognitive systems approach to health management, the C-SHIP model, by merging emotion and cognition, may lend itself to constructing psychological profiles based on networks between the constructs it outlines.

Miller (1987) has outlined two psychological adaptation styles, monitoring and blunting, which operate specifically in relation to information seeking and self-distraction but which also have relevance to the other cognitive-affective processing units in C-SHIP. Monitors actively attend to threatening cancer information while blunters avoid it. Miller finds monitors are more knowledgeable about their cancer but also more distressed by it; blunters fair better psychologically with less information. These styles have implications for how survivors react not only to threatening information, but also how they incorporate cancer into their sense of self.

There are overlaps between both models, as both focus on how people with chronic illness make assessments of illness that ultimately condition their health-related behaviors. They are useful in theorizing how survivors form identities in relation to cancer as they combine the cultural information through which the chronically ill view their disease and the biographical, biological, and personal “facts” of illness in cancer appraisal. Also, these models’ emphasis on the context in which coping mechanisms are “selected” and appraised is critical: survivors have particular personal and psychological resources that make particular coping mechanisms possible. Especially in survivorship, coping is multilayered, and many of the physical, emotional, existential, and psychosocial “problems” do not have adequate solutions. How individuals cope with these problems, then, says as much about cultural expectations of illness identities as it does about individual-level responses to disease. Kaiser explains that there has been a cultural shift in how breast cancer is approached, and that “we know little about the illness experience under overtly positive cultural meanings” (2008:81). These “overtly positive cultural meanings” influence how survivors adapt to life with cancer and survivorship identities. Coping mechanisms themselves interact with personal and cultural conceptions of disease and identity.

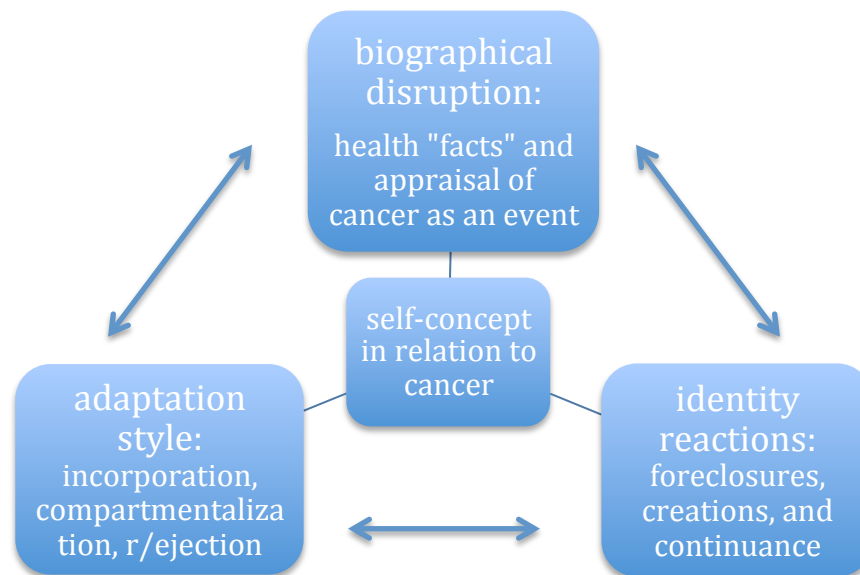
While extremely relevant to identity, neither model explicitly discusses the levels to which illness is incorporated into the self as an identity, or how illness representations and coping strategies influence the development of identity surrounding illness. How survivors interpret the event of cancer,

which both CSM and C-SHIP can help explain, also influences their identity formation around cancer. Importantly, as I mentioned above, stage of disease, severity of disease, and position in the illness career have not been found to influence adoption of cancer identity or perceptions of cancer's disruptiveness (Helgeson 2011; Kaiser 2008; Jageilski et. al 2012), although they may influence nuances in how survivors adapt to cancer and what kinds of identities they are able to craft: understandings of cancer shape conceptions of survivorship and the craftwork survivors do or do not do in presenting identities (Frank 2003; Kaiser 2008). Taking the CSM and C-SHIP models as foundations for appraisal and coping, I extend beyond these models to theorize how appraisals and particular cognitive strategies influence the construction of identities and larger self-concepts in relation to cancer.

In figure 1, I present my model for how survivors adapt cancer into self-concept. The three domains I have mapped out, biographical disruptions, identity reactions, and cognitive adaptation styles, are less causal mechanisms for one other and more interrelated parts in the process of adaptation to cancer. There are multiple ways in which one can perceive cancer as a disruption, which can influence, along with other biographical and biological factors, one's identity reactions to or formations in relation to cancer and ultimately one's style for incorporating cancer into one's overall sense of self. For example, if a survivor's cancer experience was not disruptive, then she will likely have a large degree of identity continuance, corresponding to particular cognitive adaptation strategies. It is also possible that a survivor's choice of

particular adaptation strategy *enables* her to perceive cancer as less disruptive, in combination with the “facts” of her particular cancer experience. I conceptualize these domains as interlocking and often overlapping; they influence how a survivor designs her life in relation to cancer.

Figure 1. Integrating cancer experience into self-concept



Biographical disruption. Biographical disruption is usually conceptualized as a dichotomous variable—cancer is disruptive or it is not—however disruption can be experienced in degrees and in multiple ways. If we consider the “cancer continuum” diagram I presented in the opening chapter, we see that disruption can emerge at various stages in relation to new health information or treatment effects within one illness career. The valence of “disruption” may shift as well: cancer may have a negative disruption on life when going through treatment, but a survivor may reframe this disruption as a positive

force for her when treatment is over. Time may be more important for perceptions of cancer's disruption, as the quality of cancer's disruption will change across the illness career and life course; however, I want to emphasize the "easy recall of the initial feelings and emotions associated with illness and the recovery period, a continuing concern about one's mortality, and an enduring sense of vulnerability" (Zebrack 2000: 238) that survivors experience over the course of their illness careers. They move through time in a non-linear fashion as events and other types of cues can trigger visceral memories. For example, Carol told me about sitting in her doctor's office and noticing a woman wearing a wig. That experience immediately transported her back to her own time in treatment. She recalls telling a friend, "'Look. I'm five years out, and I still cry. Like, there's never going to be—I can tell you right now. You could be 30 years out, and you're going to cry about it like it's [yesterday]—it's something that will be with you forever.'" People expect survivors to move on with time, but for those who find cancer disruptive, the trauma of the experience bends time such that having more time since treatment may not rebuild ontological security in the way outsiders expect. Thus, while disruption can be more acute at diagnosis, it is not necessarily less intense, even if qualitatively different, with time.

Identity reactions. Identity reactions to cancer or formations of identity as a result of cancer can also shift in relation to shifting appraisals as well as with the development of late-term treatment effects or new cancers. Perhaps the identities survivors foreclose for psychological or emotional reasons now can

be revisited at later points in time. Unrealistic future identities survivors project to help them cope with an ill-defined future may become less necessary if other identities are formed. Perceptions of cancer and styles of confronting risk influence these types of identity formations and activations.

Cognitive adaptation. Cognitive adaptation styles, too, may not be permanent and can be employed in relation to different social cues. For example, Breast Cancer Awareness Month may cause a survivor to move her cancer identity up or down her identity hierarchy, causing her to “eject” or “integrate” cancer more fully into her self-concept for the time being. However, I intend for this domain to represent a more holistic strategy of adaptation to cancer into one’s sense of self. I intend for cognitive adaptation styles to differ from coping insofar as they are not necessarily reactions to the problems of cancer but instead ways of experiencing cancer as part of the self. A survivor may be able to frame cancer as a purely medical problem, not thinking of it as an identity category, thus resisting reconceptualizing the self in relation to cancer. The inverse may be true as well: a survivor may incorporate cancer survivorship into her sense of self but not the health or medical aspects of cancer. Someone may be able to “r/eject” cancer from his or her self-concept while still needing to cope with cancer or its side effects.

Perceptions of cancer’s disruptiveness, part of illness appraisal that CCM and C-SHIP help define, influence identity reactions, which, together, matter for how a survivor incorporates cancer into her sense of self. This is a dynamic process, subject to various types of factors. Below I discuss some of

the intricacies involved in these domains that enable or influence survivors to select a particular pathway to how they chose to live life after, with, or beyond cancer.

Perceptions of cancer's disruptiveness

Here, I present three survivors whose experiences represent various positions along a spectrum of disruptibility of the cancer experience. Disruptiveness is tied to the physicality of treatment effects, but it is also about framing. All three had invasive treatments and advanced staged cancers. But they describe the shock of cancer and its effects on their overall selves very differently.

Perceptions of disruptiveness are related to time frame, the “facts of cancer and one’s cognitive style of dealing with cancer (compartmentalizing, incorporating, and/or r/ejecting cancer from one’s sense as self, as I discuss below.) Importantly, perceptions of disruptiveness, as the CCM illustrates and evidence shows, do not arise out of disease state alone. Moreover, disruption in the current breast cancer culture has also been reframed as a positive occurrence. These examples show the potential for disruption to last well beyond an initial cancer experience as well as for it to be staved off initially and for disruption to be reappraised.

Melissa is someone who found cancer extremely disruptive, which has lead her to try to compartmentalize cancer in her life. She is a vibrant woman who, after her cancer treatment, had a “miracle baby” at 40—completely unexpected, as most women her age are thrust into premature menopause after chemotherapy—started her own swimsuit line, and continued her

administrative position at an elite academic institution. She has a husband and two other children. She says cancer has enabled her to say “no” to some demands in her life and focus on the things she feels are important: her family, her business, her job. Even though her life sounds full and exciting, she still mourns the loss of her pre-cancer self:

Melissa: [Y]ou're given this diagnosis, but at the same time, you're saying, "This isn't happening. This isn't happening. This isn't happening. My life is going to remain normal. I'm going to remain in control." And meanwhile, the universe is telling you there's no way in hell you're going to be able to stay in control. But, so, you know—one bad thing after another just kept happening I lost all of my hair . . . my leg breaks. So, you know, at that point, you just—you've lost all control.

Me: How did you come to terms with that?

Melissa: I still haven't come to terms with that. No. You don't. Because you fight it the entire time. I mean, you kind of realize: Okay. I'm screwed. Like, this is over. Like, whatever I had six months ago, I do not have now, and I probably will never have again. [choking up a bit] So—those things are hard.

Me: You know—people talk about that a lot. Like: Okay. No more normal, but now it's a new normal. Do you feel that way? Have you—?

Melissa: I guess. I mean, I still probably try to reach for that [chuckling] normal. I mean, my kids—they haven't had [crying] normal in a long time. Whatever they—Their memories of me are basically whatever I was the last five years. You know? So, whatever that person I was ten years ago—they don't get that person. . . .

—Melissa, age 42, white, and a survivor of stage II Her2+ breast cancer. She had chemotherapy and a mastectomy. She has been out of treatment for six years.

Despite her post-cancer accomplishments, she described feeling a profound sense of loss over “that person I was ten years ago.” Her narrative is not only a powerful revisiting of the moment in which she realized “I’m screwed. Like,

this is over,” but it is also powerful because these feelings remain strong six years after treatment. To other survivors, she is in an enviable position: many use the five-year mark as a sign of reassurance that recurrence is unlikely. Others feel this is when life officially returns to normal. Yet, she still does not feel that life is or will ever be normal. As many survivors say, cancer changes one’s perspective on life. Her feelings about the predictability of life and the reliability and safety of her body have been undermined by cancer. Having kids may exacerbate her concerns about her future, as might her middle-aged position in the life course. But, like many others across the spectrum of age, cancer stage, and time since treatment, she feels that cancer has changed her worldview and sense of self. For her, there is a sharp divide in her life before and after cancer: cancer was highly disruptive and this disruption continues to figure into her life.

Clara, at the other end of the spectrum, has a consciously constructed, hard-working narrative that cancer was not and will not be disruptive (see Jordens et al., 2001, who argue that more complex narratives are related to life disruption). I quote her at length to encapsulate the nuances in her position:

Clara: I do identify with the term, cancer survivor, because I see it as—you want to overcome this. You’re not going to let it bring you down, and that you are going to survive. And that’s what the term means to me—not that I have cancer and I’m going through treatment. No. It’s what I’m thinking—because usually, people tend to associate cancer with death. “Oh, cancer. Oh, yeah, cancer. Oh, my goodness! Agh! Agh! Life is going to change.” My interpretation of cancer survivor is that I’m going to survive [pause, thinking] the stigma that is associated with cancer.

Me: Hmm. Do you still think there’s a stigma? In today’s day and age, there’s still a stigma around cancer?

Clara: Oh, sure! I believe that. I believe there is a stigma. We associate it with the term cancer itself. Meaning, you know, you have cancer. Oh, my goodness. Your quality of life is going to change. How are you going to cope? You know? . . . [Everyone] automatically thinks all is going to change, you know, topsy-turvy. And it really depends. If you allow it to—okay. I understand some people, physically, it really drains them and they really go through a lot. Like I said—I’ve been blessed. I’ve been grateful that I did go through this. I did have some of the side effects, but for the most part, I was able to overcome a lot of the side effects, or not have any at all. But I just think that, survivor means, you want to live! You want to survive! You want to overcome this.

. . . .
Because again, Jennifer—I don’t want you to misunderstand. I didn’t say I didn’t have bad days. But my attitude was always: This too shall pass. I’m not going to let it get me down. Yes, I was like, “Why me?” You know, “Why me?” But I got over that. Why *not* me? . . . But just—again—I cannot stress enough—I think attitude—how you accept things. How you see yourself. You know?

—Clara, 52 years old, African American, and a survivor of stage II cancer. She had a bilateral mastectomy and chemotherapy. She has been out of treatment for almost one year.

Clara is working hard to explain to me, perhaps convince me, that who she is deep at her core has and is not going to change because of cancer—because she will not let it. She identifies what she calls a stigma against people with cancer: that others automatically assume people with cancer are going to die or are going to have to curtail their lives. She marvels that her family and co-workers say she has not changed. She tells me that she has had bad times so that I know she is not in denial about how serious cancer is. She actually says later on in her interview that she is not in denial. She is consciously framing her experience—which is what she means when she says “attitude” and “how you see yourself” are important to moving on after cancer. She later tells me that she does not even consider cancer a disease, but an experience she has had

to go through. She identifies as a survivor *because* she has remained unscathed by this experience. Clara is trying to explain to me is that she is not going to allow cancer to be a “biographical disruption.” She and her family, a husband and two early-teenage boys, kept everything “normal” during her treatment. She says she will do her utmost to continue to keep life normal after cancer. She notes that the experience has changed her in some ways—she feels more connected to others and has joined the cancer community; she reminds me that she has “fake breasts after all!”—but she feels it was a matter of cognitive work that she did not allow cancer to disrupt her life.

Melissa and Clara have a lot of similarities: they both had stage II breast cancer, are middle-aged (although ten years apart), have spouses and children and similar household incomes, and have had invasive treatments. There are some major differences between them that could account for their differences in perspectives. Melissa is six years out and Clara is almost one year out of treatment. Melissa is white and Clara is African American. Religion is important to Clara, but Melissa didn’t mention it. These cultural aspects may shape their cognitions toward illness and how they defined their situation, as other scholars have discussed the roles of race and religiosity in shaping coping mechanisms (see Henderson et. al 2003; Davis et. al 2014). But the differences in cognitive styles they employ are striking. For Melissa, cancer had a major, disruptive impact on her life, destroying her sense of normalcy. When she was lying in her backyard with a broken leg—bone density diminishment is caused by treatment—she said she gave in and

accepted how out of control her life now was. Cancer invaded not only her body but also her life. Clara segmented cancer from her normal life, enacting a detached stoicism about the medical experiences she had to endure, but she did not let the experience change her core self. Melissa and Clara might change their cognitions about cancer as they move forward, but, frozen in time at the moment of the interview, they represent two poles in a spectrum of how disruptive they perceived cancer to be and the strategies they used for this.

Most of my study participants fell somewhere in between Melissa and Clara. Many described feeling “the same but different” after cancer. Gail has had ten years since her diagnosis, more time than Melissa and Clara have had to reflect on her experience. Research cautions against thinking time provides ultimate security (Zebrack 2000); time may help life become routinized, but existential awareness of cancer may not diminish over time. Gail’s interview was calm; she did not feel cancer upended her life at the time as she continued working through treatments. But she also struck me as a “hardy” person: she seemed even-keeled and no-nonsense, making me think that perhaps her personality helped her quell cancer’s effects. She discussed some physical limitations, but seemed to take a “that’s life” attitude about them. She seemed to accept that cancer “just happens” without wondering “why me?” or wanting to attribute larger meaning to it. She describes her stage III cancer as having, if any impact on her life, a positive one:

I don't think [cancer] really affected how I feel about myself. You know, maybe I do—it gave me more strength, because you have to go through so much and dealing with it, and I think more patience, you know. [Laughter] Because it totally slowed you down, going through all

that. You're not as impulsive and everything. I'm not anyway. It's like I think it just calmed me down a bit. It's like, I was always so busy, running around, doing this, doing that. But now, I don't worry. It's like you can't worry about things. You get done what you can. You do what you can, and that's it. You know?

—Gail, age 58, white, and a survivor of stage III breast cancer. She had chemotherapy and a mastectomy. She has been out of treatment for 10 years.

Gail describes cancer grounding her, making her stronger, more patient, calmer, less worried. Many women described emerging from cancer—some, immediately after treatment; others with more time—feeling more confident and sure of their abilities to overcome adversities. Many also felt, surprisingly, *less* worried about life's surprises after cancer: after surviving treatments, they had confidence that they could handle whatever life threw at them, even another bout of cancer (a few survivors told me their first cancer was a good trial run; they were prepared now, if it happened again). Cancer revealed themselves to themselves: it made them aware of inner resources they did not know they possessed. It strengthened their selves not only in that they felt emotionally stronger or resilient, but also because cancer concretized or made salient hidden or underdeveloped aspects of the selves. They talked about overcoming cancer like it was Mt. Everest. It was hard, it required a lot of mental and physical strength, but they learned something basic about life through the challenge. Many reappraised cancer's disruptiveness as positive or did not perceive cancer as “disruptive” to their life and sense of self.

Identity reactions to or formations as a result of cancer

Perceptions of cancer's disruptiveness are linked to the impact survivors attribute to cancer on their lives. One domain in which they experience impact is identity. Survivors feel cancer changes the self through how it shapes particular identities. I call these "reactions" because identities are formed, altered, or foreclosed because of cancer: cancer sets these identities in motion. The content of past selves and newly re-imagined future selves, of specific identities survivors hold, are dependent on the circumstances in these women's lives, but these identity reactions to cancer exist across groups.

Type 1: identity foreclosure

For some, cancer forecloses the possibility of developing particular identities or extending valued parts of one's past self into the future (Charmaz 1983). The side effects from treatments can cause pain, neuropathy, breathing problems, and cognitive difficulties, making it difficult for survivors to resume or perform certain activities. Survivors talked about how they lost access to salient parts of themselves by not being able to participate in cherished activities. These physical limitations foreclosed certain possibilities, but survivors experienced other foreclosures through their doctors' or others' proscriptive advice. Survivors also felt identity foreclosure because of their own perspectival shifts: they felt they could not sustain certain identities after cancer because they now deemed those identities harmful in some way, felt they were not worth maintaining anymore, or felt they could not keep up with

them. These shifts in perspective made a particular identity undesirable or feel impossible.

To some, these changes mark the end of their taken-for-granted health status—the end of one way of being in the world and the beginning of another. Feeling a sense of loss is related to the salience or centrality of an identity; identities low in the identity hierarchy do not present the same risk of loss to the self. These identity foreclosures result from particular cherished self-concepts being hit, directly or indirectly, by cancer (see Thoits 1991; Morris 2013; Brenner et. al 2013).

Ghosted selves

Shelley is the anti-cancer-survivor. She does not identify as a cancer survivor. She does not believe cancer had an impact on her. She does not think she learned any life lessons from cancer (other than that she likes stainless steel cookware better than Teflon). She emailed me after our interview to describe more about how she never felt cancer was a problem because it was invisible: she didn't feel it, see it, or have any pain or problems from it.

For her, the problem with cancer was the treatment. Surgery left her with lymphedema and weakness. She does not connect these effects to cancer but to the treatment. Shelly gets emotional in her interview not when describing the endless care she has to give to her arm, or the unwanted attention she receives because of her sleeve, but because she perceives cancer as a major setback to her kayaking:

The biggest regret I have is that, we'd just gotten sea kayaks. Excuse me. *This*, I'm emotional about. [choking up a bit] I can't believe I'm

emotional about this. And we had them a year. I learn physical things very, very slowly. It took me two years to learn how to swim. And I was starting to roll the kayak. . . . I was really making progress. And the people I started to paddle with—they were novices when I was a novice. They were a lot younger than me. But I was coming along with them. And then the breast cancer came and interrupted everything, and I couldn't do it for a year. And I've never really gotten back into it—I mean, we do a little bit of it here and there. But never seriously again. I tried to do Aquacize We used to swim a mile a day. . . . All I could think was: Why can't I just swim a couple of laps? [chuckling] You know, the whole time I'm doing it, it was very frustrating to me to be in the water and not being able to swim.

—Shelley, age 62, white, and a survivor of stage II breast cancer; she had a lumpectomy, chemotherapy and radiation. She has been out of treatment for three years.

Shelley discussed at length how she grew up obese, struggling for years to gain control over her weight and her health. She never thought she was athletic, and was extremely proud of the outdoor life she and her husband cultivated. They spent years learning how to canoe, kayak, and, finally, sea kayak. The wound she feels about losing these activities elicited more of an emotional response than any other part of the interview. The swimming and the sea-kayaking are not just activities that Shelley can no longer do, but they are a reminder to her that she has lost something through the process of cancer. She may not want to think about cancer, but these effects are markers of health decline, limits on personal freedom, and the lack of control people have over life. Shelley may have been able to start anew with her kayaking, but she *feels* unable to. The knowledge that she would always be permanently behind, unable to perform at the level where she thought she should be, if not for cancer, was too difficult for her. She chose to give up sea kayaking rather than perform at a lower level.

For Shelly and others, loss of an activity like this is accompanied by a loss of past self, an idea of who one was and what one was able to do. Those activities are part of one's previously "carefree" self, the self who does not have to worry about or think about cancer: implicit in this loss is the feeling that the "normal" me existed before cancer. Survivors have to come to terms with the fact that that "me" does not fully exist anymore (see Charmaz 1991).

As Amanda explained to me, "normal me is the me that existed before I heard to words, 'You have cancer.' It's a me that doesn't particularly worry about cancer. I don't think about mammograms and I don't think about ultrasounds and I don't think about cancer cells roaming free." Ariana explains this sentiment in her story about how she is not allowed to live as if she did not have cancer, despite her best efforts:

I completely forgot about everything, in the sense that I just went back to my normal life. You know, things I did before. I got off the tamoxifen, so I felt much better. And then, I went back to my doctor about the middle of July—my fiancée's family has a beach house. So, I'm constantly down at the beach—And she goes, she said something about how tan I am, that that's not really good. There are studies that show that BRCA-positive people have a higher chance of developing skin cancer. And it really brought it home. And she was giving me, not giving me a hard time, she is so sweet, but saying like—and I was like, "Oh, I wear sunscreen," and she goes, "Oh, it doesn't look like it." Or, "You could've fooled me," or something. I got really upset by that, and that really reminded me that, as much as I'd like to be normal, I'm not. I'm always going to have this in the back of my head that I have to be careful. So, now, I'm back to where I'm going under the umbrella, wearing my shirt at the beach. But, I guess that's just something you have to deal with.

So, I'm sure, next time I go back, it'll be something else that she'll have to like re-put in the front of my head. That's the hardest part, trying to feel normal, but also trying to remember—I don't know how to say it—to be conscious of things.

And it made me upset. The last time I cried was when I lost my hair. And then . . . when she left the room, to my mom and my aunt, I was like, “I forgot. I forgot that I had cancer.”

—Ariana, age 25, white, survivor of stage IIB breast cancer; she had a lumpectomy followed by chemotherapy, radiation, bilateral mastectomy and reconstructive surgery. She has been out of treatment for 5 months.

Losing “normal” activities like kayaking or going to the beach may seem minor, but they represent a larger shift in consciousness and identity. Adriana is the youngest survivor in my sample, at 25. For her, these “minor” inconveniences may be particularly difficult because everyone else in her age group is doing them. She is not allowed to be young in the same way that other people are. She also talks about how unreasonable expectations to give up alcohol or sugar completely are: “What am I supposed to do? Live in a bubble?” What was once normal is now considered dangerous: accepting these “new” limitations on life changes how survivors think about themselves, adding a mental weight to everyday life as they need to be conscious of things previously taken for granted. Who you are becomes defined by things you cannot do, as much as the things you now have to do (see Mullaney 2006).

Identity downsizing

The change in perspective that cancer causes, the careful awareness that Ariana describes above or what another survivor termed “mindfulness,” can constrain life as much as it can be used to refocus attention and energy on the self. Some used this shifted consciousness to gain more control over their lives. Survivors changed their eating and exercise habits, committed themselves to “being healthy.” Going organic, doing yoga and meditation, and

avoiding chemicals perceived to be hazardous were prevalent ways survivors tried to take control over their risk levels—but so was avoiding “stress” (I discuss these techniques as a way to gain control over cancer more in chapter 5).

Candace discusses her efforts to eliminate unnecessary stress in her life. She explains that she lives daily life attuned to her health, consciously thinking about how to help her body avoid recurrence. Because she chose to have a bilateral mastectomy in order to avoid chemotherapy and radiation, she now feels she has to be extra vigilant about maintaining a strong immune system. She made a “conscious choice” to downsize her career aspirations in order to avoid stress, which she thinks would jeopardize her health.

Candace: I have to think about [cancer]. You know, I just can’t go out everyday and not think about my health. I have to think about having cancer, and worry that it could come back. Regardless of everything [else] that I’m doing.

Me: Does that change decisions you make? What kinds?

Candace: Now, I don’t want to—I mean—I’ve been looking for work for the last two years. But there are things I don’t do now. I’m not going to do certain things to jeopardize my health, things that I might have done before, that I know I’ve done before. You know, worked in jobs that were high-pressure, a lot of stress and anxiety. I don’t do that anymore.

Me: Has it changed how you think about the future and what you want in the future?

Candace: Yeah. I don’t want to do any of those kinds of activities anymore, just to be in a job with a title and a big salary. I’m not going to do that anymore. It’s a conscious decision.

—Candace, age 59, white, survivor of stage II breast cancer. She had a bilateral mastectomy one and a half years ago.

Many survivors linked cancer and stress, and many talked about trying to find jobs with lower levels of stress. Some survivors felt stuck, unable to affect these kinds of changes. The line between opting out and being pushed out is thin. Candace may be in a better position than others because of her age and income to be able to wait for the kind of position she wants, but doing so also means blunting an identity that was important to her at one time. Many survivors told me they “just couldn’t do it” anymore: they did not want the stress, the demands, the trivial personality conflicts. But many phrased this in terms of choice: they found the rewards of the job less than they might have at one time and/or found other things more rewarding. For example, Morgan describes cutting back on activities and changing jobs because of a combination of physical limitations and changes in her perspective:

Morgan: The major [side effect] is the change in my breathing. I always carry my rescue inhalers. I dress in layers so I can pull stuff off and put it back on if I need it. And I pace myself. I don’t have the same amount of activities. I used to be like the Energizer Bunny. But I had to slow that way down because I would hit the wall and then crash and burn.

Me: So what did you cut out?

Morgan: Well, I cut out staying late here When I was Director, I would work 12, 14 hours a day. Now, I keep things to 8, maybe 9. But I changed my job, number one. I’m no longer a director. I don’t have anybody reporting to me. And that job, I leave in 8 hours. It was a lateral position in terms of salary I’m sure people would say it’s a different status. Whatever. [Laughter]

Me: It doesn't concern you?

Morgan: No. Maybe if I was 38, but I’m 58—been there, done that. I don’t care about that anymore. I used to do a lot of outside activities. [Now] I pick and choose. I belong to a couple of organizations, and I stick to that. I don’t raise my hand. I don’t volunteer. I may assist, but I

don't champion a lot of the activities I used to do. Some days, I don't want to be in charge. I just want to stay home on the weekend. And that's what I'll do. I'll stay in. Now, some people say, "Oh, well, she's depressed." No. Sometimes, I'm just comfortable with being in my bed, and I don't want to go anywhere.

Me: Has your perspective on life changed since having cancer? Is that what part of this is about?

Morgan: Yes. Yes. That nothing lasts forever. [Laughter] I was busy making plans, how I was going to fix up my house and make it a bachelorette apartment. And I was going to get out and start meeting some men and dating. Pssht! All of that's changed. Now, I just take each day as it comes. You know? At the end of the day, you know, I go to bed. You know, I've had a good day. . . . It's changed my outlook. You know, life happens when you're busy making plans.

—Morgan, age 58, African American, and a survivor of stage IIIB breast cancer. She had a lumpectomy, chemotherapy and radiation. She has been out of treatment for three years.

Morgan discusses these changes to her lifestyle as part choice, part reaction.

She says her perspective on life has changed: she no longer wants the same things. Her age helps: she has already "been there, done that." When she was diagnosed, she said she was afraid she was not going to live long enough to see her eldest son get married. Now she has two grandchildren who live with her, and she loves it. Home is very different than the bachelorette pad she had initially planned. It is not easy to untangle the physical effects of cancer from the change in life perspective as part of the perspectival shift is related to her physical limitations. She cannot do the same things she once did, but they are no longer important. Her perspectival shift is an adaptation to the situation, but her perspective also caused her situation to change.

I cannot help but wonder if part of the change in perspective women talk about is a type of acceptance of the new situation they find themselves in.

If they cannot change the situation, they cope by changing their perspective of the situation (Lazarus and Folkman 1984; Carver, Scheier and Weintraub 1989). Bourdieu (1984) discusses how people may accept and even boast about the conditions of their habitus. While I do not think survivors “misrecognize” the limitations that now define their lives, they often participate in them by spinning positive accounts: while Morgan admits that she does not have the physical stamina to work 12-hour days anymore, she emphasizes to me that she has discovered something more important in life. She notes that others may say she is depressed, but she just prefers to be in bed sometimes. Her positive spin on the conditions of her situation may normalize them, such that they are considered personal decisions rather than structural effects.

Change in life perspective affects what survivors want to do with their futures—how they wanted to live out the remainder of their days. Downgrading career aspirations or one’s identification with a role or activity may be easier to do later in life, after achievements and experiences have already been had (although sometimes these identities are even harder to give up when one is so invested in them, which is why retirement can be so difficult). It might also be more palatable to “choose” to disengage with identities, rather than feeling that options are foreclosed due to external conditions. Some survivors described “opting out” of demanding jobs or activities when they might have been pushed out (Stone 2007). Some women were able to frame their decisions to downsize in a positive light, which

helped them feel in control. By replacing their once valued identities with new ones—trading a high-powered career for time for the self—they adjusted well. It is difficult to say whether their change in perspective preempted their lifestyle change, or if limitations from treatment prompted them to make particular changes that they then accounted for as conscious and deliberate decision-making.

Selves adrift

It may be cognitively easier to reframe being “pushed out” as “opting out” if one has a replacement identity. Feeling “pushed out” had different consequences for survivors. The inability to move “forward” as planned, to have the future self imagined, left some survivors bereft: they felt their past self had been damaged and their imagined future self was now unobtainable. The emotional pain or ambivalence due to feelings of foreclosed opportunities was intensified if they were not able to fill the void with a replacement identity. Rachel, below, does not feel good about her decision to leave her intended career because she is not able to replace that intended identity with a new, valued one:

Rachel: [Cancer] not just interrupted, it changed what I wanted to do with my life.

Me: Your goals, dreams, or—?

Rachel: Yes, it did. I grew up in a family of professors. [crying] My dad’s a professor. My uncle’s a professor. My great uncle is a professor. We had professors like, five generations of my family. I’m not kidding. My father’s great-grandfather was a professor. I always wanted to do it. I knew it very young. But after two bouts [of cancer], I didn’t even want to spend the time in tenure track. I mean, it’s not that I don’t love my work. I really had to come and sit down and think about what I would—

if the worst were to come, what I would regret. . . . And I would regret neglecting the children. And not to say that people who work neglect their children, but people who work have the capacity of knowing you have years ahead with their children. I have no capacity of knowing. . . . Previously, when I was working, it's not like I wasn't putting my kids in daycare. But I thought I had years ahead. You know? [crying] Now, I don't have the confidence in the years ahead. . . . I'm exploring. I don't know. I'm lost right now, because I've only ever wanted to do a Ph.D. and become a professor since I was 8 years old. I've never had any other goals in life.

—Rachel, 37, Indian, two stage II occurrences. She is two and half years out of treatment. She had a lumpectomy, chemotherapy, radiation, bilateral mastectomy, and reconstruction.

Rachel's bouts of breast cancer, both stage II, are separated by five years. She discovered her first cancer at the beginning of her second pregnancy. She decided to terminate the pregnancy in order to receive treatment. She went back to school, finished her Master's work, had a second child, and discovered her second cancer. At the present moment, after two years filled with treatment and different kinds of surgeries (her bilateral mastectomy was followed by a year of reconstructive surgery and an oophorectomy) she feels going back to finish her degree is impossible, particularly because both cancers occurred at critical junctures in her graduate career. She itemizes a number of factors that make not finishing the degree a rational decision, but emotionally, she is distraught. She says she feels more traumatized by not finishing the Ph.D. than from the cancer: "I'm sad. I'm upset. I feel *cheated*."

Although she is still enrolled in her program, she says she no longer tells people so (although she did tell me she was working on her degree), as she does not want their evaluations of her resting upon this status. She may be distancing herself from her identity as a scholar, trying out her anticipated

status as a stay-at-home mom. She says she made a choice to spend her time with her children after cancer, but she does not seem to feel agency in making that decision. When I ask about other kinds of work she could do, she describes why those other possibilities will also not work out: “teaching is on hold, because I used to teach as an adjunct, and those classes are usually in the evenings. And there is no daycare in the evenings. I’m looking into getting some part-time positions, scientific writing [but] I’m not physically what I used to be. I have no stamina left.” She weighs the pros and cons of finishing her degree: “I’m very conflicted now, because I want my kids to remember me. And nothing might happen to me, in which case, I’ll regret not having the career I wanted.”

Rachel’s story may seem idiosyncratic, but she is not experiencing a unique form of loss: she is mourning the loss of a self and a life that had not yet come into being. She is not unusual in her feelings of indecision about what to do “next.” Perceptions of risk and fear of recurrence challenge many survivors’ ability to “move forward” and make life decisions. Rachel is at a moment where her horizons may feel too wide but also too narrow: she could make any number of choices, but some choices will make more sense than others under certain conditions—only she has no way to predict what conditions will happen until they happen. She told me that if she gets breast cancer again, it will be stage IV. Her fear of a stage IV diagnosis paralyzes her. There is no rational or scientific way for her to make decisions about how

to move forward; all she can do is weigh possible hypotheticals, risk percentages, and consequences based on scenarios.

Participants emphasized that recurrence risk is “always in the back of your mind” and “you never know” when cancer will return. They understood that risk projections are only projections. Risk statistics can be comforting, but they also add uncertainty and feelings of whimsy (Jain 2007). People interpret odds differently: I had two participants in this study interpret similar risks of recurrence as high and low. Statistics do not matter if you are the one who has the recurrence. One participant told me that the statistics are not useful: you either get it or you do not. Heather, another participant, described the impossibility of living under this kind of uncertainty:

And then you also get to the point where it's like: Well, what am I going to do? Like, waste like, years and years? And even Dr. X said that to me once. She was like, “Well, what are you going to do? You're going to be scared and frightened for the next 10 years, and it doesn't come back? And then, what happens to those 10 years? Wasted.” Right? Or, scared and frightened for 10 years, and it comes back. And then what? Wasted the time—the good time you had. So, you know?

—Heather, age 45, white, survivor of stage III cancer. She had a lumpectomy, chemotherapy, radiation, mastectomy, and oophorectomy. She is five years out of treatment.

Trying to live life according to a possible recurrence is a bit like dropping down the rabbit hole in *Alice in Wonderland*. There are possible potential selves that will not be lived out if one has a recurrence. While what one does in the present does not have to be interpreted as a waste of one's energies, choosing one path ultimately means not choosing another. Rachel knows if she chooses to finish her degree, she will be choosing to not spend as much

quality time with her children. Not knowing if she will have job prospects after completing her degree adds more uncertainty to the mix. But staying where she is now feels like lack of movement to her. She has not developed an alternative vision of her future self yet and thus is not able to make progress in bringing that self into being (see Charmaz 1991). Even though Rachel says she would regret not spending time with her children if her cancer were to metastasize, without that happening, she regrets not advancing her career. Being a stay-at-home mother is not a substitute for her career identity. Instead, it emphasizes the void she feels, especially as her children become school-aged and her past colleagues and family members finish their degrees.

Giddens (1991) discusses the anxiety and insecurity that arises from being unable to “colonize the future.” Bracketing some elements of uncertainty make movement possible, but many survivors experienced multiple levels of uncertainty at once (“cancer does not happen in a vacuum”). Survivors experienced cancer while also undergoing divorce or job loss or parental loss or other traumatic events. Perhaps survivors could re-colonize their futures if other life domains felt stable, but instability in more than one domain thrust them into profound state of anomie. Allison describes the random quality her life has taken on due to the confluence of multiple domain challenges:

I’ve had to struggle with: What do I do now? What do I do? What’s the purpose? Why do I get up in the morning? Kind of: What’s my calling? And it’s not like I know I have a year left. So I will run out and do everything I want, spend all the money and, you know, have a great year. It’s just a whole ‘nother direction and another focus besides me.

It's something I keep coming back to. That's probably one of the biggest struggles I've had, is: What next?

—Allison, age 51, white, survivor of stage IV cancer. It has been five years since her diagnosis. She is on continuous hormonal therapy.

Allison was the founder and director of a food bank in her county. She had to leave her position due to physical limitations stemming from her metastatic cancer. Leaving was a huge blow to her—"I mean, it was my choice, because you always have a choice, but it really wasn't mine"—but an equally traumatic experience was the dissolution of her marriage. She and her husband are still married and share a house, for the health insurance and financial reasons, but he disclosed to her before a year after her diagnosis that he had been having a long-term affair. Without the marriage to support her, the loss of her job feels more acute. Her children are "wonderful," but they are now college-aged, living their own lives. Her problems with neuropathy and fatigue prevent her from carving out new domains in her life. Traveling is difficult because of her pain and fatigue. She spends a lot of her time at the cancer organization where I interviewed her, or reading, sewing, going to the movies or hanging out at the diner. She tries to "find joy" in these activities, to have them be "more than filling time."

Other metastatic survivors also discussed the strange quality time takes on when living with a sense of boundedness: life was strangely "normal" in terms of their activities, but these activities took on more significance. Perhaps because "big" decisions or plans seemed impossible to make, they stretched out these "smaller" moments with meaning. Meaning becomes slippery under

these existential conditions: once valued relationships and activities cease to exist; having a nice place to sit and sew takes on new poignancy.

The parameters of these survivors' lives have shifted, destabilizing the standards previously used to measure meaning. Diagnosis foregrounds awareness of ontological and existential fragility, which can both burden and free survivors from meaning making. Metastatic survivors have a truncated future, which frames the parameters of their options and choices in different ways than earlier stage survivors. Survivors may or may not have the time and resources to accomplish (or start) new “big” things, but they need some overarching purpose to guide each day.

Allison is not looking for “big” meaning in daily life—her career and marriage have ended; her kids are not home—so she looks for it in little places: sewing, reading, going to the community center. As Melanie, another metastatic breast cancer survivor says, they need to be “in control of an out-of-control situation.” Allison's drive differs from Rachel's, the Ph.D. student, in that she knows her life is bounded by the diagnosis whereas Rachel does not. Allison's choice to leave her job was not easier than Rachel's, but she perceived it to be somewhat beyond her control, a response to the situation at hand, whereas Rachel was responding to a potential future event. They are similar in that they both expect cancer to define the terms of their futures.

Tess has similar quandaries to Rachel and Allison, and is experiencing a similar void, but she is coming at this from a different diagnosis. Like Rachel, she also was diagnosed with Stage II cancer, but recurrence fear does not

shape her thoughts of the future. She frames her cancer “a fork in the road” rather than a drop off a cliff:

And I feel that now that there is so much of my life that has changed, that it may be a perfect time for me to consider investing in myself, because unfortunately I’ve invested my time and effort in two failed marriages. And now I’m forty-five years old and it’s really been like a huge fork in the road for me. And so now I’m just seeking wisdom with “Do I want to be working? Do I want to try to get more education?” I just, I’m just not sure. I’m kind of really right at that juncture of like “Wow, what do we do with the rest of our life?”

—Tess, age 45, white, and a survivor of stage II cancer. She had a lumpectomy, chemotherapy and radiation. She is three months out of treatment.

Tess was in the middle of her second divorce when she was diagnosed with cancer. Her husband delayed the divorce to keep her on his benefits, and stipulated that he would help her financially for five years, after which time she would have to support herself. She has ample time for soul searching, but she has a deadline. She currently works as a receptionist, finding the job unrewarding and the pay low.

Tess seemed a little lost and fragile when I met her. Newly living alone, her sparsely furnished, low-income apartment looked like the ones my college rented out to students. She had almost no personal belongings in the apartment that I could see—no pictures, the furniture felt like it came with the place—adding to my impression that her life was not yet “grounded.” She described herself as a housewife without any hard skills, implying that she had not spent time developing herself, figuring out who she was or what she wanted. She now spends her time going to support group, church group, and her therapist in order to gain the wisdom she describes in the quote above. Most important

about her testimony is that she wants to use the cancer as an opening. She does not know what to do with the rest of her life, but the cancer experience in tandem with the divorce has made her realize that she needs to “invest” in herself. This was a common instinct for survivors, to pull back into the self and assess one’s life. Many survivors did not know “what’s next?,” but many tried to use cancer as a turning point, a definitive end to one part of life and a beginning of the next (see DeGloma 2010).

Some women were not able to “move on” from cancer the way they wanted to and had other constraints blocking their progress. But implicit in the turning point narrative for cancer survivors is a type of pressure to be a better self:

[T]here has to be a before and after. I don’t think you could—I don’t think you should just go on. It’s not like you have the flu, or you had, I don’t know, an accident or something. I think everything contributes to who we are. So, I think it’s important to encourage other women to get better than you were before you had the cancer—not just better from the cancer. Do you know what I mean?

—Liz, 69, white, survivor of stage II breast cancer. She had a lumpectomy and radiation. She is six years out of treatment.

In this framework, cancer becomes a gift of sorts, something to be used wisely. In some ways, they are right: if one perceives one’s cancer as a life-changing experience, a clean slate, a “fork in the road,” having this experience comes with an obligation. Many survivors are thrown into existential crisis by their cancer experience and want to find meaning in the experience, not just to find the silver lining but to claim control over it, to actively use the experience in some way, to make something good come out of it. Heather and I discussed

this process as a need for sense making, but she also adds some needed resistance to the major “positive growth” tropes that survivors use:

Heather: I think there is more a sense of urgency [in living post-diagnosis]. But maybe it should be like that. For everybody.

Me: People do say, like, “I cut out this stuff,” and “I focus on this stuff.” Does it take a major illness to do that?

Heather: I think it does. I actually think it does. I think it’s a rare person that [does it otherwise]. And I think it either takes a major event with you or someone in your family or like someone that you know well, to kind of—And I don’t know why that is. Like, it shouldn’t be like that, right?

Me: That’s what I keep thinking, is it like we’ve just gotten so far away from where we should be that like, you know, you need something to sort of kick you back to yourself in some way, or—?

Heather: I think that’s what it is. Yeah. But, I’m also hesitant to say there’s [a reason]. I hate when people say there’s a reason. I’m sure people say, “Oh, there’s always a reason I got cancer.” I’m like, [chuckling] “No. No, no reason.” Or like, some people will say, “Oh, I was really off track, and I’m so glad I had cancer, because it really put me on the right track.” I’m like, “Yeah, no. Not me.” [laughter] I’m not glad. But I just think that’s people trying to make sense of it. I really do. You know? And it’s like the same people who say, “God only gives you as much as you can handle.” No, really, it’s the inverse. You handle whatever you’re given because you don’t have a choice. That’s what it is. It is not: God gives you as much as you can handle. [chuckling] *Trust me.*

— Heather, 45, white, survivor of stage III cancer. She had a lumpectomy, chemotherapy, mastectomy, radiation, and an oophorectomy.

Type 2: identity creation

Projections of the self into the future are necessary in order to have a sense of security and full self-concept; psychologists are particularly attuned to ideas of “future self,” for not having a sense of self in the future is associated with

despair and distress. Sense of future self enables individuals to contribute meaning to present-day actions (Markus & Nurius, 1986, 1987), even if we are poor at predicting who we will be or what we will want in the future (Gilbert 2007). Concepts like anticipatory socialization and delayed gratification rest upon the ability to project the self into the future, to have a sense of what the future might hold.

Most people think of their future self more highly, as the future contains possibility, and with possibility, hope (Wilson et. al 2012; Mische 2009). Sociologists are concerned about future projections in terms of theories of agency and action; how the future is projected, what plans one makes for the future and what one thinks is possible, exists in relation to the agency individuals employ within the structural conditions and situated practices that define their lives (Bourdieu 1984; Emirbayer and Mische, 1998). The ability to have desires and aspirations for oneself is presupposed on the fact that the future exists and that one can reach this future within the conditions of one's life. Obviously, faith in the future and the ability to project the self into the future can be compromised for survivors as the future is circumscribed by consciousness of risk. Perceptions that one can obtain projected future selves are associated with feelings of self-efficacy and confidence (Bandura 1989; Hooker & Kaus 1994). Integrating life-altering events and chronic illness into projected selves may be a form of adaptive coping (Barreto and Frazer 2012).

But there is a fine line between future planning and magical thinking: some ideas about the future are not so much projections as they are

imaginations, musings. The latter are abstract thoughts or wishes, with little practical planning and little chance of them coming to fruition. Imaginations may become plans, as groundwork is put into place. But, for some survivors, these ideas of future selves stayed at the level of imaginations: they did not perceive or heed the structural limitations their positions posed to the possibility of these identities coming into being. Being able to “move on” is reliant on being able to project a sense of self into the future, which requires both that one have a sense of future self but also that one trust that one will have a future. I discussed in the above section how some survivors were paralyzed by the identity void they experienced post-cancer diagnosis; they could not image a satisfactory future self. Some of the imagined identities I present below may be more beneficial than not having any plans for the future as they precipitated future planning. Some projections may be necessary “illusions” to “buffer” the self from present threats (Taylor 1983).

Imagined identities

Sabrina was diagnosed with Stage IV breast cancer. She says she is now N.E.D.—no evidence of disease—but she is in constant pain because of the damage her cancer did to her spine. She explains that she suffers from collapsed disc because her cancer had caused her bone to disintegrate. She presents different reasons for quitting the job she loved: being in constant pain, being offered severance, being told her absences for cancer treatment would affect her performance evaluations. Without her job, she finds that life has little structure. She says she is not able to do other things consistently that

might provide structure, like go to meetings or support groups, because of her back pain. Having people visit her would be too much work: she would have to clean, then go shopping, then cook, then clean again. But she entertains the idea of getting a new job so that her life will not feel aimless:

Yeah. I keep thinking I've got to get a job. And so, I've decided it again. I've *got* to find a job. I've got to find like, *something*—I can get out and I can be with people . . . I mean, if I weren't sick, maybe I'd go back to work—I mean, sick with my back. But even that, I don't really care to go back to work-work. I would do something part time. I would do something if I'm enjoying it. But to go start a whole new career—. I thought about going back to med school last year. Dr. Rice was going to give me a recommendation. Well, I was asking him for a recommendation for the P.A. program. But then, I decided, no, because I don't—I decided—Well, I don't think I'm going to do it. I decided I don't have the energy. And my brain is not as clear as it used to be. And I also had come to the realization—and I think it's still working its way to reality—that my only real desire to be a doctor was probably because it's such a wonderful thing to be a doctor. Woo! You're a doctor! And it wasn't really so much the nitty-gritty of being a doctor . . . I would love to be a doctor. [laughter] I think it'd be fun. When I took the aptitude test back in college, the top thing it came up with was physician. But, I wouldn't do that now. It's too much energy, too much work. I mean, if I could do enough that I could go to Africa and like, be useful as—in a clinic, you know, working with people in a clinic, I would love to do that.

—Sabrina, 54, white, and a survivor of stage IV. She was diagnosed five years ago and continuously receiving targeted and hormone therapy.

Sabrina vacillates between reality and fantasy so much so that I became confused about what might actually be possible for her. She was thinking of applying for a physicians assistant program, she says she is N.E.D, and she is out doing physical therapy: maybe she could do start a new career. But her descriptions of her pain and the lack of mobility in her daily life make it clear that the imagined selves she has are not real possibilities. These ideas might be

positive illusions to help her escape her current situation (Taylor 1984). At other points in the interview, she switches into more a realistic framing of her situation: “It’s like, I have to invent a life that accepts, unfortunately, these limitations. [But] I’m not giving up on being healed. I am working toward that.” Having fantasies about her future may help her cope with her present—and they may help her find the motivation to pursue more immediate steps, like pain relief, without which her plans for “getting a life” cannot happen.

This technique was common throughout interviews, although the projected identities varied in practically. As I discussed above, survivors tended to reframe their physical and cognitive limitations as active decisions to “opt out” of stressful roles. Accepting the impact of their new limitations on their future plans and folding them into their identities was not usually done in a straightforward fashion. For instance, while Anita’s desire, described below, for a stress-free part-time job sounds a lot like Morgan’s and Candace’s desires, as I described above, she does not account for her limitations in the type of job she considers doing:

Anita: See, I'm still dealing with an issue. I have a little memory loss. And I can't remember everything now. I have to write down everything. Otherwise, I can't remember. That chemo did affect me in a lot of ways. And my tiredness would not go, and I thought: Oh, my God. If I go a full day of work, I'll be a mess out there. Now, I take naps in the afternoon. And I'm dealing with my memory loss, trying to get it better . . . My brain freezes. I can't think, like suddenly, I'll be thinking, did I brush my teeth in the morning? Oh, my God. I can't remember it. What did I make for breakfast in the morning? I can't remember it. . . . So, actually, I'm doing a memory-loss study right now. Hopefully they'll figure out if I need anything.

Me: Do you do anything [to help you]? I mean, you write the lists, but do you write down things like what you made for dinner?

Anita: No. I don't write down things, but those things I want to remember—I have to kind of go back and say: What did I keep—? What I do is, every night, take out the vegetables I need to cook the next day. So, that's how I remember. So, like, right now, I've kept in my kitchen what I have to come back and cook. . . . A lot of things, if I don't write down, I can't remember. Like appointments. . . . Actually, when I wrote it down, I wrote "Jennifer," your phone number—Then suddenly, one day, I blanked out. I said, "Who is this Jennifer? And why does she want to see me?" I was confused. I have those issues I'm having to deal with.

Me: And you're worried about going back to work? Are you going to look for a bank job, or what kind of job do you think?

Anita: I don't know. I'm looking in banking. I'm looking for nonprofits. I'm looking for sales. Because I was in sales. And the administrator job—two, three days a week. Even if I have to go to study—I'm thinking, why not? You know? If I change my career, to find a decent job, like—I was making good money, really good money, and now, I can't—I don't want a full-time career. I'm thinking to do some tax courses, and then—and any other courses which will help me to find a decent job. It should not be stressful. I should just go there, do it, come back—not think about it.

—Anita, 59, Indian, survivor of Stage I; eight months out of treatment. She had a lumpectomy, radiation, and chemotherapy.

Anita acknowledges that she has cognitive difficulties and she has designed methods of working around them, but she does not fold these difficulties into her plan for the future. She looks to what she has done in the past for examples of what she might be able to do in the future. For most people, the past is a guide: we base decisions off of what worked in the past, we frame new knowledge through cognitive frameworks we have built across time (Schutz 1967 [1932]). But for Anita, there has been an interruption in this process. Her mind may not work the same way it once did. She may be able to use the workarounds she has created in her job, but she has not folded the impact of

cancer into her imaginations. This is not to say that her plans are unrealistic, but they are still inchoate. She wants a job that will not cause a lot of stress, but which will still pay relatively well and which will afford her a certain amount of prestige. These are not defined plans but an outline. I interpret this to mean that she is not in active planning mode, but still in the imagination stage.

Many survivors used this imagination stage as filler until they felt ready to act. It could be that Anita knew very well that she was not emotionally ready or recovered, and was only entertaining ideas of possible identities for when she was ready—preparing for possibilities in her mind (anticipatory socialization). Others acknowledged their imagined identities were not fully developed, but they seemed to feel better having these options waiting for them. For instance, Julia’s plans sound more grounded, perhaps because she acknowledges she is not “ready” but is still in planning-mode:

Julia: Because I want to work with cancer patients—and patients with physical limitations.

Me: Does [Yoga Studio] have classes specifically for—?

Julia: They want me to start a special class. But emotionally, I was not ready. Because of my husband’s illness. Then I lost my hearing, and I have a hemorrhage in my right eye. I’m just going through too much right now. So, I’m getting there. I had to emotionally be ready before—I have to be there for the students. I can’t just teach and then not be there for them. And I feel that I’m getting there. So—I know I get a lot of encouragement, strong encouragement. “Come on, [Julia], you can do it.” But I think I’ll do it when I’m ready.

—Julia, 50, white, survivor of stage I; she is six months out of treatment. She had a mastectomy.

Survivors felt the need to develop new identities because older ones were foreclosed to them, were no longer satisfying, and/or because the experience of going through cancer changed how they thought their purpose in life. For most survivors, the shock of cancer caused them to refine and clarify their focus. Julia, like many others, had always desired to change her career. A long-time yoga enthusiast, she is now thinking about transforming her practice into a vocation aimed at helping others with similar limitations to hers. Survivors need to project identities into the future in order to have goals to strive toward; the critical difference between survivors seems to be how realistic these goals are and how much is at stake if they cannot fully realize these goals.

Intensified identities

I always knew I was a strong woman, having been, like I said, an Army brat, an Army wife, having gone through two deployments by myself—one with being five months pregnant, the other one with two children under the age of five. But, it definitely is a strength builder. I would definitely consider it like, empowering . . . [Not that I would wish cancer on anyone, but] I would sprinkle that on everyone. Because just coming out on this other side, knowing—You know what? I just kicked the you-know-what out of you. Leave me alone. Just—that's so empowering to me.

—Monica, 36, white, survivor of stage IIB; she has been out of treatment for two months. She had a mastectomy, chemotherapy and radiation.

Monica's feeling of empowerment resonates with many of the cancer survivors I interviewed, although most were more tempered. This kind of language might be embedded in youth cancer survivor culture; kicking cancer's "you-know-what" emerged recently in Sloan Kettering's ad

campaign for which survivors wrote letters to cancer, following the format of “Dear Cancer, I kicked your butt. Love, Jane.” But many survivors used battle-type metaphors in their narratives. The empowerment comes from going through the battle and not feeling “defeated,” which might mean something different to each individual depending on definitions of “being strong,” or “not letting it get to me.” Empowerment, the end result of surviving cancer treatment, describes a shift in self: survivors felt more aware of their resilience and strength, more capable of taking risks, more in control and able to surge forward. Many survivors used or wanted to use “cancer” as an experience to develop the self. For those who interpreted the cancer experience as an “eye opener” or “turning point,” cancer gave them the motivation to develop particular identities or hone particular skills.

While some become more other-focused, other survivors, feeling they had given too much of themselves to others, become more self-focused. Some felt compelled to use their empowered self to reach out to others, to help others going through similar experiences. Some turned inward, focusing on what was most important to them about their lives. Whether narrowing boundaries or expanding outward, these survivors felt that their selves had been changed through cancer. Not wanting to “waste” their cancer experiences, many survivors embraced the resulting perspectival shifts by creating new identities and embracing new practices. Cancer is defined as a life-changing experience when it precipitates these kinds of perspectival shifts. Survivors use cancer to help them make changes to their lives not only to give

the cancer experience meaning or to gleam some silver lining from the experience, but because they actually have gone through a transformation of self through the process of being treated for cancer.

Yvonne and other describe their cancer experience as having given them an extra edge, pushing them to do the things they always wanted to do. Cancer gives them an allowance to act, to develop implicit or dormant parts of themselves. They feel the cancer experience gave them insight into themselves—their “real” selves or their “best” selves, the selves they now realize they had always wanted to be:

I credit breast cancer. Because had it not been for breast cancer, I would not have written a book, and I've *always wanted* to write a book. I would have never started a motivational-speaking business. The purpose is to help other women to step outside the box and feel good about yourself and not be afraid to take chances. I would have never done that if it wasn't for breast cancer. I purchased my dream car, Mercedes-Benz. Always wanted that car. . . . The breast cancer showed me, or gave me, a strength and a courage and a tenacity that I had never experienced. I've always been the adventurous person. I've always loved going here, there. I'm never afraid of doing things, always loved people. . . . But the breast cancer just put an extra spin on it. And again, I think I can say, because it was a fear—not knowing if I was going to die—and then when I realized I wasn't going to die, that just put the flame to say: Go for it.

—Yvonne, 54, African American, survivor of stage II; she is five years out of treatment. She had a lumpectomy, chemotherapy and radiation.

Being through cancer—not remaining in a state of unknown, but realizing she will have a life ahead of her—prompts Yvonne to “go for it,” to start acting on her imaginations. She did not bounce back to her previous state after going through cancer, but changed her life in order to focus on the things she wanted. She explains, though, that this focus may come at some cost:

And through the process, it has been different because you lose people—sometimes friendships, sometimes family connections—because you’re focused on something totally different. And so the things that you may have done before, you might not find that interesting anymore. And a friend could feel rejected, but it’s not that you’re rejecting them. That’s just no longer something that you like doing anymore.

Yvonne discusses how she rewarded herself but also rearranged her life and networks to be able to fit her shift in life perspective. She made sacrifices to make this work: she took a new job for less pay so that she could develop her motivational speaking business on the side, she does a lot of volunteer work connected to cancer organizations, and she self-published her book. It is unclear how “successful” she has been in any of these enterprises, but she feels more in control over her life, more conscious about how she lives. These enterprises are accomplishments to her because they represent changes to her life that she made happen—proof that she now lives deliberately, in sync with her perceived purpose, rather than going through the motions of life in a habitual or routine fashion.

Cancer seemed to give some of the women I interviewed the freedom, or the right, to make “risky” choices in their lives. Many participants presented this newfound agency as somewhat serendipitous. Like Yvonne, Tanya also describes how cancer led her to a new career, which then led her to a new lifestyle. Emboldened by one change, she remained open to subsequent changes. Like Yvonne, she attributes her diagnosis with changing her life, rather than taking credit for making these changes herself:

Tanya: And you know, I was never really proactive until dealing with all of this.

Me: Until this. You think this changed your outlook on health?

Tanya: Well, not on health, per se, but just doing what I think is best for me. I started following an Ayurvedic diet when I was in massage school. . . . And it was all different than anything I learned. But I said, “I’m going to give it a try.” And since that point, I’ve been following the diet. I’ve lost weight, and I feel great. . . .

Me: Was your interest in all this stuff driven by the cancer? You started massage school after you were diagnosed?

Tanya: The massage was driven from the cancer. [Cancer] just put me in a bit of a different state of mind, and I’ve always been interested in massage. But after going through all the chemo and everything, I was trying—I’m always trying to help others. I’m doing these outreach things. And this woman I’m working with—she was complaining about—you know, she just saw a chiropractor, and her neck is out of whack, she’s a mess, he’s going on vacation. What’s she going to do? So, I started working on her, and I found the area, and I did some static on her, and she’s like, “Wow. You’ve got great hands. You should do this professionally.” It was like, ding! . . . It’s kind of all related.

—Tanya, 53, white, and a survivor of DCIS/Stage 0 cancer. She is four years out of treatment. She had a lumpectomy and radiation.

The way Tanya describes her massage career and commitment to her Ayurvedic diet is both serendipitous and active: she made these changes to her life, yet she seemed to stumble into them. Her narrative is that had she not been diagnosed, she would not have done outreach, gotten feedback about massage, entered massage school, discovered Ayurveda, and gotten to a point where she feels good. Being diagnosed “brought goodness” to her; she did not seek it out. She described several ways in which she became “proactive” and started to frame her life in terms of “doing what is best for me,” but she still sees these changes as somewhat outside her, a matter of chance. In such a

construction, she gives cancer agency over herself; she does not think she would have become active otherwise.

I had a feeling when I was talking to Yvonne and Tanya that they were not exposing their post-cancer disappointments or failures; their attention was focused on being positive, being healthy, taking chances, as if tending to negative emotions of events would stop their forward momentum. They both noted struggles in passing—Yvonne discussed her problems with weight gain, Tanya expressed boundary problems with her parents—but they largely kept their comments focused on the actions they have taken since cancer to move them forward. I believe that Yvonne’s and Tanya’s new perspectives are honest—they worked hard at reinventing their lives. They acknowledge the role that cancer played in shifting their perspective. Relief at not dying—feeling like they were given a second chance—spurred on many survivors’ desires to “live life to its fullest.” But this desire may also result from fears and insecurities: instead of being driven by joy at being given a reprieve, some survivors’ identity changes may be driven by fear.

One survivor I spoke with, Gwen, a 34-year-old survivor of inflammatory breast cancer, an extremely rare and deadly cancer, was incredibly animated. She had a tremendous amount of energy and drive; it was difficult for her to sit still. I kiddingly asked her if she was always that manic. Cancer-free at the time I met with her, she died almost exactly a year later. I have no way of knowing what motivated her: she was excited to be cancer-free and was busy making plans. Her fiancé, however, was quiet, cautious in

what he said to me. He seemed protective of her; he sat with us for the beginning of the interview, only moving so far as the adjacent room while we continued talking. I wondered on my drive home how much the person I just met was who she “really” was and how much of her frenetic manner was caused by trauma. Wanting to live each moment to its fullest puts so much pressure on the self to perform without slowing down. Amy describes the downside of this process:

Amy: I ended up treating myself a lot during cancer. I got weekly massages. I think they were very helpful. I got therapeutic massages. I did acupuncture. I bought myself a car. I bought myself a bunch of clothes. [laughter] I would treat—I have a spending problem.... Not that I'm in debt, but a spending problem, and I most definitely used cancer as an excuse to treat myself But, I put way too much pressure on 2011 being awesome, and I hit the ground running. I joined online dating in January. I hired a career coach to help me figure out what I want to do with my life. I did too much, and I was in the process of buying a house. I signed a contract of sale and everything. I was trying to change too much too quick, and it kind of came crashing down on me. And [that was] right around the same time—that [men at two bars on two separate occasions made disparaging] lesbian comments—So, I'm trying to take things a little bit slower now, and—

Me: So, how did you crash then? Did you just feel like you got run down and sick, or just emotionally?

Amy: No, I was putting too much pressure on everything, and things being amazing and different, and things just weren't changing. And just wanting to forget about the cancer and just—“My life is fine now.” And I think I just was trying to force happiness and change in my life a little too much. I just got so frustrated—[it was] horrible. And depression really set in. Yeah. So—I mean—now, I'm much better But still kind of feel uncertain about the future.

—Amy, 31, white, survivor of stage IIIB cancer. She is 5 months out of treatment. She had a mastectomy, chemotherapy, radiation, trans-flap reconstructive surgery, and embryo cryopreservation.

Advocate identities

Arthur Frank (2003) describes how survivors, by virtue of becoming survivors, are propelled toward about advocacy. Many survivors are attracted to the “survivor advocacy” identity: they have lost or dropped previously precious identities and now have an identity void and a desire to help others going through what they have just been through. Their experiential knowledge marks them as a type of expert: no one can know what they have experienced better than they do. They have also just spent a year or so in cancer-related domains; these domains may feel more familiar and intimate to them than their work or other domains. Transforming the survivor identity into an advocate and career-oriented identity is the next logical step. Survivors do feel compelled to give back to the cancer community, but they have also just invested a tremendous amount of time, resources, and skills learning to understand the ins and outs of the cancer establishment.

Jenna is very involved with her cancer support group. In fact, she heads a youth chapter in her area. Breast cancer advocacy become a second career; while she still attends group, she has moved into a leadership role, seeking support less and doing advocacy more. Her husband is also involved in advocacy efforts, and their social life has also shifted to include more cancer survivors and cancer-related events. Jenna has channeled her talents into cancer survivorship efforts, which have enriched her life. Before cancer, she was working part-time, raising her son, spending time with friends and family, and thinking about having another baby. She is still doing those activities, but

her consciousness of cancer has propelled her to carve out time for more “socially conscious” activities. Cancer has given her a mission, which she has fully integrated into her family’s way of being:

Jenna: You know—I think it impacts me in a really positive way. I’ve gotten so involved with the youth cancer group—I’m on the leadership team, I’m involved in so much planning. I have meetings once a month. I’m running the support group once a month. Komen asked me to go up in the Horizon blimp. Yesterday, I just did a photo shoot for survivors. All of these things have come up. It has affected sort of, what we do, and the fact I am actually busier than I’ve ever been in my life It’s not that I have to do it. I feel like it’s my duty as a young survivor, that I need to let other people know it can happen. They need to know that it affects young people. . . .

Me: You have a whole 'nother career blossoming, it seems like.

Jenna: Yeah! That’s it my husband said. He’s like, “Can you start getting paid for this stuff?” [giggling] “Maybe, someday.” But yeah—I think everything else is really how it was—I mean, it’s our new normal. Nothing will ever be how it used to be. But so many other opportunities have come up. My husband has gotten involved, and he does a lot of charity rides. . . . We meet new friends. . . . I’m sort of using my talent with the event planning and graphic design and public speaking, to kind of help. So, it’s kind of fun.

—Jenna, 33, white, survivor of stage IIa. She has been out of treatment for two years. She had a lumpectomy, chemotherapy, radiation, bilateral mastectomy and reconstructive surgeries.

Jenna has found a vocation through cancer; she is been able to merge her existing skillset with her new identity in order to expand into new terrain—being a model, a spokesperson, a leader. She has had opportunities to grow beyond the boundaries of her previous life. This expansion energizes her and gives her life added meaning. Being younger than the average cancer survivor is also an important part of Jenna’s drive. The sense that people are unaware and need to know that young women get cancer takes Jenna outside of herself;

cultivating a public identity, rather than keeping cancer solely a personal identity, enables her to direct her focus outward, which perhaps help her cope with her own experiences, fears and anxieties.

Gwen's experiences are similar to Jenna's, but the rarity of her cancer adds an element of urgency and desperation to her tone not found in Jenna's. Inflammatory breast cancer is uncommon and has a very low survival rate. It is always diagnosed at Stage III. Gwen does not talk about "fun" as part of her mission, as Jenna does, because of the burden she feels placed on her to represent this rare form of cancer:

Gwen: I actually am also working with my doctor. He had somewhat recruited me to work with him specifically on inflammatory and to raise awareness. Because it's so often misdiagnosed and mistreated. And he's like the leading expert in the world. . . . He's unbelievable. There are two leading research inflammatory labs in the world. One is at MD Anderson in Texas where he was, and now, the other is at Fox Chase in Philly. . . . They had e-mailed me a five-page proposal about things they're working on—specific research projects for inflammatory, and also, just in general, like, awareness about the disease. . . .

Me: And do you see this becoming more of a career interest of yours?

Gwen: I don't know. [My fiancé] asked me that question. It's a good question. I don't know. I also had a meeting with the executive director of Komen, of the Philly branch of Komen, and she was really nice, and she actually had called me in, asked me if I would be interested in becoming—a volunteer position, a publicity chair for the Race for the Cure. And I pushed back appropriately. I said, "Look, I'm so honored, and thank you so much for thinking of me and choosing me. That's so nice, but I have to be honest. I've been through such an unbelievable experience this past year, and I really need to spend this next year, number one, taking care of me physically, the most important one—making sure I'm okay. I also work. You know, and I have a social life. And so, I'm happy to volunteer, but I don't want to take on that big of a role, because I don't want to not be able to —When I commit, I deliver, and so I don't want to commit to you and then come up short." You know?

. . . .

[But Dr. C] literally helped save my life. So I'm honored that he chose me. Plus, I'm so passionate about inflammatory, and I want to be able to put a young, hip face to it. You know?

—Gwen, 34, white, survivor of inflammatory breast cancer. She is one year out of treatment. She had a bilateral mastectomy, chemotherapy and radiation.

Gwen had the same charisma and energy that Jenna expressed—she was also doing photo shoots and participating in cancer-related events—but her tone was more reserved than Jenna's about her capacity for involvement. She felt she needed to draw boundaries around herself. Gwen felt obligated to get involved, whereas Jenna felt driven to get involved. Gwen may be one of the only young people who can speak for inflammatory breast cancer as it has such a low survival rate, and, as such, she felt she owed it to her doctor and other inflammatory survivors to put a young, hip face to it.

Obviously, not all survivors want to develop a cancer-related identity or focus their efforts on advocacy. But because of my sample, most women I spoke with did something for breast cancer: they went to survivor lunches, made donations, or did Race for the Cure[®]. It is difficult for survivors to avoid breast cancer culture. Because of how prevalent breast cancer campaigns are, the moral imperative to get involved is strong. Some survivors were involved with cancer efforts other than breast for this reason: they felt breast cancer got enough coverage and other, perhaps even more serious cancers were in need of more support. But most people did something for cancer after having experienced it themselves. Cancer expanded their social worlds, made them more aware of health politics, and shifted their perspectives on what is

important in life. These visible outward identity shifts may have overshadowed or distracted them from turbulent internal states, but these advocacy efforts also reflect a change in consciousness and selfhood that is not superficial or a product of false consciousness, as Caroline's words convey:

Caroline: So, I feel grateful all the time for my life—I mean, very grateful. I think it puts a real punctuation mark on one's life. I think you're very, very fortunate if you can get cancer, survive it, and then have it be part of your very being. It's just very—I'm aware of it probably every day. Because my life has been so good. And everything has a little more meaning to it, whether it's a grandchild being born, or at 71 years old, that I can still jog and run around, and have fun and have a good job. It's been—it's definitely been the most critical part of my life for the past 17 years. . . . I haven't lost anything. I just gained this wonderful capacity to meet people like you, to participate in any research that I can, to have started a huge social network so that other people [with cancer] can talk to each other. That's just amazing stuff to me.

—Caroline, 71, white, survivor of stage I. She has been out of treatment for 17 years. She had a lumpectomy, chemotherapy and radiation.

Type 3: identity continuance

The above sections describe identity foreclosures and creations. They may happen in sequence (i.e., a foreclosure may lead to a need for a new identity imagination), in tandem, or independently—or, importantly, not at all. Some survivors, and, surprisingly, not just early-stage or long-term survivors, said cancer has had little impact on their daily lives and identities. These survivors may or may not identify as a cancer survivor. While they acknowledge that cancer can recur, they choose not to focus their attention on cancer. They decide that cancer is not going to disrupt their biography. They “move on,” some folding their cancer experience into their self and some rejecting it

outright; but they do not carve out space for a new, distinct identity or feel that they have lost a significant part of themselves.

It's just like anything else that happens to you

One strategy for reducing the seriousness of cancer is to categorize it as “just another” event that happens in life. Lumping cancer in with other negative happenings or even other tragedies reduces its potential as deadly disease as survivors focus on what cancer shares with other events, rather than what makes it distinct. It becomes another in a series of events that comprise life: that is, it becomes normal. Suzanne describes this approach here:

I mean we all have ups and downs in our lives, job losses and heartbreak. I mean, I don't know anyone whose life has been totally problem free by the time they get to my age. So, you know, there are disappointments. Their kid makes a bad choice in marriage—there's just tough stuff. Nobody's immune from it all. So I'm not dwelling on cancer. My cancer happened, just like so and so's husband ran off with another woman. That happened. But hopefully, the person can move on and—that doesn't mean their life is over and they can't find happiness somewhere else. I put my cancer back in that category, with the fictitious friend whose son-in-law turned out to be an S.O.B. You know what I mean?

—Suzanne, 68, white, survivor of stage I. She has been out of treatment for 14 years. She had a lumpectomy and radiation.

Suzanne says she put “cancer back in that category,” revealing her conscious attempt to lump cancer in with other “disappointments” and “tough stuff.”

Focusing on those common elements means she can also apply other aspects of these events to cancer: since a bad marriage “doesn't mean their life is over and they can't find happiness somewhere else,” neither does cancer. Similarly, Jane, below, describes cancer as the same sort of event as losing her parents;

but in this case, she focuses on the aftermath of those events: one does not “stop living” because things happen. These things are part of life:

I know people who say, “Wow! Once I got cancer—boy, I chucked everything that wasn't essential.” You know—one woman in my original group went and got herself a red Corvette, because that's what she had always wanted. And she said, “Well, screw this. I'm getting that car.” I didn't feel that way. It was another experience that I had to incorporate, like the loss of my father, the loss of my mother. You know—these were very painful experiences that I had to somehow incorporate into my life. Not that you want to lose your parents. But it happens, and so I try to dwell on the good things that they gave me—you know, that they were great parents, and I have a big family on account of them. I mean, I didn't stop living because my parents died. You know? I can't stop living because I have cancer. I just deal with it on a daily basis. Keep on truckin'. I haven't made any major life changes. I think retirement will be a very big life changer for me.

— Jane, 65, survivor of stage II. She is one year out of treatment after a recurrence. She has had a mastectomy, chemotherapy, and radiation.

For Jane, cancer was not “life-changing” insofar as she has not had to drastically change how she lives her daily life. Other events, like retirement, may require more changes to her daily practices. She, like others, seem to make a distinction between the major events that require adjustment to everyday practices and the events that are emotional or mental, ones that are an inescapable part of life, but ones that that can be “incorporated” into life's regular structure. Comparing cancer to other types of similar experiences still marks it as a “special event,” but doing this also takes away some of the fearfulness about it: people are resilient and if they can recover from other kinds of events, then they can recover from cancer, too.

It's part of life—move on!

A slight variation on the above technique, some survivors refused to give cancer unique status in their lives. They do not ignore the significance of cancer, but they actively refuse to give cancer a “special” place in their lives. Some felt cancer was just something they had to do; they did it and moved on (which also depends on side effects and prognosis). Others made it part of their routine: they folded cancer seamlessly into their lives so that it became part of the fabric of their life. They integrated cancer into their lives like Jane, above, but they dismissed the role that Jane gives to cancer as a particular kind of event. Jane still marks cancer as separate and distinct from the other parts of life. These survivors do not.

For example, both Rebecca and Terry have metastatic cancer. They are both highly functioning; they have some physical symptoms from the tumors and side effects from their treatments, but they consider these effects manageable. They do not give cancer any more space in their lives than they have to. In fact, they mostly proceed in life as they always have. Rebecca, younger than the average survivor, developed metastatic cancer after her initial DCIS diagnosis. Her cancer is being managed, and she lives her life “normally.” She describes her annoyance and impatience with other, older survivors who interpret cancer as a major life event:

You know? Because there's a lot of like, old women that are like, “Oh, no. My life is over. I got to quit my job. I got to—,” this kind of stuff. I've been to some support groups, and I've had to walk out, because it's like: Are you people kidding me? Like, wake up. Live your life. Do what you got to do and go. Move on. You know? They get cancer, and they're just done.

—Rebecca, 33, white, survivor of stage IV. She was diagnosed with a recurrence one year ago. She has had a lumpectomy, chemotherapy, radiation, and now continues with hormonal therapy.

Terry, another metastatic cancer survivor, emphasizes how important it is to her to keep moving on as if life is “normal,” even if that means not disclosing her disease state to other important people in her life:

Terry: I’m feeling very private about this. It’s kind of odd that I’m doing this [interview], because I have—my family and friends don’t even know I’m stage IV. I haven’t told anybody, except my husband.

Me: Really? Wow. Is there a reason why you’re keeping it from them, or, you will in your own good time, or—?

Terry: I just want to keep things as normal as possible and just keep moving forward. So, I just figured it was easier just to not tell anybody, and not have people put me in my deathbed. You know how people are. So I just figured it was easier just to—not denial, but my way of, I guess, denial. [laughter]

Me: No, you’re right. People have an immediate reaction.

Terry: So, I just—And I work with a lot of people, and I just—everyone knew what was going on eventually [when I was initially diagnosed with stage II]. So I just chose to keep it [the new staging] [private]—It’s the easiest way for me to deal.

—Terry, 45, white, stage IV. She was diagnosed two years ago. She continues on targeted therapy.

For these survivors, cancer becomes a seamless part of life: it is the way you live. Even Terry, who refuses to share her status with others, does so in order to keep life seamless. She may be in “denial,” or using “avoidance coping” (Carver, Scheier, and Weintraub 1989), but she does not want others to define her situation for her. Their reaction would make cancer disruptive, whereas she has made cancer “normal.” Survivors of metastatic cancer have a different

vantage point than others: they know their cancer is chronic and that it will most likely end their life at some point in the future. Knowing their illness is chronic and incurable, these survivors often feel that if they do not accept their condition and integrate cancer into life, they will waste the precious time they have. People with other stages are more confused about whether to treat cancer as chronic or not, as I discuss in chapter 4. The indeterminateness of cancer in those cases (will it come back?) may direct survivors to compartmentalize the illness more, either bracketing the experience (cancer was something that happened in the past, but now I'm fine) or highlighting its uniqueness as an always-possible disease (cancer can always come back, so now I need to live my life differently).

While those with more advanced cancers may desire to put cancer behind them and move on—perhaps even more fiercely because their cancers *are* more advanced—they cannot do so totally because of continuing treatments. But other, early-stage survivors can feel that they have put cancer behind them and resist cancer as an illness identity more cohesively:

Marissa: Cancer doesn't become me. I mean, I don't think I'm cancer. Well, once it's done, it's done. It's kind of like, once you have your tooth pulled, it's pulled. It's gone. . . .

Me: Is cancer something that you think about in daily life?

Marissa: No. Never. Unless I'm talking to you—and [even then] I talk about cancer not as in and of me. It's what happened to me. It's like childbirth. It happened to me then, and if I were 40, I might have another child. Yes. Do I think I'm going to? No. . . . And so, I don't think I'm going to have cancer again. If I do, I do. But I'll deal with it then. . . . But in my heart of hearts, cancer has no place. I'm over it. I always sleep well at night. I mean, maybe two or three nights when I was researching, I did not sleep. Once I make my decision, I sleep. But

I don't think I'm cancer. It doesn't have a place in my life. I don't consider cancer emotional. I don't think it's going to get me.

. . . .

I've had intestinal adhesions. So I've had like, three colon resections. So I'm pretty comfortable [laughter] with surgery. . . . And you could allow them to be debilitating also. Because you could be on a plane and have an intestinal obstruction and you could die from having a ruptured colon. But you know, you could die from tripping and falling and hitting your head, too. . . . You just have to put life in perspective. I've had a great life. I mean, I've had all these colon obstructions throughout my life. But that's a small price to pay for what I've been given. And I don't think I'll ever have another one. I don't lay awake thinking about disease.

—Marissa, 71, white, survivor of stage I. She has been out of treatment for almost two years. She had a lumpectomy and radiation.

Marissa's strategy combines elements of the ones above—she compares cancer to other events to downplay its uniqueness, she normalizes cancer as another part of life—but she also compartmentalizes the disease from the illness experience. She decides to treat cancer as purely medical, not emotional, which helps her leave cancer behind once the disease has been treated. Being able to do this is in some ways a privilege: she is able to leave the disease behind, which helps her detach from the identity. This presents a dilemma for her: she wants to be empathetic with others, and she realizes she needs to be a “cancer survivor” in order to be part of that community; but rejecting or denying cancer as an emotional experience excludes her from cancer survivorship.

Rejecting the specialness of cancer as an event, or not differentiating cancer from any other of life's experiences, means that cancer can be “normal.” It also means that cancer does not become one's most salient identity. If cancer is just like any problem, and all problems are equalized—

“we all have our things” —then cancer cannot be a “special” identity.

Survivors can achieve this type of normalization through integrating cancer seamlessly into life so that it does not stand out or rejecting it as an important part of life altogether.

No room for cancer

Lastly, some survivors felt they had too many responsibilities in their lives to carve out a special space for cancer. Cancer was something they had to go through—they did their treatment, but did not have time or space for developing a cancer-related identity. Several survivors discussed subjugating their experience to their family’s needs or occupational demands. Again, doing so depends on having the type of diagnosis where they could circumscribe their cancer; but even metastatic survivors discussed downplaying their cancer for their caretakers’ emotional wellbeing.

Roberta had DCIS, which at the time was considered early stage cancer and now is considered pre-cancer. The staging may have helped her push her illness to the background of her life. But she did experience treatment effects. Daily radiation led to fatigue, and she suffered from the side effects of her adjuvant therapy. She said it took her a year to resume her strength and vigor. But, more important than stage in pushing her cancer to the background was her role as caregiver for her husband during this period:

It wasn’t that bad, to tell you the truth. I knew it had to be done, and really, I had no choice. It just had to be done. So, I just went ahead and did it. And the radiation was not that bad. There was no pain with it. You know, and it was basically easy. I had, I think it was 36 treatments, and I did them all; I didn’t skip any. And that was it. After that, everything has been fine. . . . I just did what I had to do each day. I still

had to wash, iron, cook, clean, you know, take care of my husband, run him back and forth to the doctors and to the labs for bloodwork and stuff like that. And he was hospitalized several times. He was in therapy. I had to take him for therapy every day. So, it took me a while to actually get back on my feet, because I didn't have a period of where I could just take care of myself. You know, he is always there. I have to take care of him too.

—Roberta, 72, white, survivor of DCIS/stage 0. She is almost six years out of treatment. She had a lumpectomy and radiation.

Roberta was fairly stoic during her interview, giving short answers to my questions. I remember wondering why she agreed to be interviewed, when it appeared as though she had so little to say about her experience. But I have grown to think that quiet interviews like Roberta's are revealing. Roberta did not have time to let cancer "in"; her stoic demeanor aided her since she could not take time off from caretaking for her husband. Cancer had to be something she "just did" so that she could continue her responsibilities.

Rosemarie similarly relegated her cancer to the background. She has a husband who suffers from depression; her cancer sent him into a relapse for which he had to be hospitalized. She would go to visit him in the hospital after her radiation treatments. She was also traveling to Italy for several months each year to take care of her elderly mother. She decided to forego chemotherapy in order to take care of her husband and appear healthy for her mother. Many survivors chose the least disruptive therapies on purpose, if they felt they could choose. Because of how busy she was, cancer could have been incredibly disruptive to her life. But Rosemarie's attitude about cancer also helped her reduce the shock of her diagnosis and significance of the experience:

[sighing] I just—Oh. [sighing] The epiphany is what? That life is fragile? Nah. I've always known that. When I found the first lump in my breast, it was in 1974. I used to run my own pre-school, which was in my home. And my husband had a plaque made for me. It said, "Rosemarie's Charm School." And the woman who made that plaque was my age, had three daughters like I had three daughters. I got a [benign] lump in my breast. She died of breast cancer. So, when I got my cancer, it was not a surprise. It was almost like, "Okay. It's my turn now." And that's how I felt. And so, I wasn't angry. I was concerned. I was more concerned about what it would do to my husband. I was very, very, very upset because my daughter's mother-in-law had a double mastectomy, and there was a long history of breast cancer in my son-in-law's family. And they have two little girls. And the first thought was: Oh my God! I can't do this! I cannot give them this inheritance on my side as well. That's what really upset me.

—Rosemarie, 59, white, survivor of stage I. She has been out of treatment for five years. She had a lumpectomy and radiation.

Rosemarie did not find cancer shocking, partly because she framed it as a common experience, but also because she already has a frame for understanding illness. She is, of course, "concerned" about her health status, but she is "very, very, very upset" about how her diagnosis might affect her family. She did not allow her life to be disrupted by cancer, and, while she cannot control its impact on others, she did her best to limit how disruptive it would be on their lives.

Adaptation Styles

Numerous researchers have outlined various psychological strategies survivors use for coping with breast cancer (for example, see Taylor et. al 1984; Taylor 1983; Miller 1987, 1995; Link et. al 2005; Sarenmalm et. al 2013; Kvillemo et. al 2014; Yoo et. al 2014). Most psychological research finds that the ability to address the cancer experience, rather than deny or

repress it, leads to better outcomes. But coping is not the same thing as how survivors think about their selves in relation to cancer. Zebrack (2000: 239; *italics mine*), though writing a decade ago, notes that the survivorship literature has yet to explain how survivors “integrate the experience into their *personal biographies* (and if so, how),” as well as explaining the factors that prohibit or enable this integration and consequences for doing so.

Coping is generally discussed in terms of how people attempt to solve problems or adapt themselves emotionally to the situation (Lazarus and Folkman 1984; Carver, Scheier, et al., 1989; Lawrence, Ashford & Dent, 2006). The identity work I describe above may fit into types of coping, however identity work is about how an individual appraises different parts of the self in relation to the larger world. In the sections above, I have attempted to delineate ways in which survivors respond to cancer in regard to particular identities, conceptualizing the self as comprised of multiple identities that are activated or prohibited by particular structures, roles, situations, and cues (see Danna-Lynch 2009, 2010). Individuals attribute different *types* of importance, not just different amounts of salience or centrality, to different identities, sometimes irrespective of the time or energy they are able to invest in them. While narratives about cancer are one way of integrating this experience into one’s biography, the identity work one does can be interpreted as strategies for shaping how one actually does incorporate cancer into overall self-concept.

Survivors employed three dominant styles in incorporating cancer into their self concepts and their lives: integration, compartmentalization, and

r/ejection. Charmaz (1991, 1994) and Bury (1991) discuss the ways people suffering from chronic illness vary in how they define themselves by illness or separate illness from the rest of their lives. Survivors here are talking about the overarching role cancer plays in their lives—not their specific cancer survivor identity, but how often they think about cancer, to what extent they feel they have changed because of cancer, and how much they feel cancer has become a part of their self-concept. Survivors who compartmentalize cancer move in and out of cancer zone: they pay attention to cancer when they want or need to. For those who have fully integrated cancer into their selves, or who have no choice but to deal with chronic side effects, they accept cancer as an integral part of their lives but may define their new normal in different ways: some focus on self-growth whereas others focus on limitations, but the majority of my study participants emphasized cancer as a meaning-making vehicle in their lives. Others, who feel that cancer had little effect on their lives, eject cancer from their lives once they are finished with their active treatment and largely reject identifying with cancer as an illness identity. They say they put their cancer experience behind them and moved on: they may have a loosely constructed cancer survivor identity, but they largely do not attend to cancer in their mental or everyday lives. These styles vary by degree, time, and context, yet survivors expressed one overall dominant style to me in keeping with their identity as a survivor. While my research cannot tap into all the various contexts that cause survivors to use or rely on different cognitive

styles, I can outline the distinct styles I found across interviews that survivors use to live life after, with, or beyond cancer.

Compartmentalization

This model is the most prevalent in my sample. Most of my participants saw my notice on a listserv they signed up for through a cancer organization, although many of them were not active members of the organization. They chose to contact me, activating their cancer identity for the purposes of talking with me about their cancer experience. Survivors talked to me for different reasons: some felt an obligation, some needed to tell their story, some wanted to help me. But survivors who compartmentalize, even if they do identify as a “cancer survivor,” do not actively engage with cancer in everyday life or feel that they have fully incorporated cancer into their sense of self. They want to create some distance from cancer. Melissa is a good example of this type. I introduced her at the very beginning of this chapter as an example of someone who felt cancer’s extreme disruptiveness. But even she, despite her sense that nothing will ever be “normal” again, limits the extent to which she incorporates cancer into her sense of self:

I did not want to give my entire self to cancer permanently. I don’t wear pink. I don’t run around talking to everybody about breast cancer 24/7. I didn’t want it to completely define who I was.

—Melissa, 42, white, survivor of stage II. She is almost six years out of treatment. She had mastectomy, chemotherapy, and targeted treatment.

Frannie also describes compartmentalizing her cancer self:

I wouldn’t say, “left behind,” but segmented, yes. I don’t—I do—I’m aware, and if I’m in a room where people are talking about cancer and having cancer, I might say, depending on who they are and how the

conversation is going, I might say, “Well, I’m a breast cancer survivor.” But I never start a conversation like that, and I’m not, “Look at me. I’m still here,” kind of thing, out of the blue. You know, I don’t. Because we all have our things. Some people have asthma. Some people have, whatever.

—Frannie, 75, African American, survivor of stage I. She is nine years out of treatment. She had a lumpectomy, chemotherapy and radiation.

I commonly heard survivors tell me that they selectively identified themselves as survivors; they chose when to bring it up in conversations and with whom to disclose their status. Compartmentalizers participated in cancer events and mentored other new survivors, but they were conscious about when and where they decided to enact their cancer identities. Many identified as cancer survivors; they just did not put this identity—or want to put this identity—at the top of their list all the time. They did not use cancer survivorship as their lens for viewing the world.

Integration

Reviewing the literature, Zebrack (2000) finds that survivors who do integrate the cancer experience into their self-concept through meaning making, changing priorities, or accepting mortality have positive psychosocial “adjustments”—they are able to overcome disruptions to valued identities or roles (2000: 241). Compartmentalizers do integrate the experience into their self-concepts; but they want to draw boundaries around their core self or set limits to cancer’s influence. There were a few survivors who fully integrated cancer into their lives in my sample, but these survivors did so in two different ways: one group did so to normalize cancer, to render it less special and perhaps less dangerous, and the other group did so to make cancer

survivorship a salient and central identity. In either regard, they felt cancer had become a part of their sense of self, a filter through which they now saw the world. As Monica describes, “I don’t necessarily consider it to be a hat that I take off. I would say, depending on what I’m doing, that might be a little bit bigger and a little bit more flashy. . . . I don’t necessarily—I can’t take it off, because it’s not something that I—I don’t think I’m at the point where I can say, ‘It’s not me.’” Rather than arranging identities hierarchically, integrators merge “cancer” into their other identities. Their new normal, as a result, integrates health and lifestyle changes consciously directed at cancer. They accept cancer as their new health and identity status and acknowledge the role cancer continues to play in promoting changes in their life. Candace, for example, reconfigured her life in terms of cancer:

Candace: I was able to work through a lot of issues, give myself time to reflect, to journal, and I do that every day. And to be more cognizant of living every day, not trying to you know—attain another goal, as opposed to doing something I want to do.

Me: And how do you think you approach your health and your cancer history? Is it something that you’ve incorporated into your whole life, or is it something that you have compartmentalized, sort of put outside of what you consider you, or normal, or—?

Candace: Well, it is the norm for me now.

Me: It is?

Candace: Yeah. I mean that’s—just like it would be if I’d had an ankle, broken ankle or something. It’s just part of the deal now. So, I make sure that I keep up on things that are happening. I usually read from various websites at times, what the newest thought processes are and ask questions when I go to my oncologist. And you know—I’m trying to do everything I can do to make the possibility of me getting cancer due to something I’m doing, as minimal as possible. So, I do incorporate it into my everyday life.

—Candace, age 59, white, survivor of stage II breast cancer. She had a bilateral mastectomy one and a half years ago.

Candace seamlessly weaves cancer into her normal: “it’s just part of the deal now.” Cancer frames the decisions she makes as well as how she thinks about her body and self. She’s attuned to cancer in her everyday life and she has made survivorship a significant identity. Other survivors, like Jenna, whom I discussed above in terms of advocacy identities, threw themselves wholeheartedly into cancer work. Some regularly read cancer blogs or articles or commit themselves to a diet intended to reduce inflammation or organize their lifestyles around boosting their immune system. Integration may not necessarily be the “She-ro” identity described by Sulik (2012); survivors integrate cancer into their lives in various and subtle ways.

Even integrators might occasionally compartmentalize cancer to some degree—thinking about cancer non-stop may be unsustainable and socially unacceptable—but the difference between those who compartmentalize cancer and those who integrate cancer seems to exist on the level of self-concept: those who compartmentalize cancer can switch on and off the cancer lens whereas those who integrate cancer are usually viewing life through cancer (and not necessarily in a negative way). For example, Heather also says she has integrated cancer into her identity and her life, although she realizes the world is organized into cancer and non-cancer spheres. She has a life “outside” cancer—places where cancer is not ostensibly relevant—but she has integrated cancer into who she *is*, how she sees the world; for example, she

wears a survivor ribbon necklace, much to the chagrin of her teen-age daughter, because she wants people to ask her about it. But, like every other survivor, she is expected to move back and forth between spheres. She is not compartmentalizing *herself*, but complying to the demands of the world by moving through compartmentalized spaces:

Heather: And I have to say, like, in my regular life, there's really nobody that has had breast cancer. [chuckling] "My regular life."

Me: Do you have different lives? Do you think about them as different spheres?

Heather: I do. I do. Because there's that regular, and then there's like—if I think about Breast Cancer Resource Center, when I went to support groups—which, I didn't even go to that many, but I went to a few, because [laughter] every time I would tell my pathology, people would go, "[Gasp]." Like that. I was like, [nervously] Okay. They're right. It is a different world. . . . There's some times, every once in a while, I think it would be nice to have like a group of people who are survivors to like, get together. But I don't think there is a big call for that. Because I think people want—most people just want to get done with it and just like, try to forget about it. I think for me, I've kind of like ingrained it and woven it into me. And I'm okay with that. I know people who have had breast cancer, and they don't even talk about it.

—Heather, 45, white, survivor of stage III. She had a lumpectomy, chemotherapy, radiation, mastectomy, oophorectomy.

Heather catches herself when she says "my regular life," repeating the phrase with sarcasm. She knows that divisions between "regular" and "cancer" do not really exist for her, yet they do in the outside world. Elsewhere in her interview she describes the pressure she feels to act as if these divisions exist: other people expect her to resume "regular life" even though she says her perspective has radically changed. She acknowledges that the cancer world is "a different world" than the "regular" world healthy people get to live in; but,

in terms of who she feels she is, she has “ingrained” and “woven” cancer into her.

R/ejection model

These survivors feel they have left cancer behind, both as a disease and an identity. They are not in denial about what they have experienced or what cancer may imply for their future health—they do continue to see their doctors for follow-up cancer care—but they choose to not focus on cancer. They feel that they have “given enough power” to cancer and want to spend the rest of their lives focused on themselves and living well. Many enact strategies to normalize life after cancer, which I discuss in the next chapter. These survivors are also largely the ones who say cancer was not disruptive for them or their identities. There is variation in this type, though: some may recognize cancer as health status, but they do not want to adopt survivorship as a valued identity. Some still pay a nod to survivorship but largely live without heed to cancer. Some do not attribute cancer a special event status but insist that almost any event can trigger a similar type of new normal. And some simply feel that cancer left no mark on their selves or how they live their lives. While these survivors may not describe their framing of cancer in active terms, they choose to “eject” cancer from their lives after finishing treatment. These are the people who say that their life is not defined by their cancer experience in any significant way:

Pamela: I don’t really think [cancer changed my life]. I wish it did, in the sense that you are always reading about these people who have become better people because of it. And I always feel like, “eh—.” [laughter] I don’t think it changed me in any way. But you’re always

reading about, “I’m more spiritual. I’m more calm. I don’t let little things bother me.” [laughter] That didn’t happen to me, unfortunately. [laughter]

Me: Yeah. I think about that stuff too. Like, you know, you have this major event happen to you. You’re supposed to be different. But you don’t feel any different, or—?

Pamela: No. [chuckling] You know, I have people—people that have had heart attacks, I’ve heard say, “Oh, since my heart attack,” or “since the cancer,” or whatever, or stroke or whatever, “Oh, I thank God for every day. I appreciate every day of my life. I stay calm. I don’t get angry. I don’t—.” [laughter] [sarcastically] Right. Yeah. No. [laughter]

—Pamela, 66, white, survivor of DCIS/stage 0. She is 14 years out of treatment. She had a lumpectomy and radiation.

Pamela, a long-time survivor of DCIS, had a recent occurrence of uterine cancer, yet she does not think either occurrence drastically changed her perspective or life. She has intensive follow-up appointments now, every three months. It is difficult to imagine that these experiences have not had an impact on her. But she describes herself as an optimist with a seize-the-day mentality: “I’m a girl-who-just-wants-to have-fun kind of person. [laughter] I want to do everything that I want to do, because you don’t know what’s going to happen tomorrow.” Cancer may not have significantly altered her perspective, but it may have confirmed her preexisting cognitive framework.

Survivors with easily managed early stage cancer may have an easier time putting cancer behind them, if they disengage from cancer. I discussed Roberta, above, as someone who simply did not have room for cancer in her life; she was consumed with caring for her ill husband. She did have some side effects from radiation that affected her for a year after treatment, but, since then, she feels that cancer is far behind her. Time from diagnosis and

treatment was also a critical factor for Marissa in moving on and away from cancer:

Me: Was there a process that you needed to sort of get over the cancer and put it behind you?

Marissa: No. How lucky was I? I mean I really feel so lucky, that, I guess it's a segmenting it. That was then. This is now. That was me. I had that. I gave it away, and I'm me. So, there is no disease. In my opinion, there's no disease.

—Marissa, 71, white, survivor of stage I. She has been out of treatment for almost two years. She had a lumpectomy and radiation.

Kara, a survivor of stage I who opted for a double mastectomy and reconstruction, embodies this mentality, as well:

Me: I wanted to ask you: Do you feel that things got back to normal for you now?

Kara: Yeah, they did. Yeah, they did. I'm actually so sick of people asking me how I'm feeling. You know? It's like—the last surgery was in May, and that was like, a minor procedure. And really, since about—even March, I guess—I mean, the surgery was pretty heavy duty, but it was the end of January. So, I would say, even by March, that I was pretty much back to normal. People still—they're "Oh, how are you feeling?" You know, I'm done and I don't want to talk about it anymore. And, obviously, I know that everyone is just being nice, and they don't necessarily know that I've been feeling fine for six months now. But—[laughter]—I'm ready to talk about something else.

Me: I mean do you feel that it's sort of taken over your life in a way—that you want to put it behind you and move on? Or how do you feel—?

R: I think I already have. I just need everybody else to, too.

—Kara, 37, white, stage I. She is one year out of treatment. She had a lumpectomy, chemotherapy, bilateral mastectomy, and reconstruction.

I questioned in my notes whether Kara really was fine and had moved on, as she struck me as defensive and evasive. But, even if so, these were still tactics she was using to help her move on. She desired to move on and past cancer rather than integrate it into her identity and new normal.

Miller (1986, 1995) uses the term “blunting” to describe when survivors actively resist cancer-related risk. Kara may be blunting cancer talk in her attempt to move on, but, interestingly, she engaged with cancer on other levels: she was passionately invested in her training for a three-day walk to benefit cancer research. In my view, the three-day represented for her a way she could purge herself of cancer and show that she had overcome the illness and the experience. She separated participating in events like the walk from thinking about herself in relation to cancer; for her, she participated in cancer events *because* she had “moved on.” She does identity as a survivor but does not want to think or talk about cancer in terms of her self.

Conclusion

In this chapter, I have discussed three interconnected domains that shape how survivors live with, after, or beyond cancer: perceptions of cancer as a disruptive event, identity reactions to one’s experience of cancer, and adaptation styles for thinking about cancer in relation to one’s sense of self. These domains are interactive and dynamic: while how a survivor perceives cancer as an event may trigger changes to identity, and thus influence dominant adaptation style, how cancer affects valued identities can also shape how a survivor perceives cancer and decides to incorporate cancer into self-concept. These domains are intricately interrelated; I conceptualize them as interlocking pieces determining how survivors appraise the impact of cancer to identities and respond to cancer in reconstructing their sense of self. A survivor can perceive cancer as disruptive, have some types of identity

foreclosures and other types of identity creations, while also attempting to eject cancer as a disease but perhaps not an survivor identity. Each domain has multiple possible reactions that can change over time and with new information. For instance, within each domain, as pictured in Figure 1, reproduced here from the beginning of the chapter, there are multiple factors that interact with each other and that then influence the other domains, as shown below in Figure 2.

Figure 1: Incorporating cancer experience into self-concept

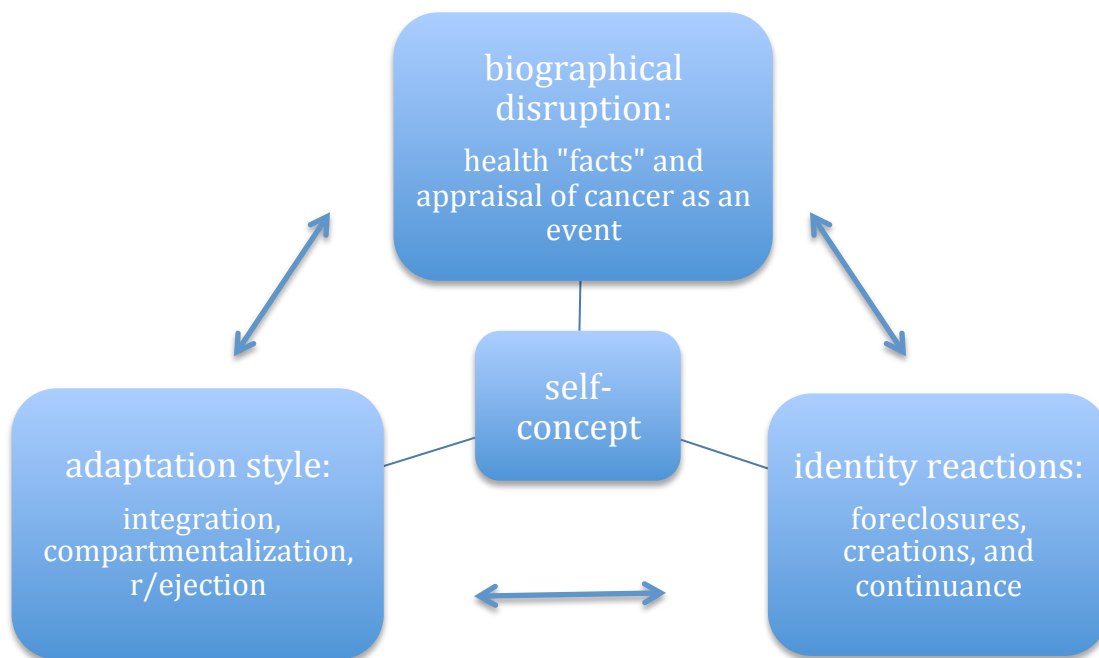


Figure 2: Variation within biographical disruption, identity reactions, and adaptation style

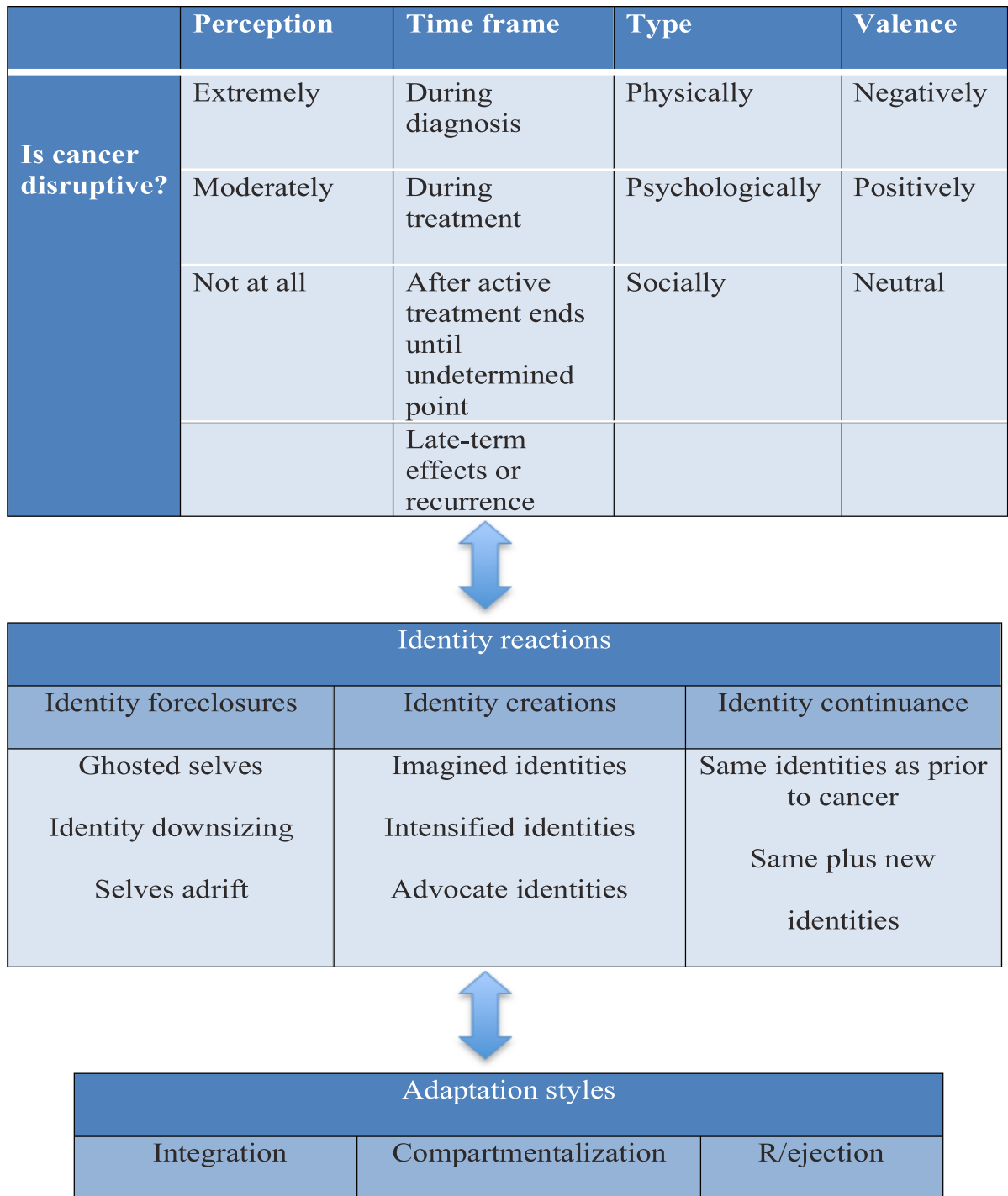
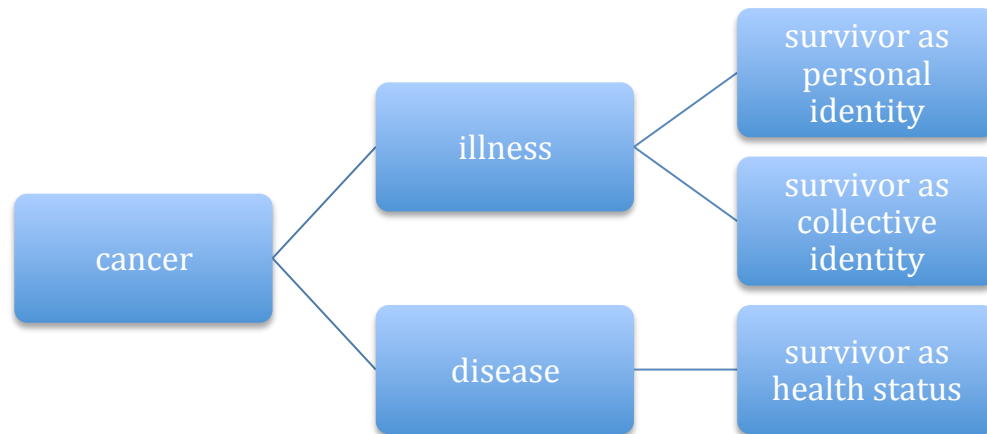


Figure 2 shows each domain represented in Figure 1 in more detail. Based on how cancer disrupts particular valued identities, one may experience identity foreclosures and creations, or foreclosures without creations, or neither foreclosures nor creations. Adaptation style to cancer—by which I mean how a survivor integrates, compartmentalizes or rejects cancer from *self-concept*, not how well or poorly a survivor adjusts to life with or after cancer—can operate on different levels, as well. Because breast cancer survivorship has become a political and advocate-oriented identity, survivors can choose to incorporate cancer as illness or as a survivorship identity while deciding to reject identifying with cancer as a disease. This is difficult to do for survivors who have severe side effects, but even they make distinctions between what is cancer and what is a result of treatment for cancer, enabling them to distance themselves from the disease. Moving forward in life following cancer, then, is somewhat about deciding how one wants to engage with cancer as both a disease and an illness experience, as well as how one wants to engage with survivorship—as a political identity, and illness identity, or a health status. These are multiple components of the cancer experience that survivors may integrate, compartmentalize, or reject from their self-concept, as shown in Figure 3:

Figure 3: Components of cancer subject to incorporation into self-concept



Self-concepts are informed by the “facts” of one’s cancer as well as how one experiences the illness, in addition to cultural and personal understandings of cancer, but how one “moves on” in life after, with, or beyond cancer is a also product of a survivor’s ability to “craft” together multiple strategies and practices (Swidler 2001, Frank 2003, Kaiser 2008). Living “with,” “after” or “beyond” cancer can be more of a cognitive choice for some survivors than others, depending on disease state; however, the adaptation styles survivors employ in incorporating cancer into their self-concepts influences their thinking in moving forward. Whether survivors move forward into a “new normal,” remain within the “same normal,” or perhaps create a hybrid of the two is influenced by the various strategies and factors I discussed in this chapter. In the next chapter, I discuss the ways in which survivors construct “normal” in their lives following cancer.

CHAPTER FOUR

Life in the “new normal”

When you’ve had cancer, you feel like you’re, in a way, no longer this bright-eyed, bushy-tailed innocent anymore, but that you’ve sort of been through the ringer. You know, you have some battle wounds and scars, and you just look at things differently.

—Deborah, 52, white, two occurrences of stage I, nine years since treatment: lumpectomy, chemotherapy, radiation, bilateral mastectomy, and reconstruction.

And I don’t feel as connected in some ways. I feel a little more disconnected, I should say, than I used to, because of having to go through all this stuff. It’s like, I had my glasses taken off, and I can see clearly, and you all can’t see it because you didn’t do it. [laughter]

—Margaret, 50, stage II, one year out of treatment: lumpectomy and chemotherapy.

No. I don’t think you ever return to normal. I think you find a new normal. . . . I just feel very positive about my life, even though I have some low moments. But I’m able to come back from those low moments and low periods and have some positive thoughts, and see a future for myself. . . . Well, it made me more aware. . . . It made me more aware of life and just, other people’s lives around me. . . . I’ve always been an empathetic person—always—but I think I’m more in tune to it now. People’s situations—you know, a crisis or illnesses, or just sad stories.

—Natalie, 54, African American, stage II, five months out of treatment: chemotherapy and bilateral mastectomy.

Most of the survivors in this study said that cancer had a significant impact on their lives. Not always dramatically, but being diagnosed and receiving treatment changed the way survivors saw themselves, the meaning of their lives, and their place in the world. They said that life did not go “back to normal” after treatment ended or stabilized. Some described life as a “new normal.”

“Normal” means different things to different survivors, depending on health factors but also their interpretation of the event of cancer and how they engaged in identity work in relation cancer, which I discussed in the last chapter. How survivors interpret cancer—as a life-changing event, an eye-opener or warning, a strictly medical disease—influences how and to what extent they allow cancer to shape their sense of normal following cancer. Survivors spent considerable mental energy normalizing life—by incorporating cancer into their lives and identities, compartmentalizing or distancing themselves from it, or some combination in between.³ In this chapter, I discuss the perspectival shifts survivors described as well as the strategies they employed in constructing normality following cancer. Survivors employed several strategies for designing life with, after, or beyond cancer—whether this be through “returning” to normal, creating a “new normal,” or entertaining a hybrid state—while retaining elements of ontological insecurity. Cancer creates a new consciousness because of the ontological insecurity produced in relation to cancer’s disruptiveness (see Drew 2003),

³ I want to emphasize that it is important to think of these adaptations to cancer as *styles*. While some research finds that incorporation of cancer into one’s self-concept has better psychological outcomes (Zebrack 2000), I am discussing here how survivors use these understandings to carve out new definitions of normality for themselves. The adaptation styles I have outlined are not meant to represent progressive stages of adjustment to cancer, leading to better or worse types of psychological outcomes, but different styles survivors employ in integrating cancer into their self-concepts. Different adaptation styles may suit people depending on their needs and skill sets. Miller (1986, 1995), for instance, finds that monitors and blunters need different interventions, not that one is a better technique than the another; they both can have better outcomes if information is presented to them in accord with their cognitive style. Thus, adaptation to cancer has to be perceived in accord to how the survivor frames cancer and understands her self in relation to cancer, amongst other factors.

but only a select group is able to harness ontological insecurity to help them live life “more fully.” Others cannot use this new consciousness to benefit them because of debilitating treatment effects or other psychosocial factors.

Ontological insecurity and conceptions of normality

Cancer diagnosis and treatment destabilizes individuals because it throws normality—the integrity of the body, conceptions of self, plans for the future—into question. Even though types and stages of cancer have become treatable, cancer still carries the threat of death: cancer is the second leading cause of death in the United States; for women, breast cancer is second to lung cancer in cancer mortality rates. Cancer continues to breed generalized fear even though prognoses vary. Moreover, treatment for cancer, which is what most survivors experience, not the cancer itself, is often debilitating and physically transformative: survivors may lose their hair, part or all of their breast(s) and sometimes their ovaries, and experience reduced arm movement/arm swelling (lymphedema), joint pain, fatigue, neuropathy, heart problems, reduced lung capacity, premature menopause, lack of libido, and reduced sexual functioning. Going through treatment for cancer breaks down the body and the mind. As Gillian, a 47-year old survivor currently undergoing breast reconstruction, often a year-long project, told me: “It’s harder than I thought it was going to be. . . . And it changes you in ways; it’s more of a mental battle, as much as it is a physical [one], and that was the surprising part . . . how much of a mental [battle it is].”

The mental battles survivors describe involve re-conceptualizing life and self after a disruption in ontological security, an intrinsic feeling of safety in the

world (Giddens 1991; Laing 1972 [1961; 1969]). Most survivors live with thoughts of recurrence, regardless of risk or time since initial cancer, such that existential insecurity becomes part of survivors' subjectivities moving forward (Drew 2003). Gillian's statement and the others above describe different aspects of this shift in consciousness. Deborah attempts to describe a qualitative change in selfhood after cancer: one is not a "bright-eyed, bushy tailed innocent" anymore, having "a little bit of the bitter that you may not have had before." Even though she is happy with her life, cancer took something away from that happiness by showing her how fragile it can be. Heather, who I introduced in the last chapter, described something similar: she said she has a "great life" now but that she had a "really great life" before cancer. Margaret's comment, the second quote above, can shed some light what this shift in consciousness entails. She talks about how a rupture in ontological security can provoke a feeling of distance or detachment from the "normal" world, making one feel excluded from a shared sociomental community (Zerubavel 1997; Fleck, 1935 [1975]). This distance and detachment is perhaps what Deborah means by "bitterness" and what marks the shift from Heather's "really great" to just plain "great" life. Most people suppress thoughts of mortality, erecting a barrier between the unthinkable and themselves (van Gennep 1960; Douglas 1966). Giddens (1991) describes this as "bracketing." What survivors are describing when they lose their rosy glasses or innocence is their confrontation with the mundanity of human existence—their inability to bracket themselves from their own mortality. Some survivors embrace this new consciousness as the defining factor of their "new normal," though; they use this

consciousness to help them move forward, rather than thinking about it as a marker of exclusion.

For this reason, I resist explaining survivorship as a type of liminal position between life and death, illness and health, even though other researchers find this appropriate (Little et al. 1998). Much research depicts survivors in states of transition from settled pasts to indeterminate futures. Baker et. al (2014) found their study participants spoke of normality in terms continuous or discontinuous with the past—“getting back to normal” or establishing a “new normal”—but that the majority held both descriptions in often contradictory ways. They interpreted this as evidence of a survivor’s “intermediate stage of adjustment” to life after cancer (2014:1). In a study of survivors with poor prognoses, Balmer et al. (2014) argue that these survivors cannot “return to normal,” remaining in a liminal state because “even when participants were effectively health and seemingly established in their ‘new normal,’ persistent reminders and an unremitting fear of recurrence made survivorship an ‘ambiguous’ state” (15). Appleton and Flynn (2014), describe “new normal” as an expression denoting “transition points in the patient’s pathway,” although they concede that this terminology, “provid[es] a way to conceptualise changing circumstances and redefine identities” (382).

I challenge these interpretations of the “new normal” or life with cancer as “intermediate,” “transitional” and “liminal.” While there is always an ill-determined adjustment period during which survivors may be “in transition” to new health statuses, understandings of self, and identities (see Hewitt et al. 2006), survivors’ descriptions of various types of normality, especially their use of “new

normal” to designate a new way of being, indicate their abilities to adapt to survivorship as a permanent state of risk and change. Researchers may impose a narrative of extended transience on survivors, expecting them to adapt to cancer in particular ways—to go back to normal *or* to move on—when in fact, survivors may not experience life in such terms. I find that survivors use multiple methods to resist feeling “betwixt and between” (Turner 1970; see also Danna Lynch 2007, 2009). Their sense of being qualitatively different than before conveys a mental space of lost assumptions but also new ways of seeing. This new perspective may blend new and old selves, days of health and illness, and feelings of loss and gain—however, as such, it is a hybrid and not an “in-between.” This distinction is important for recognizing survivors’ agency in constructing life after, with, or beyond cancer, as well as being a more apt description of survivors’ lived experiences.

Importantly, there is also a conceptual difference between liminality and feelings of unsettledness (Swidler 2001) that such ruptures or unexpected events may produce. “Unsettled” periods are those in which people are “reorganizing their strategies of action or developing new ones. . . . [They] inspire some cultural rethinking, although people also continue to rely on their existing repertoire of personal and social capacities” (Swidler 2001: 93). Unsettledness forces individuals to be conscious of their actions and thinking, to work at retooling. Liminality, a space in passing, assumes that the two states one is caught between are distinct: one is sick or one is well, and one moves from one realm to the other. Survivors merge these realms, and aspects of their lives may remain settled while

others are unsettled. Survivors may experience degrees of unsettledness, as well. Some survivors lost their footing after cancer because they could not pattern new strategies or continue the old, but most survivors learned to blend various aspects of their lives, attributing cancer different “mental weight” at different times (Danna-Lynch 2009). They felt, while foregrounding and backgrounding cancer at various times, that their selves were on a different life path because of the experience: their biographical trajectory had shifted as a whole while they negotiated cancer in daily life in both subtle and major ways. Disruption leading to unsettledness rather may be a better conceptualization of survivor experience because it highlights survivor consciousness of constructing normality as they proceed from diagnosis.

Survivors describe cancer as part of them, something they cannot leave behind. They describe cancer as “always” in the backs of their minds, although some attend to or highlight cancer more regularly in their daily lives than others. Survivors have crossed the threshold into survivorship, and, as the medical field defines survivorship, there is no returning to pre-cancer status. Yet, survivors also acknowledge that they cannot mentally engage with cancer all the time. Survivors employ particular cognitive techniques and social practices for managing cancer in daily life, making life “normal,” while also retaining consciousness of cancer. They explain that life does not slip back into a taken-for-granted settledness because their consciousness of cancer is always present.

The new normal: social practices and non-routinization

Survivors described three major ways in which their “normal” changed after cancer: their bodies and minds were altered by treatment, they modified their lifestyles and habits to reflect their new conditions, and they found their “life perspective” had shifted. These changes are interdependent: changes to their physicality and cognitive abilities influence lifestyle—both in terms of what one chooses to do and what one is able to do—and how one perceives meaning and purpose in life. Survivors alter their social practices to compensate or adjust to their new conditions and consciousness. However, these practices—while “routine”—may not become “routinized.” Their existence highlights an individual’s status as cancer survivor, bringing cancer into consciousness rather than enabling cancer to slip into the background. Moreover, not everyone’s “new normal” is positive, further highlighting one’s cancer status. Those managing bodily and cognitive disabilities have a more difficult time taking advantage of the positive benefits of the perspectival shift that other survivors describe. Survivors who mostly experience the perspectival shift—with minor side effects from treatment—are most able to harness ontological insecurity to make positive changes to their lives. For those suffering debilitating side effects, their heavy attention to these side effects may disable them from actualizing cancer as an opportunity for growth. For all, the “new normal” means that life becomes routine but not taken-for-granted.

Workarounds for physical and mental limitations

For some survivors, the mundanity of life takes on new significance, but not always a positive one. Physical and mental difficulties make it harder for survivors to conceptualize the “new normal” in a positive light. This “negative adjustment” may be what researchers respond to when they posit that survivors exist in a liminal space, because disabilities highlight the discrepancy between selves. Psychological research finds that people tend to think of their future selves more favorably than their past selves (Wilson et. al 2012). However, survivors may not do this. As people base their conceptions of the future on what they already know, the knowledge they have gained through cumulative past experiences (Schutz 1967 [1932]), experiencing a disruptive event may destabilize the platform from which they conceive of the future. These psychological and phenomenological understandings of the self may jeopardize views of “normality”: if normality is what is known, normality for survivors becomes situated in the past making “adjustment” to degraded future conditions unpleasant or uncertain. Survivors’ senses of future may be blank or hazy if their pasts cannot have predictive value. This can be painful for survivors who feel that cancer created a rift in continuity between past and future. Part of the “new normal” for many survivors is learning how to live with limitations and to bridge the gap between past life trajectory (past self and future self projected in the past) and one’s newly projected life trajectory (current self and projects of future self).

These limitations can keep survivors grounded in the present so that they do not project a distant future. Survivors devise workarounds to the physical and mental limitations caused by cancer, which sometimes help survivors reclaim feelings of mastery and independence, accepting present conditions and helping them look forward to the future. However, at times they do the opposite: remind survivors of their cancer state and predicted denouement. For example, Allison has had to become a creative problem solver because of cancer. She repurposes objects from other domains, giving them a significance that outsiders would not perceive. However, instead of boosting her self-esteem, being clever has become “boring” and “frustrating”:

I can't open the jar because my hands hurt. All the knuckles and joints feel like they're swollen, badly bruised, and somebody is sticking needles in them and jabbing them in. So, okay—that's kind of like arthritis. What would I do if I had arthritis? How would I open a bottle? Well, they make these doodads. They make things to adapt, you know, for people with disabilities [showing catalogue]. What other things have I found? I don't wear as many things with buttons because I can't always get them on. I wear more things with zippers. Necklaces—I can't always get the little things open. So I put a lot of my things, when possible, on a longer chain so I can just put it over my head. What else? Sometimes, if I'm driving, especially for a long time, holding the steering wheel can be hard. So I went out and I found garden work gloves that have like that sticky rubbery sort of stuff on them. . . . [It] gets really boring, really frustrating.

—Allison, 51, white, stage IV, five years since diagnosis. She is continuously treated with hormonal therapy.

While objects can connect people to cherished identities or help them activate those identities under stressful conditions (see Danna Lynch 2009; Miller 2009), Allison described the ways in which these objects reinforce her cancer identity, which, for her, is negative. Her frustration stems from the fact that she has no choice but to focus on mundane details. Instead of becoming routine or normal,

these workarounds make her cancer identity more pronounced. Her frustration is an important indicator that the workarounds do not enable her life to take on a routinized sense of normality, even though the workarounds themselves have become routine. She perceives her “new normal” in largely negative terms, mostly from the side effects but also because other problems in her life compound her cancer-related problems: her separation from her husband while living in the same house and her need to resign from her job because of lack of stamina weigh on her as much as the cancer. The weight of all three events keeps her immobilized in the moment.

Naomi is a good contrast to Allison. Her circumstances are similar to Allison’s, however her perspective on them is different. Her cancer had metastasized, eating away at bone in her femur, after she had been “cancer-free” for 14 years. She spends most of her time in a wheel chair although she can use crutches. Now separated from her husband, she lives in a hotel because of its ease and convenience. She can rely on the hotel employees to clean her room, wash her clothes, bring her bags to her room, and help her in little ways. While she is lonely at the hotel, going out for everyday activities requires a lot of effort. She cannot maneuver her wheelchair in and out of cars, and using crutches to go shopping or to the library, where she will need to carry items, is too tiring. She found the grocery store to be a haven:

So, usually, if I have to go out—like if I go to the supermarket, I go to the car and I asked them to take the wheelchair back in the hotel, and they keep it behind the front desk. And then when I get to the store, I have to hobble in with my crutches. Grocery stores are great. That’s a great place to go because they have those electric scooters, and you just get in them and you go, [giggling] “Oooh!” But that’s like the one fun thing that I can do. So I

like [to go]— that’s the only place I can go [on my own]. And I used to hate grocery shopping. But now, it’s like fun for me to go there, just because I see people, I talked to everybody up and down the aisles. [Laughter] I talked to the cashier, and I just have a good time. [Laughter]

—Naomi, 64, white, stage IV; she was diagnosed five years ago, which was 10 years after her first occurrence. She had a double mastectomy and chemotherapy; she is now continuously treated with targeted therapy and chemotherapy.

Naomi’s loneliness and isolation are aggravated by her physical limitations. While Allison does not take joy in the mundanity of her workarounds, Naomi seems to relish what she can still do. For both, everyday objects and activities have changed meaning because of cancer: they see these objects and activities in a different light and use them in different ways. Naomi enjoys going to the grocery store because she can be independent there—it is a source of joy rather than tedium. She knows her new normal is better than some others, making positive downward comparisons (Taylor and Lobel 1989). She also compares her life to what *it* could be. She thinks that if she were living at home, she would probably be more isolated; she would be living alone with a husband who is having an affair and, while he wants her to be home, does little to help her. At the hotel, she talks to other guests and employees and they help her. The difference in Naomi’s perspective from Allison’s could be age or that her cancer is a recurrence after 14 good years or the conditions she feels she is escaping: perhaps the severity of her cancer is a type of cognitive “emancipation,” freeing her to live her life as she wants, pursuing unorthodox solutions, rather than feeling beholden to cultural expectations for how to live (from her husband or employer or her family, all of whom she described in authoritarian terms) (see Cerulo 2006: 194). While I am

using this term differently than Cerulo does in her work—she discusses “emancipating structures” that enable people within particular positions to envision and prepare for the worst (2006: 164-232)—Naomi has already prepared herself for the worst. She may be able to reengage with what is positive about her life because the worst is defined and she no longer fears it.

Cheryl represents a more common orientation to new normal. The big structures—job, marriage, living arrangements—in her life have not changed, as they have in Naomi’s and Allison’s situations. She lives within the same structures and according to the same expectations as she did before cancer, but she needs to adjust to them now that she has changed. Cheryl discusses how she has changed her work style because “chemobrain” has reduced her cognitive abilities. She describes the frustrations of her new normal when structures do not change to accommodate her, and the necessity of developing good tricks to help her perform:

I have problems focusing. Thank God I’m not a doctor or something, or a teacher, that I have to be able to think quickly on my feet and react and to teach and to stand up in front of a class all day. I couldn’t do it. And that’s frustrating, too. I’m very fortunate that I’m a project manager. I can write things down all the time and refer to my notes, and I can work on a computer. And if I screw up, I’m not killing somebody. . . . I used to be a lot more focused, a lot more organized, a lot more attentive, and, now, I just feel like my brain cells are slogging through mud. . . . And people talk about, “well, you have to get used to the new normal.” It’s hard. Because I think of the old normal and the way things used to be, and I know I can’t do that anymore.

—Cheryl, 50, white, stage II. She had a lumpectomy, chemotherapy and radiation. She is two years out of treatment.

Cheryl feels lucky that she has the type of position in which she can compensate for her disabilities. She described having very sympathetic co-workers, who helped her transition back to work. Cheryl expected these side effects to subside—

doctors sometimes give survivors the impression that side effects will mitigate with time—however little research has been done on the cognitive effects of chemotherapy. Another survivor, Susan, shared similar workarounds for chemobrain, but explains how difficult it is for her to *not* blame herself for error: “I write things down, and [to] the people I trust I just explain I am very forgetful. I’ve learned. Sometimes I’ve assumed like if there’s been a problem it’s been my forgetfulness, but it hasn’t always been, so I am a little more vigilant now.”

Workarounds are meant to help survivors compensate for their perceived or real deficiencies, helping them gain mastery and accept their new normal; however, survivors still describe a landscape in which they feel uncertain of their abilities. They cannot help but compare past self to present self; for those who perceive their pasts as qualitatively better than their presents, and who realize their futures will be defined by decline, the “new normal” is not a “positive” state. Adapting to the present through workarounds highlights the loss of the old by foregrounding consciousness of the new. This does not make Cheryl feel that she is in liminal position: she mourns the loss while trying to work with her circumstances. Survivors carry forth what they can from the old, combining these elements with the new; they live within the overlap of these identities.

Bodily and sexual “new normals”

Survivors also used workarounds to help them appear “normal” to themselves and others. Many of these efforts remain invisible to others, or are intended to remain invisible. As people are embodied beings, we experience the world around us through our bodies. Our sense of self is tied to how we feel about

our bodies, which is conditioned by how we think others perceive our bodies (Cooley 1992 [1902]). Bodily “normality” can be a way to reject cancer to some extent, or perhaps to establish boundaries and set conditions under which cancer can be activated as an identity. Audre Lorde (1980) criticized the prosthesis for covering over cancer and leaving the structures that enable cancer (and women’s subordination) unchallenged, while overcoming cancer, in dominant survivor narratives, translates into looking as “normal” as possible—to show the world that cancer did not “beat” or take anything from you. Lorde may be right: looking normal usually means accepting the structures of normality that privilege certain political structures and ways of being. Looking normal can be a type of passing. But survivors also used looking normal as a way to erect boundaries and protect themselves when they were not ready to respond to the outside world. Prosthesis, reconstruction, and wigs remove the social pressure women feel to enact cancer survivorship in daily life (as an ascribed status). Looking normal, instead of only covering over cancer, may give them the ability to control where and when they engage with cancer. As Susan describes:

Susan: The prosthesis keeps me normal; it keeps me looking normal without people asking questions. I didn’t always have it. There were a few months I was walking around without it. That’s when all the—[stops herself].

Me: Hmm? [Imploring her to continue]

Susan: No, just after my second surgery, what went on. I just sat my supervisor down and I just said, “Here’s where I’m at.” I just said, “On this side of my body, I’ve got this drain that was attached to me. Nasty, disgusting stuff coming out of my body. I wish I didn’t have to look at it, but I have to drain it and measure it twice a day. On this side of my body, I have a needle in my port where I have to give myself IV antibiotics twice a day. I’m disfigured and my hair’s falling out. So I will do my job to the best of my ability, but don’t ask me how I’m doing unless you want the answer.”

—Susan, 44, white, stage IIB. She is eight months out of treatment. She had a mastectomy, chemotherapy, radiation, and several attempts at reconstruction that failed.

Susan says that she feels normal now that she is using prosthesis, after three hospitalizations for infections that foiled her reconstruction attempts. She does not want to integrate cancer into her life—it has caused too much pain and suffering, especially as her cancer came after losing a close family member to cancer. She describes other confrontations she had with people around this time, in which they asked her about her cancer or how she was doing. She perceived their inquiries as intrusions and disingenuous ones at that: she did not feel that people wanted to know the truth about how she was doing. “Normal,” for her, means having some semblance of physical normality so that no one will stop to ask her invasive questions that she thinks they do not really want to know the answers to anyway. Her loss of her breast is a permanent reminder to her of her cancer status, but the prosthesis helps her conform to bodily expectations so that she does not feel inundated by other people. She does not want to give them power to highlight her cancer status.⁴

⁴ This is a constant struggle for survivors, trying to feel normal or perform other roles but being pulled back into their cancer role by other people (see Danna Lynch 2007). For example, Samantha, 33, a medical writer, told me how, at work, she attended a talk given about cognitive changes in cancer survivors. A doctor said he felt sorry for these women, because “their brains get all scrambled.” Samantha told me she remained silent but was thinking, “Hello! I’m right here!!!” Monica, 36, told me a story about finally feeling normal after treatment ended and going on a trip with friends. While they were posing for a picture, a stranger commented to her how much she liked her haircut. She responded by saying, “Thank you, I love my hair growth, too.” Amy described how, in two separate instances, men at a bar responded to her short hair with disparaging comments about her being a lesbian. These

Normal, for Jade, is also tied to “getting her body back.” For her, getting her body back into the shape it was before cancer is particularly important. By this she means getting physically strong—she describes herself as athletic, running marathons, lifting heavy weights—but also finishing her reconstructive surgery. She chose to have TRAM-flap surgery, a breast reconstructive surgery in which surgeons take tissue, muscle, and blood vessels from another part of the body, usually the stomach, to construct a breast. During our interview, Jade showed me all of her scars from surgery. She described the surgical procedure to me in detail. She showed no sense of awe about these details or having gone through them, although the surgery is major. She describes the details graphically, almost crudely—not scientifically. Perhaps conveying these details can mitigate the shock of having undergone these procedures:

I have a transplant surgery, which is, you cut my belly in half—I mean, like, from one end to the other end—using my own body fat—they scooped my breast, like a pumpkin. They removed the nipple, cut it out—just like a pumpkin, and then they scooped the entire breast—threw it away, and they used my own body fat, from my belly—they pushed it up. They lifted the skin up, they twist—there are two blood vessels, something like that—attached with the nerve. . . . However, because the blood is not used to flowing the opposite direction way—it’s very numb here. It will take years before I get used to it. But, nevertheless, I have a scar from one end of my body to the other.

. . . .

comments were hurtful to her as she was trying to reclaim her heterosexual attractiveness. More positively, Julia said a man walked up to her after a yoga class to tell her how brave he thought she was. It took her a moment to realize that he was commenting on her one-breastedness. She was proud of this moment. Survivors told me tons of stories about how others highlighted their cancer status to them, inadvertently or purposefully. In these ways, cancer does not slip into routinized ways of being for them. Cancer exists continuously with their other identities and status.

But right now, I have to be patient. That patience is something I don't have, and I'm a very: Chop, chop! Get it done. You know, one of those people. My body won't allow [fast recovery]. So, that, to me, is challenging. . . . [Life] will get back to normal as soon as I have my nipple [reconstructed].

—Jade, 50, Asian, stage II. She has been out of treatment for almost two years. She had a bilateral mastectomy and is currently undergoing TRAM-flap reconstructive surgery.

Jade's description reminded me of other survivors' stories about their surgeons' lack of appropriate bedside manner. After such a traumatic surgery, her bluntness about the procedure may be a coping mechanism, an attempt to normalize the experience or reduce its importance. All of her energy had been poured into this surgery and recovery. Her focus on her body being "natural" and healthy—which is why she chose this surgery rather than implants—helped her allay her fears about cancer recurrence as well as help her feel that her body was all her own. While she also attended support groups about psychosocial issues, she equates finishing reconstruction—having nipples—with being back to normal. This is an important detail; breasts are not breasts without nipples. Other survivors felt "incomplete" without them. Naomi, for instance, described her breasts as being like cantaloupes without nipples. For many women, looking "normal" was important to feeling "normal."

Reconstruction is thought to give a sense of closure to the cancer experience, a feeling of finality, the ability to make women feel "whole." Doctors recommend reconstruction, sometimes at the same time as the initial lumpectomy or mastectomy, to accelerate mental and physical recovery from cancer. This emphasis on reconstruction is about concepts of bodily integrity, but also about understandings of normality, sexuality, and femaleness. When I asked Gillian why

she chose reconstruction, she said, “Well, I’m only 47. I’m not 80,” suggesting that youth and sexuality and wholeness were tied up for her in looking normal and resuming her life. The younger women in my study all had reconstructive surgery, joking that their new, permanently perky breasts were a benefit of cancer. Other women, mostly older, did not want to commit the time to reconstruction, describing their breasts through other frames (see Langellier and Sullivan 1998). Heather, 45, and Candace, 59, for instance, decided to forego reconstruction because their breasts were not central to their identities; they did not want to take time away from their other identities to devote to the reconstruction process. Women receiving implants spend almost a year with expanders before the implant can be placed. The TRAM-flap, as I mentioned, is a more invasive procedure, but women choose it because they feel it is safer than silicone or saline, and less objectionable than continuing life without breasts. Reconstruction is a major investment, and there are often complications and difficulties involved, requiring additional surgeries or steps. Women are often not satisfied with the results, after spending a year or more on the initial reconstruction, perhaps in part because of how reconstruction is billed to them.

Designed to make women feel normal, hardly any of my respondents said their reconstructed breasts felt normal to them (some reconstructions made women feel more abnormal). They made women look normal to other people but continued to remind women of their cancer status. While this may seem obvious—of course hard breasts would not feel or look “normal”—survivors are led to believe that reconstruction can make them look even better than before, making

them feel as if they should be able to dissociate the meaning of these new breasts from cancer: that breast reconstruction should be like any other cosmetic surgery. The surgery, while happening because of cancer, is not technically related to cancer, conducted by plastic surgeons and not oncological surgeons. Finishing this “last step” in surgery would seem like a logical point of closure, but, physically and emotionally, the process of reconstruction and recovery from cancer may never be done (see Berns, 2011, on myths of “closure”).

Although I did not ask women many questions about their body image or sexuality, many brought up their dissatisfaction and frustration with their bodies and their sex lives during the interview to convey their “new normal.” Margaret, whom I introduced above, describes how her body image and side effects from tamoxifen, an endocrine-therapy drug taken after active treatment, interferes with her sense of normal:

It’s just falling apart. [Getting emotional.] That’s been really frustrating. You know, it’s like every time you get out of the shower, you see yourself. You know you don’t look the way you used to look. It’s just frustrating. [Crying.] And that’s part of the whole, getting older thing too. It’s like: Yeah, you’re an old thing. [Chuckling.]

That’s—taken a hit—the whole relationship with my husband. I feel like I’m still dealing with a lot of the physical side effects of things. The tamoxifen doesn’t help, in terms of, you know, intimacy and stuff. And he wants to be supportive. But he doesn’t have a clue. [Giggling.] And I don’t know how to give him a clue. That’s the other side of things. So, it’s just—it’s just frustrating. Hopefully, in time, things will get back to a little bit of a more normal way of life. But—They’re not there yet.

—Margaret, 50, stage II, one year out of treatment. She had a lumpectomy and chemotherapy.

Irene, a stage-IV survivor, describes a similar situation:

It’s eroded my personal relationship with my husband. And I mean, right now, we’re okay. But one of the things that happened is, with all these

drugs—I was in peri-menopause [before cancer], but still sexually active, no issue with that. No problems. And then with all of these drugs, just everything—it’s almost like the curtain came down with a resounding bang, and you know, terrible vaginal dryness, pain on intercourse. It made it impossible.

Went to see the gynecologist, talked to the surgeon, talked to the oncologist. Nobody knows what to do. You know, “Here’s this cream. You can use this. You can do that.” Let me tell you something. None of it works. None of it works because the nature of the drugs and what happens to reduce and control the estrogen causes all of those organs to shrink and dry up. And so you know, I have constant dry fingers and hands. Everything dries up. Everything shrinks and dries up. [Pause.]

And then, you know, I am 62. So, hey: you can’t expect that the fountain of youth is going to be there forever. But it really, really is difficult, and my husband would say to me, “Oh, well, you look fine.” You know, I was working full time. . . . I’d get dressed and go to work and have a responsible job and things like that. And my husband would say, “Well, you look fine. [As if to say,] How come you aren’t completely fine?” A really big disconnect.

—Irene, 62, white, stage IV. She was diagnosed seven years ago, after two years out of treatment for DCIS. She had a mastectomy and is now receiving continuous chemotherapy treatment.

Margaret and Irene describe painful experiences of mismatches between internal and external selves, between who they feel they are and who they see in the mirror, between who their husbands expect them to be and how they feel. They often are confused themselves about what to attribute to their changes: is it the drugs? Is it just age? When researchers describe survivorship as transitional or liminal, they might be responding to comments like these, where survivors express the major dissatisfaction and frustration they feel with their lives and bodies after cancer. Understandably, survivors who feel these effects would not want to accept them as permanent and adapt to them: to do so would be to resign one’s idea of oneself to a standard one feels is insufficient and intolerable. These conditions *are* intolerable. But these conditions have to be tolerated somehow. Survivors are

offered counseling in order to adapt to them, because there are no real solutions to chemobrain, premature menopause, sexual side effects, and premature aging. The only “workaround” for some of these side effects is emotion-focused coping, which makes survivors feel as if they are the problem since they are the ones who need to adapt. They cannot change the circumstances of their problems. The only way to be “well adapted” is to accept lower standards of living as part of their new normal.

I want to emphasize that survivors, as noted above, continually used the word “frustrated” to describe their situations. They acknowledge that they had to accept these degraded conditions, but they did not want to resign their sense of self to them. They were not able to let cancer effects fall into the backgrounds of their lives. These degraded conditions became “normal” insofar as they were always present. They became part of the routine. Survivors created or tried to create workarounds for them. They adjusted life to them. But the existence of these effects and limitations continued to prompt survivors into cancer consciousness rather than enabling survivors to routinize cancer and proceed according to old normals. Even Susan could not “normalize” cancer despite her attempts to gloss over it. Heightened consciousness and (non)routinization of cancer-related workarounds defined these survivors’ new normals.

Lifestyle adaptations to cancer

Survivors’ change in status also profoundly influences their lifestyle moving forward after cancer. While I discuss lifestyle changes in chapter 4 as coping mechanisms survivors employ to help them gain feelings of control over cancer—many things are done or happen *to them* over the course of their cancer

experience; diet and exercise is one domain in which *they* can do something—here, I want to briefly highlight that these changes require a shift in thinking: like some of the workarounds survivors used above, lifestyle changes require thinking differently about objects and practices, taking these objects and practices out of old conceptions of normality and foregrounding them within a new consciousness. Many survivors paid much more attention to buying and eating “healthy” foods, exercising, reducing stress, and making more time for themselves in attempt to build their immune systems to protect themselves against recurrence or prolong their health while receiving treatment for metastatic cancer. Non-survivors also perform these activities, but these objects and activities mean different things to them. In addition, because lifestyle changes take a lot of energy and ability, for anyone, they are not something all survivors can do, especially with the added burden of cancer concerns. Perceiving these practices through a cancer lens makes survivors feel more responsible for, and implicated in, their cancer and health.

For example, Patricia made significant changes to how she conceptualized her health after cancer, starting with her diet:

Me: So, this has made a difference in your health practices?

Patricia: Absolutely. I was a little health conscious even before, but not to this extreme. I hardly eat meat. I eat a lot of salads and I make sure I have a lot of veggies every day, fruits and veggies. I drink a lot of carrot juice. I went to a naturopathic doctor. Well, actually, I went to her right after surgery. And she gave me some supplements, to boost my—she looked at my blood work, and from that, she talked to me and she had me fill out forms. She gave me a lot of information about things I should and can eat. I should eat lots of broccoli, broccoli every other day, because broccoli somehow has an effect on how your estrogen is processed through your body, which is a key factor in developing breast cancer, for me.

Extending to chemicals on hair, skin, in her environment:

Patricia: And after that, I decided I wasn't going to put any more chemicals in my hair. I wasn't going to do anything that was going to harm my body. [Chuckling.] Because I used to get my hair permed and colored and everything, and I just said, "I'm just going to wear it natural." No more nail stuff. [Laughter.]

Me: So, that convinced you that, the whole chemical part of it, because chemo is so chemical that you should not do anything else chemical?

Patricia: Exactly. I said: I had enough damage to my body. I wasn't going to do any more, sit up in a nail salon and smell all of those chemicals. Nah. [Chuckling.]

And to her ideas about health in general:

I don't fear illnesses. I just try to do more to prevent it. I am really paranoid of germs now. [Chuckling.] I walk around with all of these Wipe-ees. I have a little package of Wipe-ees, and if I go out—in class, I wipe off the keyboard. You know, I don't touch doorknobs, coming out of the bathroom. [Chuckling.] And I'm, you know, very cautious about that. And if I'm around somebody who's coughing and sneezing, I go home and I really pump up my immune system medication or something.

—Patricia, 63, African American, stage III. She is two years out of treatment. She had a mastectomy, chemotherapy, radiation and reconstruction.

Patricia may enact activities that other people do, but she perceives these activities through the lens of cancer now. She perceives germs in relation to her cancer status because of their connection to a weakened immune system. She sees her body more holistically—everything is connected, so that the food she eats and the chemicals she breathes have an impact on her immune system, which she needs to support in order to prevent cancer recurrence. These attitudes are becoming more common as “wellness” becomes a promoted field. Anti-GMO, organic food, and theories of alkalinity or the

body's pH levels converge with scientific skepticism and neoliberal subjectivities. But Patricia frames her health behaviors through cancer, not only general health promotion or science skepticism. She reinterprets the activities she used to take for normal as related to cancer now. Patricia's attitudes about her role in her preserving or protecting her health are common among survivors. For example, Candace is also focused on "do[ing] everything I can do to make the possibility of me getting cancer due to something I'm doing as minimal as possible," as Candace says. Many survivors become extremely vigilant about their health behaviors because they now perceive the body as a system in which disturbances in other areas could link back to cancer. Cancer, for many but importantly not all, becomes the master status through which all other information is interpreted.

Survivors mostly felt that other survivors' approaches to lifestyle issues were "personal": they did not want to moralize about other survivors' health choices. They felt the information on cancer-causing agents was confusing and inconclusive, as cancer could have different causes—some related to genetic disposition, some to environmental factors, some to hormonal changes. As such, they felt a one-approach fits all policy to cancer prevention was counterproductive. Nevertheless, most doctors and community organizations push "healthy living" (see Bell 2012), even if these lifestyle recommendations have nothing to do with cancer. The downside of this, as Allison says, is that maintaining a "healthy" lifestyle becomes all-consuming:

But when you get a diagnosis like this, it's like you think you have to change everything—how you eat, how you sleep, your activities. It affects

every part of your life, and if you think how hard it is for people to stay on a diet, and now all of a sudden, they're expecting you to change your diet, change your sleep, change your thoughts and all that sort of stuff—it's really hard. And you can be sucked into it, so that you're not getting any better, you're not feeling any better: you're tiring yourself out doing the things you think you're supposed to do.

—Allison, 51, white, stage IV, five years since diagnosis. She is continuously treated with hormonal therapy.

Some researchers have pointed out the self-regulatory machine at work in cancer survivorship: survivors have to be “activated patients” who take their lives into their own hands, and this involves turning health into a moral responsibility (see Armstrong 1993; Rose 2007; Lupton 2012). Survivors might also feel pressure to conform to these regimes as well, as one's body has become yet another site of regulation and surveillance (Bell 2010, 2012; Ristovski-Slijepcevic and Bell 2014). These pressures can backfire, making some survivors feel even less efficacious in their lives than they already do:

Margaret: I wish it did [prompt lifestyle changes], but I just feel like I'm on a treadmill, running like crazy this to keep up. So, trying to do anything extra for me or to take care of myself or something—. I'm not going to totally change everything we cook and all of the sudden go crazy organic or something like that. Because I just don't have the energy to do that kind of stuff. And I know some people would make all kinds of major changes. I just can't get there. It's like—we have whole wheat bread instead of white bread. That's good enough for me. Small changes, I can do, as they happen, gradually. But I'm not going to totally like—totally change things.

Me: Well, do you feel pressured to change things?

Margaret: I do know some people who have done it, and they are like, “Oh, you should be eating this, and you should be doing that,” and giving me all kinds of advice and books and information. And it's like, “Thank you so much. I really, really appreciate that.”

Me: It sounds like that's adding a little bit more stress to your life?

Margaret: Yeah. It's like—I don't need to be pushed into—or been told that I'm doing something wrong. You know? It's like: it happened. It's not something I did.

—Margaret, 50, stage II, one year out of treatment: lumpectomy and chemotherapy.

Despite cancer being (potentially) disruptive, survivors are expected to “adjust” to cancer in particular and perhaps conflicting ways. Survivors may feel pressured to return to normal by friends and family and yet to engage in new (healthier, better) practices than before by doctors and survivorship groups. They may want to incorporate cancer into their lives but find the structures of their lives do not enable this. Some survivors resented being treated as if everything were the old normal: Heather says, “It was kind of like: [nonchalant voice] Eh? You know, Heather is sick. But she'll still make dinner.” Deborah reveals, “You know, he never did any food shopping for me or picked up Burger King or anything if I was feeling not so great. Everything just went on as it had a year ago, before I got sick.” Others felt that being held to old standards meant life was stable:

[T]here is something to be said for just sort of living normal life. My husband was [sighing] being difficult about something, or I was frustrated with him about something and I was talking to my therapist and she says, “Well, he's not treating you like you're dying.” I was like, “That's a good point.” And neither are my kids, and neither is my boss. He still holds my feet to the fire and I still have to work really hard to keep up and to, you know.

—Alexis, 46, white, stage IV. She was diagnosed one year ago, after her initial occurrence seven years prior. She had a mastectomy, chemotherapy, and an oophorectomy. She is on continuous targeted therapy.

Routines may become normal, and health might be normal, but survivors' consciousness about normality had changed. Their physical and mental conditions reminded them—intermittently or continuously—that they were not the same as

they were before: in some ways stronger, in some ways more vulnerable. Their new normal involves adapting to or compensating for these changes in order to feel independent and whole. But those who experience cancer as a major disruption do not regain ontological security: some are able to use this disruption for growth while others, particularly those forced to spend energy managing treatment effects or those with little perceived social support, cannot.

Vulnerability, growth, and the new normal

Survivor's adaptations to ruptures in ontological security and fear of recurrence, as well as the physical and cognitive effects of cancer treatment, define their sense of normality following cancer. Some research finds that incorporation of the cancer experience into self-concept—as opposed to segmenting, compartmentalizing or denying cancer—is related to more positive psychological well-being (Zebrack 2000). Other research finds that negative affect or low well-being is also associated with benefit-finding or positive meaning making. For instance, Helgeson (2011) found that survivor centrality was only associated with poorer psychological well-being outcomes when the survivor framed the illness in negative terms. She also found that, for those with greater distress, identity centrality was also associated with greater perceived benefit-finding. Park et. al (2011) also found that illness centrality for young people was related to both poor psychological outcomes and post-traumatic growth, suggesting that those who identify strongly with survivorship, perhaps because of psychological distress, reap intrinsic rewards from the identification. Bower et. al (2005), in a longitudinal study of cancer-free survivors, found that “positive meaning” and “vulnerability”

were highly correlated in both early (1-5 years) and late (5-10 years) time points, suggesting that the factors that increase the disruptiveness of cancer lead survivors to make positive and enduring changes to their lives *and* to feel more vulnerable (243). While they found that feelings of vulnerability are tied to poor well being and negative affect, they also found perceptions of positive meaning were associated with positive affect. They explain that the relationship between meaning and adjustment may be obscured by the relationship between meaning and vulnerability.

I interpret these findings to suggest that feelings of vulnerability (or ontological insecurity) related to perceptions of cancer's disruptiveness can lead to positive or negative well being—or somewhere in between—depending on the ability of the survivor to craft positive meanings out of the experience. The ability to craft positive meanings out of one's cancer experience is related to various other factors. Distinct pathways may lead survivors to adapt life to cancer in different ways: (1) those with negative effects from cancer may not be able to avoid incorporating cancer in daily life, although they may incorporate cancer in positive or negative terms; (2) those with negative preexisting conditions may seek out positive benefits from the cancer experience, or they could incorporate cancer into these preexisting schema; (3) those who experience positive outcomes from cancer may incorporate cancer as a positive force in their lives or simply leave cancer behind; and (4) survivors who do not experience cancer as disruptive may not benefit from the positive life changes that such a disruptive experience can

initiate. The majority of survivors in these studies claim they have experienced a positive change in perspective from cancer. As Frank discusses, many survivors feel profoundly changed by cancer, compelled “to do something because [they] are part of something” (2003). How much of this positive change is a result of dominant survivorship narratives and cultural imperatives is up to question, as is the extent to which survivors actually do receive benefits from their cancer experience. But what is clear is that survivors have to think about cancer in particular ways and experience the physicality of cancer in particular ways in order to be able to tap into the “positive benefits” of cancer’s disruptiveness.

The majority of survivors in my study did try to redefine their lives in positive ways, propelled in part by the disruptiveness of their cancer experience. Those who experienced cancer as “too” disruptive were not able to refashion the experience for positive growth; those who did not consider cancer a disruption at all were not interested in refashioning the experience. Survivors in the “middle zone,” who experienced some disruptiveness but did not experience debilitating after effects from treatment, were most able to use their change in perspective to promote ways of living that helped them gain more meaning out of life. In this way, cancer became a tool they could use. They defined their new normal mostly by how they felt their inner selves had changed as a result of cancer, but this shift in perspective was difficult for most survivors to describe: their internal self had changed but their lives remained basically the same as before cancer, reminiscent of Danna Lynch’s

(2007) categorization of hot (deliberate) cognition but cool (automatic) behavior in defining role enactment. This “partial overlap” (Danna Lynch 2007: 389) may enable survivors to reap positive benefits because they can think about survivorship without being debilitated by these thoughts, due to a context of treatment effects, lack of social support, or other preventive structures.

To explore this category of survivorship in the “new normal” perspective more deeply, I introduce Linda, an African American survivor of stage I breast cancer. Some research finds that African American women report higher levels of positive meaning from cancer than white women, hypothesizing a link between spirituality and purpose in life, strong in African American communities (Bower et al 2005; Tomich and Helgeson 2002, 2004). But Linda’s narrative describes some fundamental aspects of the shifts in self and perspective that all survivors experienced:

I don’t think [cancer is] ever too far from my psyche. I don’t know if there is a day that goes by that somewhere in my mind or my consciousness, that I don’t think about cancer. You know, it definitely changes your life. I don’t think you are ever the same. Because I believe that it’s a part of that new normal that they talk about—you know, that it’s a part of you now. There are constant reminders. . . . I’m just more mindful of it, where, I don’t think that I was prior to being diagnosed. Like, I knew about the [community organization for women with cancer]. But I didn’t really pay attention to it . . . I think that now, this is a part of my life experience. Now, I’ve experienced it. You know? I’ve had cancer in my body. I’ve gone through all of these procedures and processes related to it. So now, it’s not something that I see, and it’s not like, over there anymore. It’s over here. You know, it’s in my life. . . . And I think that’s a permanent stand.

Linda describes how experience shifts consciousness: without experiencing cancer, it remains “over there,” abstract. Now cancer is “over here,” an embodied

experience, part of her. Part of this experience, she describes, is its intense focus on the individual, making survivors intensely aware of their singularity and existential aloneness. Produced by ruptures in ontological security, this hyperawareness of self can propel survivors into life change or it can overwhelm them, causing them to become paralyzed by distress.

[I]t was like a lone experience, especially going to radiation. You know, I drove every day by myself. For that period of time, I'm in the car [alone]. You're thinking about it. And it was very much high profile in my mind during that time. I would just have my moments where I felt so alone, and I don't even think I thought I felt alone until I was sitting in the waiting room with a woman, she was waiting for her treatment, and we just started talking. She said, "Don't you just feel so alone sometimes? You know, like, it's just you?" People can say, "I understand how you feel," but they really don't. You know? Nobody can really—even if you've gone through it—that was your experience. I don't think that I know how somebody else feels.

When you go to the support [groups]—sometimes, somebody will say something, and I'll say, "Oh, I never felt that way. I never thought of that." You know? So, everybody has their own feeling about it. And I think mine is just—it's something I want to be selfish about. I don't want to—Some things, I don't [share]—it's just mine. Whether its weariness or tiredness or unhappiness or whatever, you know, it's just, sometimes, you're just alone. It's just you.

—Linda, 61, African American, stage I. She is two years out of treatment. She had a lumpectomy, chemotherapy and radiation.

What seems critical for Linda is the sense of being alone that she experienced:

"It's just you." The cancer experience produces a heightened sense of self by isolating the self from the community. Linda does not mean "loneliness" but existential aloneness. She was pulled into an acute awareness that made her attend to the boundedness of her existence. She is not resentful about being thrust into this state of consciousness. It sounds like she wants to protect it. Whatever it is that she has realized or learned about herself through cancer, "it's something I want to be selfish about.... [I]t's just mine." Most survivors I interviewed felt

something similar about their cancer experience: it shifted their awareness in particular ways that they did not want to lose, even though holding onto it meant holding on to cancer—and the uncertainty and threats that come with it.

Survivors used metaphors, clichés, and vague language to describe this shift in perspective—“eye-opening,” “wake-up call,” “different,” “not the same”—because it is difficult to find language to convey what these shifts in existential and ontological awareness actually mean. They describe being more “mindful” of little details or moments in life, being more “in tune” or empathetic with others, attributing these shifts to going through cancer. While they may wish they could return to pre-cancer life, they also want to retain these shifts in consciousness that highlight the meaningfulness of life’s details.

Sally and I discussed what these shifts in consciousness entail and how regaining normalcy might actually jeopardize this type of consciousness:

Sally: You keep finding those [moments of joy in everyday life]. There’s little things that are such blessings that we don’t stop to really acknowledge sometimes, I think, when you were just going through the routine of getting through life. But, people—I think everybody needs to stop and smell the roses. We use some of the little phrases. But just look around. Before you go to sleep that night, think of three good things. Think of one good thing that happened that day—something you can be thankful for or grateful for. I think it would do us all a world of good.

Me: That’s really nice advice. Because, I mean, you’re right—that it’s sort of a cliché saying, but it’s true.

Sally: It’s very true, and—I know I didn’t do that a lot. I think—the grandchildren helped me a little bit, just to so appreciate that they are there and what a joy they are and how much I look forward to the next time I see them. [chuckling] But it’s still not pulling all of the joy out of every single day.

Me: Hmm. That sounds like a challenge in and of itself.

Sally: I think it always—I mean—I think it is through all of life. I think this is just coalesced and made it really come back to mind a little bit more.

I: That's a good point—that mindfulness about it, right?

Sally: Um-hmm. Mindfulness is a very good word—to be mindful about a lot of things. And I could stand to be mindful about more. It's easy—It seems like it's getting to slip back into just the way—into some things just the way they were before. But, I'd like to be more mindful.

Me: Do you have any strategies for not slipping back in? Is there anything you do to remind yourself not to? Because, in some ways, slipping back into the routine is what being “normal” is all about.

Sally: I know. I know. And it is nice to be back in a routine. It is nice to feel normal again—which has only been, for me, in the last probably five weeks—six weeks since treatment, five weeks since I got the oncologist piece. And again—yet, that even more normal after ditching the wig and getting some little bit of style in this short, little hair. There's a feeling of normalcy, even though things call me every now and then. I'm feeling the numbness right now, and it's not normal. Except for the new normal. But the—

Me: No, but I mean, I think you're highlighting that tension, right?, between kind of slipping back into “life”—but stepping out and being mindful of it and going back and forth somewhat?

Sally: Yeah. It would be good if I had—I don't know—a bracelet that I wore every day, a ring that I wore every day, and I looked at the ring and thinking—ah, yes, be mindful. What can I be thankful for here? What has happened today?

—Sally, 61, white, stage II. She is three months out of treatment. She had a lumpectomy, chemotherapy and radiation.

Sally told me how, during cancer treatment, she would send out newsletters to her friends and families, in which she would recount the daily “blessings” she encountered. She thinks it's important for everyone to “stop and smell the roses,” and notes that it is “easy to slip back into” life's routines. “Pulling all of the joy” out of each and every day does not sound easy in her framework; it sounds like conscious work. In our conversation, I note the tension involved in having

“normal” life but also being “mindful”; she notes that she needs a cue to remind her to attend to this mode of cognition, although she also mentions that her numbness (neuropathy) is a reminder that she is living a new normal. I think what Sally is explaining is that it may not be possible to stay in a heightened state of consciousness, as, with time, routines begin to rebuild structure and distract people from the deeper meanings in life; on the other hand, survivors are drawn back into this awareness either by choice or the circumstances of survivorship.

Even survivors who do largely incorporate cancer into their lives vacillate in their mental engagement with what it means to have or have had cancer. Living continuously consciously engaged, with cancer or anything, is not possible: people move back and forth between deliberative and automatic thinking and need both to function (Kahneman 2011). Survivors learn to maintain a dual mind where they know they have had cancer, and try to carry forward parts of the meanings of that status with them while ignoring or bracketing the unsettling parts, if they can (Giddens 1991). They want to carry forward *some* of the shock of cancer—*some* of the ontological insecurity it creates—but *not all* of it. They use many cognitive strategies for protecting themselves from too much insecurity but enabling themselves to be motivated by just enough. Instead of having their entire selves taken over by cancer, which would be overwhelming, they want to carry just enough insecurity with them to be motivating.

Cognitive strategies for making the most of the “new normal”

In the last chapter, I described how survivors largely fell into three types in terms of how they adapted to cancer: some integrated cancer into their lives, some

compartmentalized cancer, and some r/ejected cancer. These strategies determine to some extent how they conceptualize normal, as old normal, new normal, or somewhere in between. All survivors employed strategies for managing the effects of ontological insecurity because feeling too much insecurity paralyzed them.

While one cognitive style does not have a monopoly on any particular normalization strategy, some strategies “fit” better with particular cognitive styles or are used at different points in a survivors’ illness career. For example, all survivors may “bracket” specific kinds of cancer thoughts, but those more intent on leaving cancer behind—“ejecting” cancer from their lives—may bracket all kinds of cancer thoughts and do it more consistently. Those who fully integrate cancer into their lifestyles may not need to bracket cancer as much. Those without a choice—metastatic survivors or those with severe side effects—may not be as able to bracket cancer-related thoughts and concerns although the need to might be more pressing or less, depending on adaption strategy. The following strategies are methods survivors used in daily life to move on with, after, or beyond cancer.

Bracketing

The following are variations of bracketing. They all are techniques survivors use to keep them from thinking too hard or too seriously about the terrorizing implications of their illness (Giddens 1991). Several survivors told me they did not want to “dwell” on their cancer experience. Many feared they would lose themselves in the uncertainties of the disease and perhaps not mentally recover. They explained that they did not want to lose good time to worry and anxiety. This is different from denial: they knew very well that they were putting thoughts aside

for another time, and that they would most likely have to confront these thoughts at some point—but they planned these confrontations for times when they felt more resilient, capable, or in control. Unfortunately, survivors do not have ultimate control over when and where confrontations happen, as I discuss below. Bracketing was not intended to completely block out thoughts of cancer, but to control the conditions under which thought of cancer emerged: when, where, and what kinds of thoughts of cancer.

Keeping busy

The number one way survivors coped with anxiety about their illness was to stick to a routine and keep as busy as possible. Giddens (1991) claims that social practices are essential to bracketing. Others discuss the nature of routine to blunt anxiety (Ayerio and Swistun 2009). Of course, this only worked for people who felt well enough to engage in mental or physical activities. Most survivors wanted to continue working, if they could, through treatment (although some were too fatigued or sick to continue and appreciated the time off). One survivor, not very affected by chemotherapy, described running errands and doing laundry for her family members to keep herself occupied. Another regretted not being able to work because her job, pre-school teacher, exposed her to too many germs. Being busy is different from going on “auto-pilot”—survivors needed to keep their minds and bodies engaged in other activities so their thoughts would not drift to dark thoughts (see Danna Lynch 2007). Sticking to routine can blunt deep deliberative thought, if one can enter a flow state (Csikzentmihalyi 1990), but routine can also encourage deliberative and creative thinking if the routine is not

mentally engaging enough (Heimer 2001). Thus, routine did not always work to stave off fears and anxieties, but survivors found keeping busy provided them with a stable and purposeful foundation to structure their lives around.

And so, even after, when I really fearful, really, nobody knew that. But what was happening was, I was really going through the motions. People were saying how great I looked and, “Oh, it’s so good it’s past you.” . . . And in my head, I’m like, “Are you fucking kidding me? It is *so* not past me.” But I’m like, “Yeah!” And then, I got to a point where like, my kids—I remember sitting at the island in the kitchen, and the kids are doing homework, and I was almost—I don’t want to say, manic, because that’s not it. But I was always moving and always doing stuff and always straightening up or always—and I just think it was a way to keep busy, to not think about it. . . . My kids would want help with homework, and I remember answering their questions, but in my head, thinking: “Oh, my God. Someday, I won’t be here.”

—Heather, 45, white, stage III. She has been out of treatment for five years. She had a lumpectomy, chemotherapy, mastectomy, radiation, and oophorectomy.

You know, just stay busy. It didn’t bother me. A lot of people said, “How could you just keep working?” And I said, “Well, I think it’s better. It just keeps me busy.” It keeps my mind off of everything, rather than sitting home and thinking about everything or feeling sorry for yourself. You know, there’s nothing you can do about it. You know, you have to deal with it.

—Gail, 58, white, stage III. She has been out of treatment for 10 years. She had chemotherapy and mastectomy.

Gail and Heather both describe keeping their mind off of cancer, but Heather reveals that even when she is engaged in her routine with her children, her mind would drift back, or be “involuntarily pulled” (Danna Lynch 2010), to cancer because the children themselves were a cue for her worries. “Being busy” can free the mind to think about cancer, as busyness can be automatic and background behavior without engaged cognition; thinking about and doing the activity both

need to be “hot,” or activated, in order for the activity to monopolize the person’s enactment of the role—mothering, working—in that moment (see Danna Lynch 2007). Gail, importantly, was not saying she wanted to suppress thoughts of cancer—she acknowledged “you have to deal with it”—yet she feels thinking about cancer 24-7 would be unhealthy. Keeping busy enabled her to “deal” with cancer but not succumb to depressive or fatalistic thoughts.

“Switch!”/Running parallel tracks/keeping cancer on the backburner

When survivors found themselves slipping into uncharted and threatening mental terrain, they enacted various cognitive techniques to submerge these kinds of thoughts:

Me: Is there something that you do to make that more manageable—those kinds of uncertainties?

Deborah: [sighing] Trying to enjoy the day as much as you can is a big thing. And I don't know—Sometimes, *you have to push it down*, you know, and almost smother the unknown feelings, which probably is not the healthiest thing.

—Deborah, 52, white, two occurrences of stage I. She is nine years out of treatment. She had a lumpectomy, chemotherapy, radiation, mastectomy and reconstruction.

But I find, if you let yourself—if I let myself think too much, it’s a slippery slope, and I think you can end up in a hole that’s really hard to get out of. So there are things *I guess I consciously force myself not to think about*. It’s like: No, if I go there, I’m dead. I’m doomed, and I—I’m not going to be able to get out of it. So, I think, just—it’s a routine. You know, you count the pills into the little pillbox, and you open it up every morning and every night, and you just swallow them. And that becomes life.

—Allison, 51, white, stage IV. She was diagnosed five years ago. She is on continual hormonal therapy.

I guess it’s *almost like a choice*. But don't get me wrong. I'm still like, scared some of the time. [Chuckling.] But I mean—I think about it, and then

I kind of shook back. Because what else can you do?

—Heather, 45, white, stage III. She has been out of treatment for five years. She had a lumpectomy, chemotherapy, mastectomy, radiation, and oophorectomy.

And so, for definitely a couple days before each scan, it was hard for me to go to sleep, because I couldn't shut off my mind. I kept thinking about every scenario. I said, "Oh, my God. Well, what's going to happen?" So, I pictured like, one of the doctors telling me, you know, some bad news. And I kept trying to say to myself, "Gwen, stop! Or "switch!" Just to change the direction of my thinking. I saw a massage therapist that does this type of energy moving. And we can talk about that. She taught me *how to just say, "Switch."* You know, just *change the process.*

—Gwen, 34, white, stage III. She is one year out of treatment. She had a bilateral mastectomy, chemotherapy, and radiation.

I italicized the words in these passages to emphasize survivors' consciousness in employing these techniques. The words they use are vague—"shook back," "switch!," "push it down," "force myself to not think about it"—but they convey a sense that survivors are navigating different frames of mind or types of cognition; they enact vigilance over their own thoughts to avoid going to places of despair and grief. To some degree, they have learned how to stop thinking about the elephant by making their thinking about the elephant conscious and naming it.

Most survivors described having two trains of thought running at all times—the thinking that guides their practical daily life and the things they have to do to maintain their jobs or their households, and their conscious awareness of their cancer. Running these two lines is a type of bracketing insofar as cancer thoughts are not and cannot be foregrounded at all times in order to proceed through other obligations; but these survivors are not trying

to deny cancer access to their present state of being, even if they do run cancer thoughts on the “back” track. They switch back and forth between these two lines as necessary. Survivors who describe this cognitive strategy say they are always aware of cancer’s presence, even if they are not focusing directly on cancer at the moment.

Cognitive scientists might describe what these survivors are talking about as system 1—system 2 thinking: system 1 is for conscious, deliberative thinking, whereas system 2 is for route, habitual thinking. Social scientists also describe these ways of thinking as deliberative and habitual, stemming from Dewey’s (1922) understanding of habit and impulse. Giddens’ (1984) depiction of practical and discursive consciousness builds upon theory of the relationship between routine and habitual thinking and impulse and new thinking or consciousness. More recent work builds upon these conceptualizations. Auyero and Swistun (2009) discuss how routine can prevent deliberate thinking about toxic hazards. Heimer (2000) illustrates how over-routinization can actually activate deliberate thinking. Zerubavel (1997) describes how attending to some details means disattending to others, and Danna Lynch (2010) shows how switching from one identity to another may be a matter attributing more or less weight to particular social cues. Danna Lynch also discusses how, through a combination of hot and cold cognitions and behaviors, a person can be subsumed by one role or able to perform multiple roles at the same time (Danna Lynch 2010). Because of cancer’s “hot” emotional and cognitive aspects (Diefenbach n.d.), survivors may

struggle in attributing equal weight to cancer and other events in their lives—which is perhaps why so many fear losing themselves in or being consumed by thoughts about mortality and suffering. Survivors do learn how to switch back and forth between their cancer identity and the other roles they have to play. Alexis discusses the tendency for cancer to be greedy in consuming one's attention, although she has found ways to relegate cancer to the background:

Alexis: You learn to sort of develop parallel minds. I think about—when I go to eat something—I don't heat anything in plastic anymore. I don't drink diet soda anymore. I try to eat organic fruits and vegetables. I try not to be around pesticides or just spray things or if they spray the lawn I'm concerned. I try not to be around smokers. [I don't eat soy protein because soy protein is a natural estrogen and I have an estrogen-fueled cancer so I probably shouldn't eat estrogen. That would be dumb. I read labels.] So in those sorts of little everyday decisions, yes, it is on my mind. . . . But I still carry on a normal life. I work and I—. While I'm reading the academic catalog [for work] I'm not necessarily thinking about it. But I do think and act about it in my everyday life all the time. I don't think of it with the same terror that I did originally. I have times where I think, Where is this headed? What's gonna happen to me? What's gonna happen to my family? [Sighing.] But I can't waste the time I have right now trying to figure all that out. So the thoughts are there. You try not to just live there.

Me: I think that's interesting. The parallel-mind thing. Do you feel that you kind of ping back and forth? Or that one's always going while you're in the other or how—?

Alexis: I think they go down the road together. I'm not always conscious of the cancer car while I'm driving the other car. But I think that it's always there. I might be reading the academic catalog and might find that I'm proofreading it [unintentionally, as her job is in the marketing department of a university]. I might find that there's course on cell biology or drugs and human behavior or aging and cognition, and think, How do those relate to this other side of my life? . . . There is crossover. But it's not—. There are darker places there that I could go and I do from time to time. I take sleeping pills because if I wake up in the middle of the night and the house is all quiet and I've got nothing else to do but think. That would be a hard thing to deal with.

Me: So avoiding those dark places or going to those dark places is helpful?

Alexis: Well I think recognizing that they are there. It's okay if I'm scared. But, I can't be scared all the time. There's living to do.

—Alexis, 46, white, stage IV. She was diagnosed one year ago, seven years after her first occurrence. She had a mastectomy, chemotherapy, targeted therapy, and an oophorectomy.

Alexis uses the metaphor of “parallel minds” to describe how she has two modes of thought operating at all times. Most survivors told me that “cancer is always there” even when they are not actively thinking about it. Alexis discusses how she has relegated some cancer-related behaviors to the back track not only because, over time, they have become habitual, but also because consciously thinking about them is too cumbersome and taxing. She says later that she has made peace with herself by accepting that she cannot control the future and that she has done all she can do—an understanding I heard echoed in other survivors’ stories.

Many survivors said they did not want to “dwell” on cancer. But, for some, not dwelling on cancer or living in cancer land requires careful negotiation.

Allison, also a survivor with metastatic cancer, describes the tension inherent in balancing these different tracks or cognitions. On one hand, she needs to attend to the seriousness of her cancer status, and wants others to, as well; on the other, she does not want to have cancer be so loud that it drowns out the other melodies in her life:

That's a weird thing, because I know—I think metastatic cancer is serious. It's an illness. It's bad. And yet—and it's a funny thing—I don't know how to straddle that: Yeah, I got this terrible thing, but because it's not real visible, nobody really knows it, and you can almost forget about it for a little while. And do I really want to fall into the role of being the victim/patient/illness thing? Or do I want to—to do as much as I can with whatever I've got? But then, it's frustrating because people forget. It's like,

“I can’t walk that fast. Sorry, guys.” You know, it’s just not going to happen. Or you know, 8:00, I’m in bed. I’m tired. I’m pooped out. You know, I don’t get up till about 9:00. So it’s a lonely thing. No matter how many people are around and how many people help—and there have been some wonderful people along the way—the bottom line is, at the end of the day, it’s just me. [Pause.] I don’t think I think as much about it as I did in the beginning. But it’s always there. And I liken it to having a radio in your head, and the radio is the cancer, but you can never turn that radio off. And you can’t unplug it. It’s always there. It’s always going. And the best you can do is turn it down as far as you can, and that’s the goal—so that it’s not the first thing in the morning and the last thing at night that you think about, and so you don’t dream about it. But it’s always there.

—Allison, 51, white, stage IV, five years since diagnosis. She is continuously treated with hormonal therapy.

Allison describes bracketing, to some extent, in so far as her goal is to keep the cancer noise down, but she also wants and needs others to accept the role cancer plays in her life. She has stopped working and tries to find ways to fill her days. But thinking about metastatic cancer all day long is impossible: she cannot live paralyzed by thoughts about her own mortality. Cancer is “always there” mentally and physically for metastatic survivors in ways that it is not for early stage survivors. There is a certainty to metastatic cancer: one “knows” one will die of cancer, even though the finer details of that have not been worked out. The uncertainty of early stage cancer is about whether cancer will return or originate anew or if cancer cells remain in the body undetected. But this feeling of having “parallel minds” is not unique to metastatic cancer survivors. The weight of cancer is always there for early stage survivors, too. Early stage survivors describe a similar process of moving between mental tracks to keep cancer in its place:

I can never wipe cancer away. It’s a part of me. It’s a part of my life. It’ll never go away. It can’t go away because it’s always back there.

—Donna, 57, white, stage I. She has been out of treatment for one year. She had a mastectomy, chemotherapy and radiation.

Oh, no, you can't segment it. It can be on the back burner. It's not on the front. It's not. It's a part of you, but I don't give it any power. Um-um [no].
—Bonnie, 64, African American, stage I. She has been out of treatment for nine years. She had a lumpectomy, chemotherapy and radiation.

Candace: And you don't know when that's [recurrence] going to happen. It could never happen, or it could happen today. It could happen five years from now. It could never. You never know. That's the part that's the most difficult, and I'm sure that's part of what you are finding.

Me: Yeah. Exactly. How do you deal with that uncertainty?

Candace: I do think that it gets a little bit easier with time. Because you begin to trust that it's not going to happen. But it always is there. It's always there.

—Candace, 59, white, stage II. She is almost two years out of treatment. She had a bilateral mastectomy.

Early stage survivors are trying to stave off fear of recurrence while doing what they feel they can to prevent recurrence and rebuild their health. What is “part of you” for them is not the cancer but the cancer experience. Yet, survivorship is not only an identity but also a health factor that shapes future risks and potentialities. The uncertainty of recurrence or new cancer is part of the experience that can—or needs to be—put on the back burner in order to function in daily existence. The trust that Candace describes, in the last quotation, is part of rebuilding one's ontological security—one's trust that existence will continue safely—but even she says there is always risk and uncertainty in the back of one's mind. Metastatic survivors deal with a different set of risks and may not be able to place cancer on the backburner as much or as easily as early stage survivors. But cancer survivors as a group need to find ways to cope with the uncertainties and certainties of cancer. Time builds trust and reassurance, for both metastatic and early survivors, as survivors rebuild routines and meaning-making practices: but they are all

aware that cancer initially caught them off-guard and could very well do so again.

Keeping positive

Part of keeping away from the dark places that Alexis describes, and that most survivors mentioned to me at some point in their interview, is to “think positive” about life, to focus on what brings pleasure and happiness. The skew toward positive thinking is cultural, not only psychological (Cerulo 2006), such that the emphasis on positivity within breast cancer culture is part of a larger cultural bias. But the emphasis on positivity within breast cancer culture may be even more exaggerated, as the worst-case scenario survivors are trying to eclipse is death. The medical profession, particularly oncology, is unlike other professions in that practitioners are trained to imagine worst-case scenarios (Cerulo 2006: 165-177). But within this professional perspective, even they are not immune to positivity bias: oncologists have been criticized for extending harsh treatments into end of life, jeopardizing quality for quantity of life; they may have a difficult time knowing where the boundary between “active” and “palliative” care lies because of emotional attachments to patients, practice-based imperatives to save lives, and shifting health cues (Earle et al. 2008; Baszanger 2012; Schildmann et al. 2013; Brown 2014). Survivors themselves are vigilant in screening their bodies for signs of cancer returning or worsening, focusing on ferreting out disease; yet they can be overly “optimistic” about prognoses and treatment potential. They may frame end of life differently once they are there, so that they want to endure treatments to gain short periods of time, or they may misperceive the nature of treatment,

placing stock in treatment's curative power when treatment is really being applied for palliative reasons (Weeks et al. 1998; Matsuyama et al. 2006; Brody 2012; Van Laarhoven 2014). Survivors and oncologists are both trained to look for the worst but, perhaps because of their proximity to death, they still hope for the best within these structures.

Larger breast cancer culture, on the other hand, overemphasizes the best-case scenarios in order to instill hope and feelings of triumph over cancer in survivors and larger society. This focus on survival obscures death, even while death is acknowledged. Ehrenreich (2001) and others (Sulik 2012, King 2008, Klawiter 2008) criticize the positivity movement present in cancer communities and pink-ribboned displays for its exclusivity and forced feeling roles: the emphasis on the positive shifts public perspective from the suffering of survivors of advanced stages, preventing exploration of particular causes of breast cancer and interrogation of the politics and theoretical perspective behind cancer research (see chapter 2). Over-emphasis on positivity can censor survivors' negative feelings and expressions of harsh experiences, becoming internalized as a type of self-surveillance.

However, it is also important to examine the function of positivity for the survivors who use this strategy (see Wilkinson and Kitzinger 2000). Survivors in my study employed "keeping positive" not as a conscious rejection or denial of the hardship of the cancer experience, even though this strategy relies on exclusion of others who cannot share this viewpoint. As a self-enhancing technique, survivors talked about being positive as a way to keep their minds open to new experiences

and meaning-making opportunities. Focusing on the self is an exclusionary act to some degree—it involves disattending to others, erecting boundaries between the self and others, in order to attend to the self (Zerubavel 1997); developing and protecting the self in this way requires bracketing what one does not want to bring into the self. Survivors who tried to “keep positive” did not deny the possibility of death; *because of* their confrontation with death, they felt keeping positive was a more fruitful way to live. Survivors often spoke about not “dwelling” on the uncertainties of cancer or on their own cancer experience because they did not want to give any more of themselves to cancer than they already had. They felt spending too much time worrying about things beyond their control was a waste of time; time was precious to them and could be better spent.

But, as I discussed above, some survivors feared they would not reemerge whole if they followed darker thoughts (see Cerulo 2006: introduction). I found survivors’ use of positivity talk to be a cognitive trick survivors used to keep their minds focused on the good parts of their lives, on how fortunate they were to be alive—and this often meant they bracketed darker thoughts about the disease and dying. Some survivors expressed clichés of positivity because they felt there was nothing else to say. A few did tie being positive to promoting health and preventing cancer, but most felt being “negative” would only make their situation worse. They had already thought about what *could* happen; now they wanted to file those thoughts away until they were needed:

You know, so I try not to think about that too much, because you are never going to get an answer. [Crying] . . . So, it’s kind of pointless, but at the same time, you know, there is a part of you that always kind of wonders, you know: Why me, and not anybody else? Yeah. But you know, you just—

I just try to be positive about it, and I've gotten through it and can go back to pretty much normal at this point. And I do feel like I'm a little bit stronger, and I do feel like I can put a lot of the trivial stuff aside. . . . I believe that life is what you make it. So, if you're negative about it, it's going to be that much worse. You know? If you are positive about it, it still sucks, but [laughter] at least you just try to not make it suck for everybody around you.

—Kara, 37, white, stage I. She has been out of treatment for one year. She had a lumpectomy, chemotherapy, bilateral mastectomy, reconstruction.

And then you also get to the point where it's like: Well, what am I going to do? Like, waste like, years and years? Like, so—And even Dr. X said that to me once. She was like, “Well, what are you going to do? You're going to be scared and frightened, you know, for the next 10 years, and it doesn't come back? And then, what happens to those 10 years? Wasted.” Right? Or, scared and frightened for 10 years, and it comes back. And then what? Wasted the time—good time you had. So, you know?

—Heather, 45, white, stage III. She has been out of treatment for five years. She had a lumpectomy, chemotherapy, mastectomy, radiation, and oophorectomy.

I think you have to learn to accept things as they are. The more you fight it, the more pain you're in. I think as soon as I realized that I didn't have to [fight it, I felt better]. I'm not working anymore, and I'm tuning more in . . . you get that feeling of peace. And I think everybody has to strive to have that peace and just recognize that you can't do everything. You have to reach out to family, friends, and just go with what you have. I'm lucky to have what I have, and how I feel—I'm lucky for that. And why ruin it? Why make myself sick?

—Barbara, 53, white, stage IV. She was diagnosed one year ago, 14 years after her primary occurrence. She had a mastectomy, chemotherapy and radiation and now is treated with continuous hormonal therapy.

These quotes represent a type of Pascal's Wager: there is no way to know for certain whether cancer will or will not return, so live like it will not return.

Positivity, for these survivors, is about avoiding distress and depression so that they could get the most out of life; it is a philosophical position for them as much

as it is a psychological one. Almost every survivor expressed to me that she had had her own “dark thoughts” or moments of fear, but some felt they could choose to think positively in order to enjoy life more, carve out more moments of meaning. Not everyone can avoid these thoughts and, importantly, not everyone framed these kinds of thoughts as pointless. But many survivors were vigilant in bracketing out what they perceived as “too much” of the negative, as I discussed above.

Notably, survivors switched frames so that they did not continuously or consistently engage in positivity talk—even Kara’s discussion is punctuated by tears—but used it at particular moments (see Wilkinson and Kitzinger 2000). Acknowledging that worrying is a waste of time or that it detracts from living is not the same as avoiding planning for the worst—survivors could express these sentiments and still talk about their living wills or thoughts about recurrence (although many survivors felt their first occurrence would make them more able to gracefully handle a second or new cancer experience). But these survivors are trying to redirect their cognitions and frame life in the best terms they can given the new parameters of their lives. Part of thinking positively is bracketing out the negative effects of uncertainty, and some cancer events and groups are certainly less tolerant of what they define as “negativity” than others (I witnessed some of this first hand at Race for the Cure[®] and other events for which I volunteered); but, individually, survivors knew they walked a fine line between hope and despair within their own emotional battles; many chose to “keep positive” because they

felt it was the better option. They thought frame of mind was something they could choose.

Re-drawing boundaries: expanding and contracting

As part of their “new normal,” survivors described becoming more aware of the basic structures of life, more in tune with other people and their needs, more conscious of the small details in life that hold meaning. Survivors felt awakened to “what’s important in life” after going through cancer experience; the rift in their ontological security made them see the things they took for granted through a new lens. They described how this new lens caused their worlds to both expand and contract. They tried to withdraw from situations and people that caused stress and anxiety, and focus more time and attention on the people, places, and things that held deep emotional meaning for them. In doing so, survivors were re-drawing boundaries around the self: they let in new people and activities and cut off relationships, jobs, and habits they considered toxic. I found boundary redrawing manifest in several ways, categorized below, but all of them can be conceived as ways of protecting the self and carving out time and space for meaningful moments.

Carving out time and space

Survivors often talked about cutting things out of their lives: people who disappointed them, jobs that were too stressful, activities that were burdensome. They wanted to free their time for “the things that really matter.” Many people, survivors or not, do similar mental accounting, but cancer seems to give survivors permission to break norms of friendship, family, or obligation that bind others.

Survivors wanted to simplify their lives and reduce background noise so that they could have more bandwidth for creating meaningful and satisfying moments.

Friends that are on the outskirts of your life that annoy the hell out of you, but you get together with them once a year because you feel you still have to—I stopped all of that. So, I basically live for me and my family now. Period. And by that, I mean, my immediate family. I mean, even my own parents, or my husband’s parents, we have said no to them. Where, we used to be—My husband’s the youngest of four. So wherever they told us to go, whatever they told us to do, we did. We don’t anymore. So, I guess in that respect, that’s probably what has changed the most.

—Melissa, 42, white, stage II. She has been out of treatment for six years. She had a mastectomy, chemotherapy and targeted therapy.

I’ve made some very specific choices in terms of some people that I want to spend time with and not spend time with—two friends in particular who, in the middle of my treatment, were upset because I didn’t want to go out with them and do something. . . . I’ve just made choices. . . . So, I just don’t—Whereas, I used to—I would have, in the past, been much more accommodating and bend over backwards and do whatever some of these—you know, somebody would have wanted.

—Margaret, 50, stage II, one year out of treatment: lumpectomy and chemotherapy.

These quotes are about protecting the self and one’s time from undeserving people. I see this as a way of tightening boundaries, increasing the quality of one’s experiences by limiting the quantity of those accepted into the fold. By constricting social boundaries, survivors inflate the time and space they have for “what really matters.” Those experiences, then, take on more significance, as survivors are less distracted by other demands and frustrations. They talk about making these decisions consciously: it is not that they drift away from friends or that their involvement in activities peters out. They attribute these changes to a change in consciousness:

I guess things become more clear-cut. In certain ways, there are not as many gray areas. [Sighing.] You see what's important.

—Deborah, 52, white, two occurrences of stage I, nine years since treatment: lumpectomy, chemotherapy, radiation, bilateral mastectomy, reconstruction.

It's made my existence a lot more fragile. You know—things I didn't get upset about before, I—I don't know—even answering this out loud now, I feel like I'm going to change my answer again. But there are certain things. Life has become a lot more clear, and I have streamlined my existence in many ways. You're much more focused on the things that matter to you the most. For example: Maybe I would have volunteered for a lot more stupid things at the kids' schools before I was diagnosed, and then I stopped doing that once I was diagnosed.

—Kara, 37, white, stage I. She is one year out of treatment. She had a lumpectomy, chemotherapy, bilateral mastectomy, and reconstruction.

[I think about] all the events that I missed in [my children's] lives. And then, I would do all this work in reinventing corporations and new strategies for them, and then they would just downsize or reorg or whatever. . . . So, I decided that I was done—that corporations were not going to have me anymore. Cancer really was a defining moment to me in what I chose to do. . . . And I've developed a much more spiritual life, and much more internal life, a much richer, deeper connection—soul connection—so that life isn't about what people see on the outside, in terms of, you know: Is she wearing the right Armani suit? Does she have the right accoutrements on her? Is she getting invited to the right meetings? Or whatever. I don't own a suit anymore. I gave every suit that I own to Dress for Success. . . . All of my life is a contribution and a self-expression that I choose.

—Marna, 61, white, stage 0. She has been out of treatment for seven years. She had lumpectomies, radiation, bilateral mastectomy and reconstruction.

These survivors talk about how “clear cut” life has become, causing them to “streamline” their lives and remove themselves from the aspects that do not matter to them anymore. “Choose” is also an operative word here. Survivors want to have control over their lives in ways they did not when going through treatment, and in ways they still do not have in terms of risk factors and future recurrence

possibilities. Drawing boundaries is an active measure they can take to assert control over their lives. Survivorship forces people into a type of consciousness where the “little things” matter deeply, and they draw boundaries in order to protect these spaces.

Conscious decision-making becomes much more important to survivors, whereas before cancer they both had different priorities and did not stop to think about the deeper consequences of the decisions they made. For instance, Janet discusses her conscious focus on the small pleasures in daily life now that she has had cancer. She wants to pull those moments “we take for granted” into sharp relief, because those are the moments she has identified as adding meaning and joy to her life:

For me—I'm a pretty even-tempered, even-keeled person. So, I can get up in the morning and be happy in my own thoughts. I just would like to have a peaceful life with my family, my children, my grandchildren, my husband, and do the things that I would like to do. And they don't have to be grandiose. They could just be, get up in the morning and be happy. You know, sit down, have your coffee, read your paper, listen to the birds, see the flowers. I mean there are so many things in this world that are beautiful, that we take for granted and we don't even notice them in the course of a day. And I just had one of those moments with my youngest granddaughter last week. . . . It was so beautiful! I was like: Oh, my gosh. You know? But those are the things that make your life worthwhile. And it's the spreading of love and joy that's so important. I guess that's what I'm looking for.

—Janet, 65, white, stage II. She has been out of treatment for almost two years. She had a mastectomy and chemotherapy.

Janet's approach to life is enviable: we all want to be in a position where we can spend quality time with the people who matter most in our lives, to find love and joy in simple moments. Janet is at a stage in her life where she can slow down and take the time to enjoy her coffee and paper, spend time with her grandchildren.

But what I want to highlight about this passage is Janet's conscious focus on these moments; she invests her mental energy attending to these details, meaning she is not focusing on other details by default (mental bandwidth is limited). Living consciously is a way of focusing the mind on particular details and not others: she chooses to focus her attention on moments that will bring her joy and not on thoughts of recurrence.

Focusing on particular moments to imbue them with greater meaning is also a technique in time design. Truncating time helped to reduce anxiety about the future (by bracketing it) but it also increased the meaningfulness of today's moments. Survivors were able to expand and contract time to increase meaning:

Me: And what are your plans for the future? What do you think about the future?

Naomi: I don't have any. I'm working with a counselor, and I see her every week. And we are working on the present. And the future is, the day after.

Me: Is that conscious that you don't—want to think about the—Like, so that you focus on the present?

Naomi: Yeah. And I'm not sure what I want to do. So, until I know what I want to do—I have to work on: Who am I? I'm not used to that. I've always focused my energies on other people and pleasing other people. And I have to discover who I am and what I want. And then I'll think about the future. [Chuckling.]

Me: [Chuckling.] Okay. So you're focusing on you now?

Naomi: Right.

—Naomi, 64, white, stage IV. She was diagnosed five years ago, after her first occurrence, which was 10 years prior. She had a bilateral mastectomy and chemotherapy, and is not on continuous targeted therapy and chemotherapy.

Naomi's focus on the present makes sense because she knows that treatments will not last forever. Right now, she is feeling good: every day is probably the best day she will have as treatment options will only get more extreme if her cancer progresses. But many of the examples I have already discussed also display this element: survivors narrowed their focus to small moments, and by doing so increased the meaning of those moments; time felt fuller, longer, and more meaningful, so that even if survivors felt that they had less time left in their lives, they felt that they were making the most of it.

Putting me first

A major way survivors erected boundaries was to reserve space for the self. Survivors discussed putting their selves "back on the list," borrowing the language from support group. Focusing on the self is a hot topic for survivors: support groups emphasize "reinventing" the self, taking classes for the mind, body and soul, and promoting health as a way to achieve self-actualization. As all my participants are women, it is not surprising that "the self" emerged as a strong theme: women traditionally take care of others at the expense of themselves, and these women were no exception. They juggled demanding jobs, families, and community commitments. Although most of my participants described themselves as good patients, going to doctors for preventive health care, they noted ways in which they had become healthier after cancer: taking more time for exercise, eating "healthy" foods, spending more time de-stressing and on activities that enriched them. They talked about "balance" and "taking time out" for themselves.

Focusing on “me” often required that survivors “stay centered” or “be in the moment.”

Although they discussed the self from a holistic, almost metaphysical standpoint, their descriptions also revealed how much self-surveillance they now did. “Putting me first” means that the self is always in focus, under scrutiny. Even if this scrutiny is ultimately done to protect the self, the survivor enacts cognitive vigilance in watching the self, which requires some detachment from the self: the self becomes something one needs to monitor and control, even if the outcome of this is beneficial to the person.

I think the impact has been to just be mindful and be more in tune and more selfish, and without feeling guilty, because I think selfish is ugly, and when people are selfish, I just don’t even understand it. But I think it’s me first. If I have a doctor’s appointment, I’m going, and I don’t care if it’s to get an ingrown toenail taken out. I’m going. I don’t miss it. And I just take better care of myself, I think, in terms of watching out, you know, for me, and making sure that I’m okay first.

—Linda, 61, African American, stage I. She is two years out of treatment. She had a lumpectomy, chemotherapy and radiation.

Putting herself first is a drastic change for Linda. As a single mom, she worked three jobs and put the kids first. Cancer made her look back and reflect, “And I wondered like, when I was just running around, doing all this work, was I taking care of me enough?,” as if she shouldered some of the responsibility for contracting cancer. Not paying enough attention to the self quickly turns into irresponsibility once disease happens, whereas before illness, self-sacrifice is often viewed as a virtue. Focusing on the self sheds the stigma of self-indulgence or selfishness to become a positive behavior after something like cancer damages the self:

[S]ometimes I just get, just tired and say: You know what? I'm running around too much. I'm going to take care of myself now. And maybe that's one of the big changes in my life, that I'm paying more attention to myself.

—Anne, 62, white, stage I. She has been out of treatment for three years. She had a lumpectomy and radiation.

Gail: You've just got to take that time for yourself. You know, you just can't always be worrying about everything and getting everything done. You have to put yourself first a little bit. You know? Not that you don't care as much about everybody else in your family and everything. But it's like, I think I'm a little more that way.

Me: Is there anything differently you do for yourself now that you probably didn't do before?

Gail: Well, really, going through something like that, too, it makes you more worried about your diet. You know, exercising more. I smoked. I quit smoking. It's like you think about all the little things that aren't good for you. I'm a lot more careful with my diet.

—Gail, 58, white, stage III. She has been out of treatment for 10 years. She had chemotherapy and mastectomy.

Anne and Gail have both made behavioral changes to improve themselves, but their mental focus on the self is what makes these behaviors remarkable: people can enact the same behaviors without the same emphasis on “taking care of myself” or putting “yourself first.” While this rhetoric of the self is not specific to illness experiences—the self has become a project in modern life (Giddens 1991); we even have a magazine called “Self” marketed to young women that is mostly about health and the body—it has taken an illness of the magnitude of cancer for these women to feel entitled to take care of themselves and put themselves first. Naomi, who I introduced above, is a prime, albeit extreme, example of this emergent feeling of self-entitlement. Yet, she still expresses some ambivalence about doing things for herself:

I was always a very strong person, but I think I'm even stronger now. I would have always been afraid to leave [my husband]. I wouldn't have felt justified to go and live in a hotel by myself. It's very wasteful economically. I am paying the equivalent of our mortgage. We're paying the mortgage on our house. And I'm paying the equivalent amount of money in the hotel. And I have never been able to say before to myself that: You know what? This is what I need, and I'm worth it. I mean, I used to laugh at those commercials, you know, with the L'Oreal —whatever that commercial is for the hair—"I'm worth it." It's like: Yeah, you're worth it. Fifty bucks—you're worth it. [Laughter.] No big deal. [Laughter.] But on the other hand—certain things, I guess I'm still not there, because I won't spend the money on a massage for myself because I think that's excess. But this [living in the hotel] is for my health and for my survival really, so I think it's worth it.

—Naomi, 64, white, stage IV; she was diagnosed five years ago, which was 10 years after her first occurrence. She had a double mastectomy and chemotherapy; she is now continuously treated with targeted therapy and chemotherapy.

Naomi may be on the other end of the spectrum from survivors like Yvonne, who bought herself her dream car after her diagnosis. But, in either case, the struggle over boundaries of the self and the ambivalence over the right to “take care” of oneself are highlighted. Cancer, because of life-threatening potential, makes women grapple with social scripts of gender and selfhood, and, in many cases, gives women the allowance they need to promote their own well-being instead of depriving themselves of their needs and desires. What taking care of the self means is defined by our particular cultural context that emphasizes health and beauty, but many of the women in my study felt that the ways they now take care of themselves were luxuries before cancer. They have redefined these luxuries as essentials, which I take to mean that they have reprioritized themselves in their lives and are no longer willing to make sacrifices that cut into their “me” time and space.

Pushing the boundaries

Survivors tightened and expanded boundaries in order to maximize the self. They restricted others' access to them so that they could do the things they felt were more meaningful. For many, by cutting out old activities, people, and habits, they freed time and space for trying new things and challenging oneself. Survivors wanted to grow; they wanted to be sure that they were making the most of their lives. In pushing the boundaries of their selves, they could feel like active agents rather than passive recipients of illness:

I learned, as I said, to appreciate every day, every single day that I have, that so many people that I love don't have any more. And to enjoy—and to be with people—to be with people whom I love that are alive now and that I—You know, I try to be with them and with friends, and I try to enjoy my life, because I just don't know when it's—Not just cancer. You don't know when you're going to be hit by a car [chuckling] or something bad's going to happen to you or to them. So, [my mission is to] just to enjoy and appreciate every hour of every day. That's why, you know, I said—when I saw the e-mail [you sent], I said, “Well, you know, it's an opportunity. Somebody is doing a study. So, go for it.” I mean, just whatever I can, I go for it.

—Christina, 55, Latina, stages I and II. She had a recurrence four years ago. Her primary cancer was 14 years ago. She had a lumpectomy, chemotherapy and radiation for her primary, and more chemotherapy for her recurrence.

It hasn't been a bad experience. I mean, I certainly would rather not have cancer. But it's certainly been very rewarding in a lot of ways. The people and the doctors—I don't know. I think it's made me a better person. [laughter] I mean, you definitely change. Or, I think you do. I did. I think I've changed. Just by doing the things like—the fashion show [for the cancer benefit]—I mean, I would never [have done that before cancer]. I'm doing this [interview]. I would never do that. Getting up and going to the gym. I'm sure my husband was just like, “Yeah, right. You're going to go to the gym? Yeah, ha, ha—we'll see how long this lasts.” It's been a year and a half later, and I've been going every day. He's like, “Oh. You're going to the gym.” [laughter] So—.

—Terry, 45, white, stage IV. She was diagnosed two years ago and is on continuous targeted therapy

Christina and Terry are trying to push themselves to “go for it,” to take advantage of opportunities. Christina seeks out new experiences and sees them as opportunities for learning something new, ways of bringing new meanings into her life. Terry has been pushing herself beyond her comfort zone. She describes the new activities she’s taken on as completely unlike her: she signed up to be a model in a fashion show for a cancer organization, signed up for my interview, and transformed herself from a “sleepy-time gal” to someone who goes to the gym every morning and runs 5Ks. Terry was very reserved in her interview, frequently bewildered that she was telling me private information about herself; she has not told anyone outside her husband that she has stage IV cancer because she wants to keep her cancer experience private. These experiences foreground the self by taking it out of its usual context. These experiences help survivors experience mastery since they thrust themselves into a new situation where they can learn something new about themselves.

Sarah presents this feeling of mastery in a slightly different way:

Well, I was always sort of outspoken. But now, I’m even more so. You know, if I don’t like something, I’m just going to put it out there. I’m not going to tolerate it. I’m not going to do it in a nasty way, but I’m just going to let you know. Our number could be up tomorrow. So there’s [laughter] no reason for me to take anybody’s crap. Obviously, like, I don’t tell my boss off. But I mean, I will just pipe up and, “Blah, blah, blah, blah, blah.” . . . I feel like, you have to stand up for yourself, and I just think that cancer has given me—more of an edge. More of an edge, and it’s made me become more of a take-charge person, because I know that I could take charge of something, and I could overcome any adversity.

—Sarah, 49, white, stage I. She has been out of treatment for two years. She had a bilateral mastectomy and reconstruction.

Similar to Christina and Terry, Sarah pushes herself to speak up and take charge, which is connected to feeling like she can “overcome any adversity.” While survivors may not have control over cancer, they do have control over other challenges. Pushing themselves into new arenas helps them feel they can overcome tough challenges that lie ahead. Gwen, whom I discussed before, was high energy, filling her calendar and throwing herself into as many activities as she could following her cancer treatment; it felt to me like she was running on adrenaline, as if she were trying to squeeze as much meaning as possible out of each moment. I asked her in a joking fashion if she was always so manic. I recorded in my field notes that her rapid speech and hyperactivity made me think that she was still reacting to the trauma of coming so close to death. Survivors might try to push themselves to take advantage of each day out of fear—Gwen had inflammatory breast cancer, which has a very low survival rate—or out of gratefulness and awe. Both sets of emotions are reactions against the pure randomness of getting cancer. Dawne clearly sums up this process:

How has it changed me? I still have things that upset me. But I always say to myself, in the end cancer was something that I had no control over. And the tears and anxiety and the stress that I felt with that—that was not my doing. Certain situations that I get myself in—I can control. So what I do, I said: Okay I can’t control this one. So I’m going to step away. . . . So, cancer let me know that there’s something in my life that I can’t do anything about. There are other things I can. . . . Cancer, I couldn’t do anything about. This, I could do something about, and I tried to cut that negative feeling shorter.

So, it has changed me, to let me know that when there are things that you could control, you work with that.

—Dawne, 64, African American, stage 0. She has been out of treatment for 13 years. She had a lumpectomy and mastectomy.

Harnessing the Insecurity

As is clear from the examples above, many survivors—but not all—used cancer as a self-awakening. The experience enabled them to be unapologetic about their wants and needs. Combined with confrontation with one's mortality, this moment is powerful in helping them reclaim ownership over their lives. They could use cancer as a catalyst for life change: cancer prompted them to redefine what is important to them, to exert more time and effort in enacting behaviors they thought were healthy and cancer-preventative, and to limit their activities to those they deemed beneficial and enriching to their selves. Studies show both recently diagnosed and longer-term survivors report some kind of positive change to their lives as a result of cancer (Taylor 1983; Antoni et. al 2001; Cordova et. al 2001; Tomich & Helgeson 2002; Sears et. al 2003). Some research finds more affluent women are better able to do this (Bower et. al 2005).⁵ Economically disadvantaged women may not have the financial and psychosocial resources to transform cancer into a positive experience, but they may also embed cancer in a narrative of continuing life hardship or “life flow” (Hubbard et. al 2010), such that they do not perceive the experience to have the same disruptive power as other

⁵ Other research finds that earlier-staged and younger cancer survivors are more able to find benefits in their experiences (Lechner et. al 2003; Mols et. al 2009). Benefit-finding is not the same construct as post-traumatic growth or life-change after cancer (see Sears et al. 2003), although they are closely related: personal growth can be perceived (and is often operationalized) as a type of benefit. Various factors interact in determining who can make use of cancer and find positive benefits in the experience, like age, stage, and income, but I also want to reiterate that perceiving cancer as biographically disruptive is a necessary precondition to benefit-finding and using cancer for self-development, and, as such, perceiving cancer as disruptive is not necessarily dependent on stage or severity of cancer (Helgeson 2011).

survivors. Many survivors in my study perceived cancer as an event that prompted and enabled them to focus on their selves, which may, in fact, be both a privilege but also a cultural imperative for middle-class women.

As I also discussed above, many of my participants, across categories, described bracketing aspects of their experience but also holding onto a certain degree of ontological insecurity as they moved into their survivorship identities. Drawing on ontological insecurity enabled them to redraw boundaries in their lives and focus attention on their selves in ways they were not doing previously. While self-regulatory health practices, feminist ideologies/the women's health movement, and environmental awareness overlap in breast cancer survivorship to produce "activated patients" and actualized subjectivities, my participants also discussed how the existential and medical uncertainties of their experiences led them to create new spaces for meaning in their lives. They used their cancer experience to erect self-protective boundaries in their lives against the grain of "normal" expectations and demands, redefining the status quo as harmful to their selves. This new perspective often did not translate into political consciousness. Instead, they turned inward and made changes for self-protection and self-promotion. As such, many survivors transformed cancer from a debilitating disease into a strategy for better living.

Some of the quotes above show how survivors thought cancer made them better people than they were before. They said they were now more attentive, focused, empathetic, stronger. Monica remarked that, if she could, she "would sprinkle that on everyone." Survivors also felt obligated to make something out of

their cancer experience, not just to find a silver lining, but to use their new insights to benefit themselves and others. Their intense awareness of the fragility of life pushed them to develop themselves. This kind of humility made them more aware of their humanity, which, they think, made them better people:

I want to hope to say that it's made me a better friend, a better mother to my children, a better wife. I think because I'm taking time for myself now and doing everything I can for myself, that maybe I'm helping my family, too. I think I'm a better person now. I'm reaching out more to other people that I never did.

—Cheryl, 50, white, stage II. She had a lumpectomy, chemotherapy and radiation. She is two years out of treatment.

Well, number one—I think that, because cancer puts everything [in perspective], I mean, it is a reality check, like I said before—I think you begin to prioritize. I think you have to. Your priorities have to be in the right place. And when I get up every day, I want to enjoy that day. I don't want to waste the time. So, if I think about cancer, it's like: Get out of my way! Get that "C" word out of my way, [chuckling] because I'm going through the rest of the day, and you're not stopping me. It's there, and whether the sun is shining or it's snowing or it's raining or—it's a great day, and you're going to do the best you can with it. [Smacking table for emphasis.] So, I think very often, cancer changes your life for the best, because you now know that life is precious.

—Janet, 65, white, stage II. She has been out of treatment for almost two years. She had a mastectomy and chemotherapy.

And so, there has to be a before and after. I don't think you could—I don't think you should just go on. It's not like you have the flu, or you had—I don't know—an accident or something. I think everything contributes to who we are. So, I think it's important to encourage other women to get *better* than you were *before* you had the cancer—not just better *from* the cancer. Do you know what I mean?

—Liz, 69, white, stage II. She has been out of treatment for six years. She had a lumpectomy and radiation.

Liz sees cancer as a unique event that survivors should harness to change their lives. She does not describe cancer as a gift, but she sees cancer an opportunity for change. She describes cancer as an experience that comes with a moral obligation: not everyone survives cancer; those who do should use the experience wisely. Interestingly, being a better person seems to involve going deeper into the self, becoming more self-focused, in order to then reach out to others. Cancer gave these survivors the time and space to think about what they really wanted out of their lives and their selves, to contemplate their futures and make self-improvements. Ironically, sickness gives people a “time out” from normal life so that they can engage in deep, therapeutic conversations with themselves. It gives them the allowance to take this time for themselves, but the experience also imbues many survivors with renewed drive and motivation. Without cancer, they say, they might never have had found the strength or drive to make these kinds of changes. Many use cancer to draw a line in their lives, before and after, so that they can start over, in a sense, by living consciously.

Conclusion

Despite these different strategies, most survivors describe subtle shifts in how they perceive the things they always took for granted. Survivors largely wanted to retain some of the ontological insecurity they felt because it enabled them to appreciate life more and live life more fully. Some survivors, in particular, used this ontological insecurity to make powerful changes to their lives. One would expect that resuming past routines and mental habits would reestablish feelings of normality over time. But most survivors resisted this explanation of their experiences. Cancer put them on a different life trajectory. They adjusted life to

cancer, but most survivors in my sample claim they did not “go back” to life as they knew it, even if their practical routines did not change much.

Many did not feel that they were the same, even many years later. I interviewed survivors who were 10 to 17 years out of treatment and who remained cancer-free. These survivors still felt “different” because of cancer, supporting the research that shows time since diagnosis does not dissipate identification with the survivorship identity, ambiguity, or overall uncertainty (Bower et. al 2005; Decker 2007; Helgeson 2011). They felt cancer would never fully be out of their lives. Survivors receive follow-up care for cancer for the rest of their lives, even if this is only once or twice a year. If they have treatment effects, they see cancer doctors for these concerns. Other cancer reminders—weird aches and pains that may or may not be attributed to cancer or treatments, TV commercials, news of others’ diagnoses or recurrences or deaths—make cancer present in their lives. For some survivors, these reminders triggered fear and anxiety. For others, they inspired gratefulness and renewed mindfulness.

Notably, not all survivors described life as “new normal.” Some conscientiously did what they could to make sure their normal stayed “the same.” They did not deny or bracket cancer altogether; but they spent the majority of their efforts making sure life ran according to the same rules and structures as before. They did not feel the need to work on the self according to a new life perspective or philosophy—or they did not attribute these ways of perceiving life to cancer. Their conscientious enactment of normal, and refusal to perceive life as drastically different after cancer, marks this group as somewhat different from those who

experienced cancer as disruptive, incorporating this disruption into their new normal. This group had a pragmatic approach to life after cancer, framing their cancer experience as something they had to go through, but as a bounded experience. They incorporated this condition into their life, but limited its effects on their usual routines, habits, and self-conception. In this way, they limited their ability to use cancer as an opportunity for growth, too.

Also important, not all participants had the resources to be able to “make meaning” out of their cancer experience. A few of my participants, those with more severe cases of cancer or those constrained by finances, responsibilities, and lack of support, were at a loss about how to transform their identity and move on in life after cancer. Treatment effects were too severe for them to actualize their desires for a better self after cancer, or they were overwhelmed by the multiple roles they had to juggle and could not add “cancer thriver” to the mix. Harnessing insecurity means being “on edge,” switching back and forth between one’s cancer status and one’s other roles in order to use one’s confrontation with mortality to one’s advantage.

Research shows that more affluent survivors, younger survivors, and African American survivors are more likely to erect a positive frame around cancer, using cancer as a catalyst for self-transformation (see Bower et. al 2005; Davis et. al 2014). Because young women with cancer usually have more advanced cancers, and because of their positions in the life course, their interviews focused on their children and cancer advocacy: they concentrated their efforts on family life and shut out people and experiences they deemed

unworthy of their time, but opened themselves up to cancer organizations. While some research has found stage or severity of cancer to be unrelated to perceptions of cancer's disruptiveness (Helgeson 2011; Hubbard et. al 2010), these factors may shape how survivors perceive disruptiveness in nuanced ways, directing them to take particular kinds of actions. Some of the "gravitas" a survivor attributes to her situation may be related to what kinds of treatment she receives, and survivors of more aggressive cancers, like younger survivors, have more aggressive treatments (see Bower et. al 2005). These kinds of experiences may direct survivors into more serious activist roles (Frank 2009). The older women in my study were at stages in their lives where they had already proven themselves in their careers, already raised their kids, and were financially stable. They *could* construct narratives about de-stressing, focusing on what is important, and maximizing self-growth. These women, while participating in cancer events, often felt that it was time they focused on themselves, as they had spent so much of their lives on family and careers. Ironically, illness gave them a space and the opportunity to focus on their selves—a direct comment on the ways women's lives are structured, such that they need a major illness to give them the opening or permission to focus on themselves. I also found the most early-staged breast cancer survivors interpreted cancer as an "eye-opener," which thrust them into a period of self-reflexivity, turning their gaze inward.

After considering these different types of reactions and strategies for harnessing cancer, I theorize that there might be an "ideal" level of ontological

threat that prompts people into the “awakening” that many of my study participants discussed: too little causes no change while too much is paralyzing. While the qualitatively richer stories about life and meaning tend to come from those with more advanced cancers, the individuals who make the most outward changes to their lives are often those in the middle of the spectrum. Stage 0-I and stage IV tend to be pulled into the self, for different reasons, and while they all may experience a shift in perspective, they may not be propelled into action or be able to perform outward life changes. “Mid-stage” survivors, not usually considered as a category of their own, may have a unique driving force, as their cancer is close to stage IV but not a “baby cancer,” as one of my survivors described hers, either. Mid-staged cancers may not be perceived as life-threatening, but they cannot be brushed aside, either. However, as noted, perceptions of cancer’s disruptiveness may not be enough to enable people to use cancer as an opportunity for growth. Other variables, like age, income, and ethnicity, moderate the ways in which survivors seek out positive life changes through cancer.

CHAPTER FIVE

Perceptions of cancer: what is it, why did I get it, and can I be cured?

How survivors think about cancer—how they frame their cancer as an experience, what they attribute as its causes and its effects, and how they perceive it temporally (short-term/acute, long-term/chronic)—has implications for how survivors reconfigure their identities, plan for the future, and define meaning. Many health scholars have proposed models that link patients’ beliefs about health and diseases to outcomes like psychological well being or adherence to medications or use of coping mechanisms (Miller et. al’s (1986) and Leventhal et. al’s (1980) models are notable for their influence in this area). Investigating how breast cancer survivors perceive their cancer is important at this moment in time because the cancer world is changing: many cancers, including breast cancers, have become described within the field of medicine as “chronic disease,” and, because of the success and influence of the breast cancer movement, dominant discourses of positivity embedded in survivorship may influence survivors’ thoughts and reactions to cancer in new ways, as well (Kaiser 2008).

With the advent of new therapies, patients are living longer with higher qualities of life. Stage IV may not be an immediate “death sentence” anymore, as it can be managed for longer periods of time than in previous decades. Early-stage cancer survivors embark on “follow-up plans” that recommend intense surveillance for five to ten years after treatment. Survivorship clinics within nationally recognized cancer institutes are poised to monitor survivors

for the rest of their lives when they no longer need special treatment by oncologists. The growth of community cancer organizations to care for survivors' psychosocial needs is an important development. These organizations give survivors a place to craft their identities and "reinvent" their lives after, with, or beyond cancer. Participation in cancer organizations, medical spaces, and in particular health recommendations shape and is shaped by survivors' thoughts about cancer as a disease and experience.

While much of the medical and community response to cancer fits within Frank's (2009) description of "remission society," in which everyone walks around as a permanent (pre-) patient, individuals' experiences of life after or with cancer are not completely taken over by medicine. Stage IV survivors may live for long periods of time "in remission," but the survivors I interviewed did not devote the majority of their moments to thinking about cancer. "Highly functioning" metastatic survivors adapt their lives to treatment but do their best to "make it normal." Early stage survivors are not considered to be "in remission" if they have "no evidence of disease," but this does not mean they are "cured," either. Early stage survivors live in a landscape of chronic prevention. While many may have recurrences, and a few in my sample did before and after my interview, most of the survivors I interviewed did not carry thoughts about recurrence around with them. Survivors of various stages changed their time scope to avoid ambiguity: for now, I am cancer-free; for now, I am cured; for now, my cancer is dormant. This enables them to avoid living in a liminal position between "healthy" and

“sick.” Survivors were able to endure and accept the cognitive ambiguity surrounding cancer in this way, turning it into their new normal—not a liminal stage, but a new way of being.

In the previous chapters, I discussed changes to identity, cognitive styles for incorporating cancer into one’s self-concept, and strategies used in creating one’s new normal or keeping life in accord with one’s past normal. In this chapter, I analyze survivors’ perceptions of breast cancer as a disease and discuss how these frameworks correspond to particular strategies for thinking about cancer and the role survivors themselves feel they (have to) play in their health. I discuss the conceptual distinctions implicit in survivors’ classifications and definitions of their diseases.

First, I analyze how survivors conceptualize cancer and how they think about what caused their cancer. I find that some ways of thinking about causality enable survivors to feel control and mastery whereas others require survivors to accept more uncertainty. The relationship between uncertainty and control is not straightforward but mediated by one’s belief in cancer causality. For instance, survivors who feel cancer is relation to environmental causes may feel they can control recurrence through their own actions, but they may experience more anxiety than survivors for whom cause is not important in their meaning making of the experience.

Next, I analyze how survivors think about their cancer in terms of curability and temporality—if they think about cancer as chronic or incident-based. The medical world may conceptualize breast cancer as a chronic

disease, like diabetes or hypertension (Hewitt et al. 2003), but this conceptualization does not match how certain groups of survivors perceive their disease. How survivors think about cancer influences their strategies for living “with,” “after,” or “beyond” cancer, determining how survivors employ those prepositions in defining their lives.

For this chapter, I separated the early-stage breast cancer survivors, stage 0-III, from the metastatic survivors because of the medical and experiential divide between “early” and “late” stages but also because of the conceptual divide survivors themselves had between these categories. The stage system is tool created by the medical establishment based on size of tumor, number of lymph nodes infected with cancer cells, and location of cancer in the body (localized, spread to lymph nodes, spread to other parts of the body). Doctors may use staging as a heuristic, although these models have become reified in practice (Smith and Hemler 2014), presenting a much more consistent and coherent model of cancer to survivors and the public than actually exists.⁶ While there may not actually be such distinct divides between

⁶ As I discussed in the introduction, staging is only a basic model. Large tumor size may place a tumor at a later stage even though lymph nodes are not involved, whereas an earlier stage could have lymph node involvement. People tend to interpret the staging system as progressive and teleological, as if a person will progress from stage I to II to III to IV over a determined amount of time, but tumors do not all progress nor do they progress in the same way or at the same pace. Tumors also vary in response to estrogen and progesterone and in binding to the protein HER2 so that some tumors are more aggressive than others, regardless of stage. Doctors acknowledge that they cannot tell which cancers will spread and which ones will not. Tumors can be tested for “oncotype,” which tells the composition of the tumor, but, yet, all that can be offered is potential risk of recurrence. Molecular differences to cancers are just now being explored.

stages, each stage has come to mean something different to survivors in terms of fear and perceptions of “seriousness” of the disease. Stages 0-III make divisions amongst themselves, but they all compare their cancers to stage IV, creating a deeper divide between early stage and metastatic cancers. Stage IV is marked by cancer that has spread to some other part of the body, in breast cancer, usually liver, lung, bone or brain, yet some metastatic survivors live with no evidence of disease or are in remission to the point where they are living more active, “normal” lives than their earlier staged counterparts. Thus, the staging system may not yield an accurate representation of disease or quality of life, but it does shape perceptions of disease. I analyze stage IV survivors separately because their perceptions of their cancer and their relationship to cancer causality and of chronicity of disease are different than those of the other stages.

How do early-stage survivors think about cancer?

Cheryl described her cancer as an “ugly growth, and pieces of that little growth can break off, float around your body and attach itself to other things and start growing. So it’s just a mean monster... more like a jellyfish-type thing.” Ariana described hers “like a person! . . . this golf-ball-sized thing that was with me...that was in my body, and it’s just weird to me.” Margaret pictured hers as “a nasty little blob, like those things in the commercials for the toenail fungus [laughs] or something. Just this nasty little blob that you can control, but you got to scoop it out and get rid of it.” A few people described visualizing water or bright light rushing over them, cleansing their bodies.

Some talked about their bodies feeling alien, as in *Invasion of the Body Snatchers*. “I don’t feel that my body has betrayed me. I feel it’s something that happened to my body,” Rosemarie explained. A few survivors did feel that their body betrayed them, regarding that breast suspiciously now, or feeling that they needed the mastectomy immediately “to just get it out.” Others visualized their cancer more in line with images online or that their doctors showed them. Only one survivor described cancer as a natural bodily process. Most perceived cancer as a foreign invader, which may be created by but also helps perpetuate the militarized language around cancer: people want to “beat” cancer or “kick cancer’s butt.” Although cancer comes from their own bodies, their own cells, survivors tend to think about cancer as something “not-them,” making their breasts and bodies feel foreign, coopted, invaded, turned, or transformed. Conceptualizing cancer as something foreign that needs to be attacked helps justify the types of treatments Western medicine has for cancer—“slash, poison and burn,” as Jane described them—but it also shapes how survivors think about what caused their cancer and what they can do to prevent recurrence.

Despite picturing cancer as a foreign invader or non-self object, most survivors told me the same story about cancer. Agnes explains, “Well, everybody has got cancer cells. I read that somewhere. I hope it wasn’t just somebody’s opinion. And then there is something, some signal, that makes them go off.” Sarah’s version is slightly different, but still holds the same central point:

From everything that I've read—and I'm still very on the ball when it comes to anything with cancer—I believe that everyone has, not, per se, cancer cells, but everyone has cells in their body that mutate in a certain way that might divide and multiply abnormally. Usually, your immune system takes care of that. I think that there's got to be something environmentally, where, we are being exposed to something. Everyone has their own level of toxicity threshold, and I think that if something is compromising our immune system, and it's just allowing these cancer cells to just take over.

—Agnes, 54, white, stage 0. She has been out of treatment for 10 years. She had a mastectomy and radiation.

Survivors expressed variations on this message, perhaps saying instead of everyone having “cancer cells” that everyone has cells that break down or go awry. The part about a compromised or deficient immune system is critical to most explanations: if the immune system is at fault rather than the cells, logic follows that something caused the immune system to become deficient, and, if that is the case, then something can be done to boost it back into proper operating. Some people categorized cancer as an inflammatory disease, which can be aggravated by stress and cortisol. Others discussed the role of aging and cellular breakdown. For some, just this explanation of cellular dysfunction is enough: that's what happens, end of story. But for many survivors in my study, deficient immune response is only part of the story. *Something* needs to happen to make the cells mutate and/or disable the immune system. The *something* that causes cellular dysfunction helps survivors situate cancer as an external enemy to fight.

In this line of logic, cancer needs a triggering agent, a cause. This triggering agent becomes a key point in dialogues about prevention and control—and, importantly, feelings of blame and personal responsibility.

Survivors attributed several different “causes” to cancer, which, I found, put them on different paths in terms of the personal responsibility and control they felt over preventing their cancer and the feelings they had about the likelihood of their cancer recurring, which I discuss in the next section.

What caused MY cancer?

How survivors thought about what caused their cancer influenced their perceptions of cancer as chronic, cured, or somewhere in between. This, then, influenced if and how they mobilized themselves to prevent future cancers or recurrences. Survivors generally fell into six categories in terms of how they thought about cancer causes:

(1) Disease frame/not relevant

These survivors accepted cancer as a disease that “just happened” to people. They did not think cancer happened to them for any particular reason or that cancer did not happen to other people for particular reasons. They felt cancer was a disease like any disease, and, as such, there are only medical explanations for why it happens. Some of these survivors went one step beyond this and said that it did not matter why cancer happened to them, the cause was not relevant since they now had it. Many considered their cancer a “fluke,” which was all the answer they needed as to why they got it.

(2) “Environmental” causes

I collapsed several explanations into this category—thoughts about chemicals, plastics, GMOs, use of hormonal therapy for menopause, air

and home pollution—but all share the conception that cancer was caused by an external triggering agent. These agents could be pesticides on food/soil, estrogenic and polluting properties of plastics, stress that causes cortisol levels to rise, etc. A few survivors discussed “cancer pockets” or wondered if living in New Jersey in particular could be a cause since New Jersey has a large cancer population.

(3) Family history/genetics

Many survivors had a family history of cancer or tested positive for one of the BRCA gene mutations. However, survivors did not necessarily find the results of genetic testing conclusive. Some survivors tested negative, but still maintained family history was the strongest factor in their cancer. Others tested positive, but still wanted to know what the triggering agent was, since other members of their family did not get cancer. At the time of the interview, scientists had found two BRCA gene mutations linked to breast cancer. Many survivors thought that other genes could be responsible for causing breast cancer but that these links had not yet been discovered.

(4) Multiple factors interacting

While survivors in the “I don’t know” category rattled off a list of probable carcinogens or risk factors for cancer, they ultimately threw their hands in the air, proclaiming that no one really knows. This group is different in that they specifically said that factors interacted or acted

in tandem, usually genetics and environmental factors, to cause their cancer.

(5) No theory for why/“I don’t know”

These survivors offered a slew of possible explanations, but concluded that ultimately “nobody knows,” or that the medical community does not know what causes cancer. Unlike the survivors above, who actively dismiss explanations outside of the actual medical mechanisms for how cancer happens, these survivors are more plagued by the uncertainty of why. They wonder why it happened to them, especially those who considered themselves ultra-healthy to begin with. They want a satisfying answer for why they got cancer, but they cannot find one.

Differences in causality beliefs matter not just for what these causes are but also for what they convey about the nature of cancer. All but the “I don’t know” category have a theory for what caused their cancer. Having a theory may be cognitively easier for survivors than not having one: they can create an account or justification, putting the issue to rest. Having a theory also enables action: they can do something about their cancer if they think they know its cause. As many survivors said, “if they don’t know what caused it, how are they going to cure it?”

Next, not all causes are created equal. Survivors who think that their cancer is triggered by certain environmental causes or by multiple factors interacting act differently than those who think their cancer is purely or mostly genetic. Those who tested positive for BRCA mutations usually opt for more

surgery: most consider bilateral mastectomy and oophorectomy. Some survivors choose not to get tested because they would not consider doing these surgeries. Others, whose tests come back negative, remain firm in their belief that their cancer is genetic; they, then, have to make tough choices about whether or not to proceed with preventative measures. Generally, if survivors think their cancer is genetic, they usually do not think their lifestyle or food consumption is related to cancer. While tumor type matters in terms of “aggressiveness,” positive genetic results seem to indicate a level of seriousness to survivors; test results give a sense of known-ness in a world otherwise plagued by uncertainty. This known-ness then requires a particular protocol. Doctors do not like to watch and wait these cancers, particularly when they have information and a protocol to follow (see Smith and Hemler 2013). “Genetic” cancers push survivors down a path of surgical options and are can be considered more serious than “accidental” cancers.

Those who posit environmental or multiple interacting causes for their cancers take a different frame of action. They feel they can prevent their cancer by controlling the environment (or what they can of it). If attributing multiple causes, survivors generally focus on the one cause they can influence. As I discussed above, the dominant explanation survivors have for why cancer happens is failure of the immune system. For survivors who think the cause is environmental, or environmental and genetic, they act to boost their immune system. They want to create an anti-cancer environment internally and externally: they reduce stress, eat organic, remove chemicals from their homes

and offices, try to exercise more and get more sleep. Some survivors bemoan that they did all of these things before and they still got cancer. Those survivors are generally not in this category. These survivors ramp up their focus on these activities. They purposefully engage in particular lifestyles as preventive measures, not just to improve their general health.

Lastly, those who do not need a theory of causality, or who believe there is no explanation beyond what happens on a cellular level, may be the group that asserts the most control over their experience: they decide the extent to which they want to think about cancer and let it shape their life. Most of them say they “beat” cancer. Many said they “left the uncertainty to the doctors” or resisted Googling information, relying on their doctors’ expertise. They were “activated patients,” meaning they were extremely involved in their care; but they did not research online, listen to idiosyncratic information, or compare their cancer treatment to other people’s. They largely did not change their lifestyles after cancer. Instead they engaged in a mental fight with cancer. They considered chemo and surgery warfare against cancer. Cancer, to them, is a disease that they overcame. They may carry the survivor identity forward with them, but they do not think they have the disease.

Relationship of theories of causality to disease characteristics

While the numbers of my subgroups are too small to make any statistical statements, my findings in Table 1, below, suggest trends for future research. I dissected causality attribution by stage of cancer, time since treatment, and treatment type, hypothesizing that these factors might influence how survivors

think about cancer's causes. Research has been mixed about how much these variables influence perceptions of cancer. My findings can only suggest possible explanations.

Table 1. Survivors' theories of what caused their cancer

	Stage					Time since treatment						Treatment type				
Cause	0	I	II	III	total	0	1	2	3	4	total	C	M	B	N	total
Disease frame/ Not relevant	2	3	5	4	14	3	7	3	1	0	14	4	2	7	1	14
No theory/ Don't know	1	6	10	0	17	3	8	5	0	1	17	7	2	4	4	17
Family history/ Genetics	2	2	2	1	7	1	1	1	2	2	7	1	1	4	1	7
"Environment": Lifestyle Food Chemicals Stress HT	4	8	4	1	17	3	5	3	1	5	17	5	3	3	6	17
Multiple factors	2	1	7	2	12	1	7	0	1	3	12	3	2	6	1	12
n=	11	20	28	8	67	11	28	12	5	11	67	20	10	24	13	67
N=67; I excluded two participants because of incomplete information. Time since treatment: 0=less than 1 yr.; 1=1-3 years; 2=4-6 years; 3=7-10 years; 4=10+ years. Treatment type: C=chemotherapy; M=mastectomy; B=both; N=neither.																

Stages 0 and I are the earliest stages of cancer, usually the most routine to treat. More survivors within these stages thought their cancer was caused by environmental factors more than other possible causes. These survivors usually did not have a family history of cancer. Their cancer was found early during routine mammography. In the absence of family history, environment

is a plausible answer: if survivors think something external caused their cancer, what else would it be? These survivors, I pose, wanted a reason behind their cancer; because their cancers were so early and supposedly non-life threatening, they were able to place the cause outside of themselves. An environmental cause made sense as their cancers were small or contained—something had to set the body off. These survivors felt they could do something to prevent cancer's return, particularly because their cancers were caught so small, so early.

A close second theory of causation for stage I was having no theory for their cancer (“No theory/I don’t know”), which is also the largest response for stage II survivors. “No theory” means survivors had no answer—but wanted one—for why they got cancer. These survivors explained that the medical establishment has no answers for why cancer happens to some people and not others, but these survivors did not attempt to fashion their own explanations. This position comes with some anxiety, because without a theory of cause, there usually was not anything the survivor thought she could do to affect her future health. These survivors expressed shock about their cancer, and, without determining a reason for it, had more trouble managing the uncertainty. Stage II survivors also thought “Multiple factors” caused their cancer, such as a combination of genetics and environment, which is almost as unwieldy as not having any theory at all: survivors either gave a laundry list of possible things that could have mattered (No theory/“I don’t know”) or

described complex interactions between elements (Multiple factors), both of which left them with little they could do on their own to prevent cancer.

Although my sample of stage III survivors is small, half of these survivors employ the “Disease Frame/Not Relevant” causality; they thought of their cancer as a disease that just happens, that has no cause. The pattern underlying thinking about causes might be related to perceived seriousness of the disease: the earliest stages provided less complicated causal explanations than the more advanced cases. Stage III is treated aggressively so that it does not metastasize; these survivors may be given different medical messages by doctors than those with stage 0 or I about the nature and complexity of their cancer (survivors know when they have an “easy” cancer because their doctors tell them they got “a good one,” as Anne told me). If their cancers are caused by estrogen, which is an easier cancer to treat than triple negative or HER2+, survivors may think the causes are simpler: hormones in food, hormonal treatment, stress levels. Stages II and III are more likely to be perceived as more complex diseases, and, thus, survivors may think about the causes in more complex ways, too. This also may leave them feeling like there is less they themselves can do to control or prevent their cancers, especially if survivors place cancer within a purely biomedical frame.

Time since diagnosis gives a different insight into survivors’ beliefs about causes. Survivors less than a year out of active treatment and one to three years out of active treatment do not have a distinct choice of cause, but survivors of four to six years out of treatment hold the “No theory/I don’t

know” causality more than other possibilities. Those ten or more years out of treatment mostly think environment caused their cancer. Perhaps the longer one lives free of cancer, the more “cause” ceases to matter and the more positive lifestyle changes do. If cancer has not recurred, survivors may feel more control over their cancer or attribute its cause to something they can control. However, survivors often experience late-term effects from cancer or recurrences after 10 years, which may undermine feelings of control. Some in this group may have taken hormonal therapies for menopause, which they can control by not taking it.

And, lastly, treatment type could also play a role here. Those survivors who had both chemotherapy and mastectomy, which could be those with the most aggressive cancers and/or the most anxiety about cancer, framed their cancer as a disease, the causes of which are irrelevant. Those who had a lumpectomy and chemotherapy, mostly stage I or II, have “No theory” about causes or “Don’t know.” Those who had neither chemotherapy nor mastectomy, the survivors who had a lumpectomy and radiation or who refused chemotherapy, mostly selected environmental causes—perhaps because their cancers were small, caught early or non-invasive, and perhaps perceived as not “major” cancer. Thinking that something in the environment caused one’s cancer may or may not be easy to correct, depending on if one can remove oneself from the source. But survivors tended to believe they nipped those cancers in the bud and could prevent others through increased vigilance over their lifestyles and environments.

These conceptualizations shape the aftermath of survivors' cancer experiences: how think about their cancer influences how they live life after, with, or beyond cancer, what strategies they put in place for coping with uncertainty, or how they define meaning in their lives—and vice versa. I hesitate to claim that attributions of cancer cause produce these changes as survivors can arrive at these attributions from different pathways. I conducted interviews after cancer treatment, so I do not know what survivors thought at time of diagnosis. It is likely that disease conceptions changed as survivors progressed through phases of diagnosis and treatment. But designating a cause for cancer, and settling on a particular belief, is a strategy for coping with illness as much as it may be related to scientific fact. Because so much uncertainty surrounds cancer, arriving at a causal theory says as much about who the person is and what is in their tool kit as it does about the scientific state of the field.

Causes, control, and certainty

Because the medical community does not know what causes cancer to occur in some people and not others, survivors are left to determine for themselves how to filter troves of information and inconclusive studies that point to myriad possible causes. Doctors know risk factors, but risk factors are not determinate causes. Most survivors would go through the list of risk factors with me and tell me which ones they had—or, usually, did not have. They were aware that they contracted cancer usually without many if any risk factors at all. Giving an account for why, then, they got cancer when they were ostensibly healthy

before cancer is important: even coming to the conclusion that there is no cause requires deliberation. This process, though, is more taxing for some than others. For example, Candace explains her uncertainty about cause and how that relates to her shock of getting cancer:

Cancer is something I never thought I was going to get. Because I thought, if I do all the right things, then it's not going to happen to me. Well, obviously, it did. And so, I went through a period of time when I was really angry about it. You know?

I have a sister who just does everything wrong. And I mean, everything. And, she'll probably never get anything. I mean, when it's in your own family, you're thinking, oh, my God. But it doesn't work out that way. Your genetics are *your* genetics. And all of us have something, no matter what we do—we're going to deal with something.

—Candace, 59, white, stage II. She is almost two years out of treatment. She had a bilateral mastectomy.

If being healthy does not inoculate a person from cancer, and if doing “everything” wrong does not cause cancer, then what is a person to think? For Candace, genetics can only be part of the answer (if it were the whole answer, her sister would surely be affected, too). She needs to find some other way to account for what happened to her. I commonly heard sentiments like “I was so healthy,” which is part of why cancer catches so many people off-guard. Cancer is often painless, and is detected more and more often before a lump can be palpated due to regimented screening and more advanced imaging techniques—other reasons why a diagnosis is such a surprise. But accounting for the “why” of cancer, even by rendering this “why” unimportant, can help survivors gain a sense of mastery and control:

That was the first thing my doctor said to me. She was like, “Now, everybody wants to know why, or how.” And she goes, “Those are two questions I can't answer for you.” And I go, “Well, you're lucky. I'm not going to ask you those two,” [laughter] “because, honestly, it

doesn't matter at this point, because I've been diagnosed." So— .
 Because some people do really want that "Why?" or it nags them. And it's funny because, after my chemo treatments were done, my sister put together a photo book, and the letter she put in there, she was like, "You never complained. You never asked why. You never questioned it." And I never did. And I still—I don't. It's like: Okay. It happened. So— [chuckling].

....

Because most people [say], "Well, how did you react?" Well, I was pissed, and got up—picked myself up and said: Okay. We are ready to fight. . . . It was like—that's it. You've basically messed with the wrong woman. [laughter] So, I found—I personally find it to be very empowering. Unfortunately, I've seen the flipside, where it actually hurts people, and they get lower self-esteem and do all that—which, that saddens me.

....

I'm convinced, mentally, that that's why I'm so above water about it right now, is because I didn't sit and think: Why did I get it? How did I get it? What could I have done differently? I didn't think about those things, because one, I knew those were things I couldn't change.

—Monica, 36, white, stage IIB. She is two months out of treatment. She had mastectomy, chemotherapy, and radiation.

Using different causal attributions, other people may not be able to reach the same amount of security as Monica. For example, Patricia, who believes her cancer was caused by multiple factors, can only control certain ones:

I have a lot of thoughts about what caused my [cancer]. Every time I hear something that causes cancer, and it's something that I was doing, I say, "Oh— ." I mean, little things, and then I say, "Nah, it couldn't have been that." And I have heard people say, "You know that if you drink out of plastic bottles and you let them sit in the sun, or you freeze them— ." And I said, I used to do that. I would buy a whole big thing of water and leave it in the car sometimes if I couldn't bring it in the house right away, and it would get hot, and then I'd bring it in and put it in the freezer, and never knew about that. They said something happens to the plastic, and it becomes toxic in the water or something. I mean, I don't think that had anything to do with it. But I heard if you use an anti-perspiration deodorant, that if it has aluminum in it, that it clogs up your pores and could cause problems. And I did that. But I think, all those things—I really think it probably was just something in my—not my genes, because I don't think it was hereditary—but, I think [it could have been] a lot of things. I had a very stressful job. Things were very

stressful with my husband being sick. And I think stress plays a large role. But then, I think too, the fact that I had other issues—the estrogen—I probably was producing a lot of estrogen because I didn't go through menopause. . . . So that, I figure, probably that played a larger role than anything else and then too, I was overweight. Which, they say—obesity is another factor. So, that's what I feel. I think most of the things could've been controlled, other than the fact that I was a late starter in getting my menstrual—and then I, you know, went later than most people.

—Patricia, 63, African American, stage III. She is two years out of treatment. She had a mastectomy, chemotherapy, radiation and reconstruction.

Patricia gives me list of items, some of which cannot be proven or dispelled simply because studies have not or cannot be done. They exist as theories or assumptions, and they get perpetuated on websites and in support groups but not through medical channels. In order to cope with the uncertainty that theses “causes” generate, Patricia has to resort to different kind of strategies than Monica. Patricia relies on naturopathic supplements to boost her immune system, she has cut out all the chemicals she can from her environment (no more hair or nail salons), and she has started an exercise regimen with a fitness trainer. She shops at Whole Foods. She has switched jobs to decrease the stress in her life. She puts herself first. She uses wipes on most surfaces to eliminate germs. But that is not enough. She also believes in positive thinking, and relies heavily on her spirituality to guide her through. Since she believes in multiple causes for cancer, she attacks it on multiple levels. She thinks she is cured, but she does not live for the future as much as Monica; she still exhibits some reservations:

I mean, I think I live more in the present now than I did before. I try, you know, not to dwell in the past or not to even dwell too much in the future because you just don't know what tomorrow is going to bring.

While her caution is likely also related to her stage (she was III whereas Monica was II) and her age (she's 63, and has an ailing husband, whereas Monica is 36, and has young kids and a Army husband), Patricia's approach to cancer's "cause" and her methods of prevention place Patricia in a position of more anxiety and uncertainty than Monica. But simply having a theory for what causes cancer may be better than no theory at all (those who "don't know") because it provides people with logical actions they can take on their own to help prevent cancer from recurring.

Survivors describe feeling "lost" when transitioning from their active cancer treatment to follow-up care because they stopped seeing doctors frequently, but, more importantly, they also felt that they were not doing anything themselves to prevent or care for their cancer: doctors often did not give them directives for self care (Hewitt et al. 2006). This is one of the reasons the IOM advised physicians to give survivors follow-up plans, so that they could feel more in control of their care. Most of what survivors can *do* for cancer prevention, though, is to be "healthy": to eat well-balanced meals focusing on particular foods and spices, avoid known carcinogens, and exercise. But, for some, this is unhelpful. As Frannie said rather dismissively, "You know, that's just nebulous information. . . . They tell you, eat certain foods, exercise. Oh, please. You do that for good health. Period." And she's right. Some scholars criticize oncologists and cancer doctors for using cancer as an opportunity to promote health behaviors that may not help prevent cancer at all (Bell 2012).

But some survivors latch onto these calls, delving into nutritional science and searching out foods with “cancer-fighting” properties, like Terry and her asparagus diet or others on broccoli diets. Although some feel that having the trifecta of treatments—surgery, chemo and radiation—is doing all that they can do for cancer, for others, cancer care includes controlling diet, environment, exercise, sleep, and stress. Many, but not all, survivors in my study did reach a point where they felt comfortable knowing that they “did all they could” to prevent cancer’s recurrence, which helped them relax and move forward. Those more anxious about recurrence exerted the most intensive life changes; having something to do may have helped them feel more in control than they would have otherwise, but it also kept the anxiety and fear of recurrence alive. Deborah explains her relationship to food as a method of feeling some control over cancer:

Me: Well, in terms of the exercise and the eating and stuff—is that something you attended to before cancer, or is that kind of a result of the cancer?

Deborah: Yes, I did. Not so much the exercise, but I was always pretty careful with eating. But now, more so. So, yeah.

Me: And have your reasons shifted? Because I’m just thinking—some people eat well because they want to maintain their figure, and then some people eat well because they—or they’re concerned about the vitamins and nutrients and what they eat, or what’s not in the food that—

Deborah: More the health reasons—much more the health reasons. The antioxidants in broccoli.... trying to really stock up on that sort of thing in my system, to try—I think it helps when you feel like you’re not helpless with this disease—that there are certain things that maybe you can do that can help prevent recurrence. And I’m not so sure that they help. They don’t know if there’s a connection or a correlation with

any of that. But maybe it does. And if you kind of think that, maybe that's the best thing. [chuckling]

Me: [chuckling] Do you think there is a link between food and cancer?

Deborah: Yes, I do. I do. Yeah. In certain ways, maybe, unfortunately, a person might get cancer at some point in their lives. But maybe it can be put off, if you're trying to live in a healthy way. For a little while at least—you know? I sometimes think maybe I would have been diagnosed at 35 instead of 39 if I hadn't—Who knows? You don't know. Maybe if I had done even better with the food and exercise, I wouldn't have been diagnosed until I was 50! So—you know—yeah, but I do. And maybe it's just the whole idea of having some control over the situation.

—Deborah, 52, white, two occurrences of stage I, nine years since treatment: lumpectomy, chemotherapy, radiation, bilateral mastectomy, reconstruction.

Deborah seems to realize that she is tricking herself in a sense—immediately after telling me there is no settled knowledge within the medical community about a lot of preventive actions survivors take, she tells me she believes in the link between food and cancer—but she acknowledges that this kind of trickery might be helpful to gaining control over an uncontrollable situation (see Bell 2010).

If having some theory of causality helps some survivors gain control, what about having no theory, no idea of what causes cancer? Oncologists may understand the mechanics of cancer, but they do not know what causes cancer to occur in some people and not others, and they cannot identify, at the current moment, which tumors will spread and which ones will remain self-contained. Survivors in the “No theory/Don't know” category know that this is the state of the science, although they are mixed about the implications of this (lack of) knowledge. Some find a way to reach acceptance through generalizing disease

risk—Jade tells herself, “Forget it, Jade. You could be black, white, Chinese, yellow, fat, ugly. . . anybody can get cancer” —while others, like Sally, decide the reason she got cancer does not matter because no reason will be satisfying:

I know enough scientifically, that there are some hereditary factors that some people have that make them more disposed to having cancer. I don't have any of those factors in my background. So, there are theories—again, just going back from the scientific piece—there are theories that we all have cancer cells floating around in our bodies that, apparently, occasionally, for some reason, take hold and grow. I know there are risk factors for breast cancer. So, did I bring a piece of it on myself? I don't know. It's just a factor. To me, it hits more randomly. . . . Maybe because I have more experience with cancer from this kind of background [she works for bio-pharmaceutical company]. We don't know. Scientists don't know why people get cancer. I mean, they know that people who smoke are more apt to get lung cancer. My dad died from bladder cancer. He was a printer. . . . so there are environmental things. Do I think something particularly environmental caused mine? I know people go crazy and go to organic foods and they go to, you know, all, maybe, overboard. . . I don't want to be judgmental. . . . I'm not going that route because. . . I guess I don't want to dwell on it. It's there. I got it—wherever it came from. It's gone. I don't want it to come back.

—Sally, 61, white, stage II. She is three months out of treatment. She had a lumpectomy, chemotherapy and radiation.

Thinking that cancer hits randomly or that anyone can get cancer might help these survivors worry less about why they in particular got cancer. It becomes something that just happens. The cause becomes irrelevant. But most survivors retain some uncertainty in their narratives:

We don't know what my triggering agent was for cancer. Statistically speaking, I should not have had cancer. No breast cancer history. Not overweight. Nursed three kids. Never smoked. [My doctor] Doesn't know where it came from. There are people who never smoke and get lung cancer. We don't know. It's either not there [now] or its dormant—there's no way of knowing.

—Rosemarie, 59, white, stage I. She has been out of treatment for five years. She had a lumpectomy and radiation.

I was pretty healthy before cancer. I really used to question “why me?” because I have two other sisters and none of them had it. Why am I the one in the family?

—Yvonne, 54, African American, stage II. She is five years out of treatment. She had a lumpectomy, chemotherapy and radiation.

There is no explanation. Which is a difficult thing to live with because if you don’t know what causes it, you don’t really know what to do to prevent it.

—Gillian, 47, white, stage II. She has been out of treatment for five months. She had a lumpectomy, chemotherapy, mastectomy, and reconstruction.

For this group, uncertainty led not to lifestyles changes aimed at prevention or health maintenance, but to a closing of the ranks. If there is no rhyme or reason in getting cancer, and if survivors were healthy before getting cancer, they do usually not ramp up their healthy lifestyle to prevent new cancers or recurrences (a few actually noticed a decrease in their usual health-conscious activities). Instead of focusing on lifestyle changes, they focus “living more fully” than they did before. Many in this group withdrew from the outside world, curtailed their extracurricular activities and responsibilities, and created a rich world with an intimate few.

These survivors expressed feeling less in control over cancer, which may be why they focused so intently on making every moment matter.

Lacking control may not be a negative in all circumstances. The downside to feeling that cancer is controllable through lifestyle is then feeling responsible


for cancer: the pressure of maintaining cancer-free status rests on one's continued vigilance, and if cancer recurs, then fault can also be assigned (Bell 2010, 2012; Broom and Tovey 2008; Sinding and Gray 2005). For example, Vanessa, 44, maintained what I consider to be an extremely "clean" diet before cancer. But she attributed her cancer to times when she had "slipped," redoubling her efforts after cancer. If there is no cause, and nothing one can do about cancer, the fault lies outside the individual: while there may not be any action steps to take, besides staying reasonably "healthy," this attitude removes some of the feelings of personal responsibility involved in other survivors' approaches.

I found that each type of cause afforded survivors different levels of control and feelings of certainty in relation to their cancer. I theorize these in Figure 1, below. Survivors who fell into the "Disease frame/not relevant" (1) category exerted a moderate level of control and high certainty over their cancer: the cause of their cancer simply was not relevant to them as they framed cancer as a disease that one simply gets. They did not worry themselves over why or how they got cancer. They felt that their doctors were experts and that it was their job to fight cancer. Most felt they had vanquished their cancer. While they had no control over getting cancer, they felt they had control over beating cancer. They did not need to change their lifestyle or adapt their health regimen after cancer, other than taking reasonably good care of themselves, because they had "kicked cancer's butt." Those who identified environmental causes (2) and genetic causes (3) for their cancer had high


levels of certainty, but varied in control; those who believed in environmental causes had actions they could take to make their lives healthier, cleaner, less toxic. This enabled them to feel some control over their cancer, but it also created anxiety as they could not let their health routines and lifestyle changes lapse. Those who felt their cancer had genetic roots had no control over the genetic mutations or family history of cancer, although many of these survivors took extensive steps to rid their body of tissues susceptible to cancer. Their control came by way of mastectomies, oophorectomies, and hormone therapies, if appropriate. Survivors who had complex explanations for multiple causes (4) had varying levels of control and certainty: they might not know how factors interact to cause cancer, although they suspect they do; and they certainly cannot control all the interacting factors. They mostly fell in moderate range for control and certainty as they took steps to address what they felt they could control and prevent, which were mostly lifestyle changes. Those without a theory of causality, or who think they cannot know cancer's cause because doctors do not know (5), expressed more uncertainty than other groups as the lack of knowledge bothered them. They also did not know what they could do to cure or prevent cancer since they did not know how they got it. They had low certainty and low control.

Figure 1: Qualities of cancer causality

Level of certainty afforded by theory of causality	Level of control afforded by theory of causality		
		Low	High
	Low	Unknown cause/ No theory (5)	(2) Food Stress Lifestyle
		(4) Multiple	factors Chemicals Environment
	High	(3) Family history/ genetics	(1) Disease frame/ Not relevant
		Internalize – “in/of me”	Externalize – “not me”



- Not “cured”
- Always a risk of recurrence



- Majority said “cured”
- Low risk of recurrence

I categorized these causal explanations by how survivors were able to use them and where they situated the agents of control. For instance, although those who place cancer within a disease frame (1) locate the source of cancer within the body, they do not feel they need to change their body’s internal landscape—they did not talk about their immune system or PH levels, for

instance. Instead, they talked about leaving medical decisions to their doctors, which takes some of the responsibility out of their hands. They fight cancer by suffering through treatments. Cancer is a disease: it is something attacking them; cancer is not them. Likewise, thinking the cause is environmental (2) displaces the concern from the body to the world outside the body. The cause and mechanism for fighting cancer are both outside the body. Alternately, if cancer is caused by genetics (3) or factors unknown (5), these causes tend to be located in the body. Survivors did not externalize cancer—cancer was something produced by their bodies. Externalizing sources of cancer enabled survivors to think of cancer as “not me” whereas internalizing sources of cancer made survivors think more of their cancer as part of them, “me.”

How survivors live life with, after, or beyond cancer is related to what cause survivors attributed to cancer. Survivors used these causes to help them assess the nature and chronicity of their disease. Broadly, those who fell on the “externalize” side were more likely to claim that they are “cured” and less likely to be worried about recurrence; they considered their risk to be low. Those who fell on the “internalize” side were less willing to say they are “cured” and more likely to think there is a good chance their cancer will recur. Both tend to think that their cancer is not chronic, which I discuss below; but there is a distinction in how survivors think about recurrence and cure based on how they think about its cause. This distinction involves perceptions of control and certainty: with externalizing comes more control, more willingness to say “cure,” and less worry or perception of risk of recurrence;

with internalizing comes less control, fewer perceptions of cure, and more acceptance of recurrence risk. These findings complement social psychological research that find active problem solving techniques have better mental health results than emotion-focused coping (Lazarus and Folkman 1984; Carver et al. 1989; Thoits 1995; Mirowsky and Ross 2003; Lawrence et. al 2006) and Miller's (1986) research on monitors and blunders. However, here, survivors who are actively engaged in making lifestyle changes fair well because they have something to do. While this keeps them thinking about cancer to some degree, which may make them anxious, it also gives them a way to manage their anxiety and feel in control. Those who determine a cause and pose a solution feel in control, for the time being. Survivors who just "move on," like those who use the "Disease Frame," rely on other cognitive mechanisms to neutralize threats of cancer, while those with uncertainty about cancer's causes, who have "No Theory" or "don't know," find little comfort in preventive-type activities, preferring meaning making activities involving self and living life to the fullest (they may engage in lifestyle changes to "be on the safe side," but they do not place stock in them as actual preventative practices).

Am I Cured?

The word "cure" is somewhat taboo in cancer circles: although some survivors told me their doctors told them they were cured, and some considered themselves to be cured, most doctors and patients were more comfortable with ambiguous language: "cancer-free," "no evidence of disease," "in remission,"

“gone, but with possibility of recurrence.” This language connotes a current state of wellness but leaves open the possibility for future sickness. This understanding of cancer—as uncertain, ambiguous, unpredictable—was understandably the most upsetting aspect of cancer for most survivors. This language could trap survivors in a strange liminal space (Little et. al 2006), or within permanent patient status (Frank 2009), but survivors have strategies for navigating these boundaries. For one, they poise cancer follow-up care as “preventative,” which means they do not consider themselves “sick” or as “cancer patients” but can instead think of themselves as vigilant participants in their wellness. Although this vigilance comes with perceiving oneself through a medicalized lens, they do not necessarily see themselves as “pre-patients” or even permanent patients waiting for a recurrence: they view themselves as active participants in managing their own health. Survivors are able to live with ambiguity to differing degrees: most do not consider their cancers to be chronic conditions, which I discuss below, but they do not feel cured, either. And some feel cured—at least for the time being.

As shown in Table 2, below, the majority of survivors said they were not cured, across stages, although half of these survivors preferred to use another term or phrase, like “no evidence of disease,” or “it’s gone.” One might think survivors of stage 0 or I would be the most likely to think they are cured.

Table 2: Survivors belief about whether their cancer is cured or not																
	Stage					Time since treatment						Treatment type				
“Cured”	0	I	II	III	total	0	1	2	3	4	total	C	M	B	N	total
Yes	4	9	10	3	27	4	11	6	3	2	27	7	5	8	6	27
No [Of these, those who use other terms]	8	10	18	5	40	8	16	6	2	9	40	12	5	17	7	40
	4	5	8	3	20	4	7	4	2	3	20	6	2	8	4	20
Don't know	0	1	1	0	2	0	1	1	0	0	2	1	0	0	1	2
n=	12	20	29	8	69	12	28	13	5	11	69	20	10	25	14	69

N=67; I excluded two participants because of incomplete information.

Time since treatment: 0=less than 1 yr.; 1=1-3 years; 2=4-6 years; 3=7-10 years; 4=10+ years.

Treatment type: C=chemotherapy; M=mastectomy; B=both; N=neither.

Stage 0 survivors have non-invasive cancer, meaning their cancer is still trapped within the ducts or lobes. Their cancer is most likely curable, but they have a high risk for recurrence, which prevents many of them from thinking they are cured. Stage 0 is also now thought of as “pre-cancer,” so a few of these survivors did not think they even had enough cancer to be in a position to be cured; instead they were in a chronic state of being at risk—which makes them not cured as they are waiting for cancer to occur.

In stage I, there was more of an equal division between those who thought they were cured and those who did not, probably because of mixed messages given to survivors about early detection and chronic disease. Survivors of stage I may think that they got their cancer diagnosed “early” and therefore “nipped it in the bud,” as one survivor said, but they are also aware that once you have cancer, your chances for a new cancer become higher.

Stage II and Stage III are split in terms of cured/not cured, although many in the “not cured” group use other terminology: they do not think in these dichotomous terms, and use techniques for maintaining that they are both not cure but not chronic, which I discuss below.

Interestingly, against what conventional wisdom might imply, survivors who had the most intensive treatment, those who had both mastectomy and chemotherapy, had the highest percentage of survivors who did not think they were cured amongst all treatment configurations—either because these survivors had more aggressive tumors requiring more aggressive treatment or because these survivors were more anxious and wanted more aggressive treatment. Studies show that prognosis following a mastectomy and lumpectomy are the same, but many survivors feel more reassured if they have the most aggressive treatment possible.

Also, one might also think that the more time since diagnosis, the more survivors would begin to trust they are cured. However, survivors close to 10 years out of treatment have usually seen other survivors have recurrences, if they have not experienced recurrence themselves. Those right out of treatment do not feel cured because they have not recovered emotionally or physically from treatment; many are still finishing their breast reconstruction and are taking hormonal therapies, so cancer is still fresh in their minds. Instead, we see that survivors are more likely to think they are cured in the “middle” of the cancer trajectory—this might be a safe zone, and many survivors cling to the “five-year mark” as a sign they will not recur.

Survivors with a family history are also unlikely to think their cancer is cured or that cancer is curable. But these factors do not explain why other survivors like them do indeed maintain that they are cured. Looking a little deeper into why people think they are cured or not—and how this differs from their thinking about chronicity of disease—can help explain some of the nuances involved in survivors' cognitions of cancer and the strategies they use for moving on with or after cancer. I begin with survivors who do not think they are cured, as they represent the majority.

No—I'm not cured

As I did not interview early stage survivors until after they completed their active cancer treatment, all of these survivors could be considered cancer-free, to have no evidence of disease, to be in remission, or to be cured. The terms have slightly different meanings, to which survivors are attuned. Those who did not consider themselves cured might embrace one of these other terms, but, overall, they felt cancer was not a curable disease, even if it might not be chronic. Because of the chance of recurrence, even if low in their particular case, they felt they could not in good faith call themselves cured. Some survivors had doctors who expressed to them that cancer was not a disease that could be cured, which led them to think this way, but others simply believed that cancer cells could always be present in the body—and that doctors had no way of knowing with current medical technology. Survivors discussed the uncertainty embedded within cancer terminology and within current state of

medical knowledge about cancer, as well as their risk of recurrence, as reasons they could never call themselves cured.

No good word for it

Heather describes her feelings about all cancer terminology leaving something to be desired. None of the words quite fit; they all connote a state she does not want to think about:

Me: What do you think about words like “in remission,” “no evidence of disease,” “cure?”

Heather: “Cure,” I would be afraid to use, because—[chuckling] it’s a little magical thinking, but I feel like it’s tempting fate. But I don’t even like those words—“remission”—because it makes you feel like it’s definitely going to come back. You just don’t know when. So, “remission” is weird. I guess “no evidence of disease” is probably better. But then, there are also people who are stage IV that end up having no evidence of disease, but they’re still stage IV. Right? Like, “no evidence of disease” just means, like, the test didn’t necessarily pick it up. It doesn’t mean it’s not there. I don’t even—I don’t know if there’s a good word for it.

Me: Because you're doing follow-up. So, you're checking for recurrence. But yet—you don’t feel like you have it now?

Heather: I don’t feel like—Yeah, exactly. And [lowering voice] I don’t feel like there’s ever going to be a point in time, for me, where I think: Oh, it definitely won’t come back, ever, until like, I’m 85 and I die of something else. [chuckling] . . . And nobody’s ever said that. So, I guess it’s sort of like, tentatively, cautiously going [chuckling] under the assumption that it’s never going to come back. But I also know, there’s that little chance that, sure, it could. But it’s also that little chance of like, you know, the neighbor down the street, who’s never had something, having something that kills them. So, I don’t know. I think if I look at other people who have had cancer in the past, I would say: Oh, yeah. That person’s cured. It’s been 10 years. But I wouldn’t think that about myself. And I could guarantee that Dr. X would never say, “You’re cured.”

—Heather, 45, white, stage III. She has been out of treatment for five years. She had a lumpectomy, chemotherapy, mastectomy, radiation, and oophorectomy.

Heather, five years out, is still cautious about feeling too safe and secure in her wellness. Her doctor has the reputation of being a straight shooter, emotionally detached but effective. She knows her doctor would never guarantee her anything; she presents her with risk statistics, but no definitive answers.

Heather has come to accept this, even though she wishes her doctor would tell her different news. Heather thinks “you just don’t know” what is going to happen in the future, but this stance prevents her from thinking she’s cured, too. The other terms do not seem right, for other reasons. And while some survivors use time to help them think they are cured, Heather rejects this technique, as well: echoing a common sentiment, she says she won’t be cured until she dies of something else. She chooses to move tentatively forward, “under the assumption that it’s never going to come back” while acknowledging that there is a possibility it might.

Kara also cannot use “cure” because of the possibility of recurrence, no matter how slim. Statistically, her risk will never be zero; no woman’s risk is ever zero because simply being a woman is a risk factor for breast cancer. As Heather said, the only time she will have zero risk is when she’s dead. This fact makes being permanently cured always an impossibility, despite treatments, time passed, or type of cancer:

It’s hard to use that word. Because there’s these percentages. You know, it’s all about percentages. [Putting on her doctor voice:] “Well, the Oncotype test says that you have this percent chance to have a recurrence. But if we do these drugs, then the chance goes from here to there and—. You know? But it’s never zero.

—Kara, 37, white, stage I. She has been out of treatment for one year. She had a lumpectomy, chemotherapy, bilateral mastectomy, reconstruction.

Oncotype testing tells survivors their possibility of recurrence, and survivors interpret these results in different ways. As I mentioned in an earlier chapter, Jade thought her “20% chance” of recurrence means she is cured, whereas Kara thinks her eight per cent chance is high. Even though these statistics are personalized based on readings of their tumor type compared to others who have had a similar tumor, they can only present potential risks; they are not predictions. Since these statistics will never be zero, survivors have to determine how they feel and think about the statistics for themselves. Jade decided to be cured; Kara uses this statistic to support her claim that one is never “cured.”

Sally also has problems with the word “cure,” even though she does not fear recurrence. She thinks her cancer is “gone,” but she does not feel “cured”:

Sally: I think for me, personally, I think my surgeon got everything. For me, the chemo and radiation were kind of an insurance policy. He got everything, but just in case— [nervous chuckle] —we’re going to take out this little insurance and make sure that anything that might possibly have slipped through the cracks someplace into my body is now gone. That’s kind of where I came from.

Me: Do you feel that the cancer is gone, that they—?

Sally: I feel it was gone—

Me: After surgery?

Sally: Yeah, December 28th, I think it was gone.

Me: What do you think about words like, cured and remission and that sort of stuff? Do you feel like, “Okay. I’m cured now”?

Sally: I do not feel cured. Well, no. I would never call it “cured,” I think. I think I would say, “I have a history of breast cancer.”

—Sally, 61, white, stage II. She is three months out of treatment. She had a lumpectomy, chemotherapy and radiation.

For Sally, even though she thinks the cancer has been removed through surgery, and any other cells that might have been present were killed by the

chemo and radiation, she still does not “feel” cured. It is safer to avoid that word; for her, “a history of breast cancer” makes sense as past history shades current and future experiences. Cancer continues to influence her life, and have an impact on her health, even though it has been treated and is “gone.” The word “cure” does not carry future implications within it: to be cured is to not have any future repercussions or effects from the disease. Saying “cure” is like tempting fate.

There is no cure

Another group of survivors said they were not cured because, simply, “there is no cure”: there are preventative measures and treatments, but not cures. They thought of cure not as something given to treat a disease, but as something that would eradicate the disease altogether—like the Polio vaccine. They seemed to think about cancer in the abstract when talking about a cure, rather than thinking about individual cases: human beings as a species will not be rid of cancer until there is a cure to wipe out cancer. One survivor even said that as long as others could still get cancer, she would not consider herself cured.

Another survivor said being cured felt too passive, considering the fight she just enacted and all the treatments she went through. A few people remarked that they did not think there was any incentive or motivation for the medical community to “discover” a cure, commenting on the cost of chemotherapy and other drugs. But, mostly, these survivors implied that treatments were not cures because cancer is too complicated, and medical knowledge too incomplete, for there to be a “cure” for cancer.

You can control it, not cure it. You can get new drugs for it. How can you cure something that has not—we haven't been able to cure the common cold because that virus keeps mutating. Here, you don't even know what all are the contributing factors. You can manage it better. You can catch it early. I read somewhere that the only time you can be considered to be cured of cancer is when you die of other causes.

—Rachel, 37, Indian, two stage II occurrences. She is two and half years out of treatment. She had a lumpectomy, chemotherapy, radiation, bilateral mastectomy, and reconstruction.

The radiation oncologist said, “You should think of yourself as cured.” I said to him, “Well, I hope God's reading the same report you are.” [laughter] Because I don't really think we have the power to cure cancer. I think it's too complex. It's affected by too many things that we know or we don't know. You can throw all kinds of drugs at it. . . . But cancer is kind of sneaky, and the older you get, the longer you live, the better your chances are of having cancer, because your body malfunctions, like a machine. Something goes awry. Even if you get your oil changed regularly, at some point, your motor's gonna die.

—Jane, 65, survivor of stage II. She is one year out of treatment after a recurrence. She has had a mastectomy, chemotherapy, and radiation.

Gail: No, they don't have a cure. There is no cure—no easy way that, oh, you're never going to get it again. You know? There is no vaccination that's going to save you. And you can get a different type of cancer, too.

Me: So, you feel that the cancer that you've had—do you feel that that particular one is in the past, and you can move on?

Gail: Well, I still have one more breast. So, you know, I could still get it on the other side.

— Gail, 58, white, stage III. She has been out of treatment for 10 years. She had chemotherapy and mastectomy.

Because of its lack of cure, cancer takes on a godly type of power: it seems omniscient and unavoidable, outwitting the human body and modern medicine. Since we do not know all the factors involved, a cure is impossible.

Against this backdrop of complexity, individual human beings cannot consider themselves cured.

You can never know

As Heather says, above, “I think you just don’t know.” Medical knowledge is limited, and there is no way to predict the future with certainty. Survivors expressed this state of uncertainty the most in reasoning why they could not consider themselves cured. “Cured” expresses a finality with which risk statistics cannot be reconciled. Any possibility or random occurrence can undermine confidence in cure if one defines being cured as a permanent state:

And my primary and the oncologist say I might have a cancer cell that moved over here, moved over there. You know, you don’t know. You don’t know. So, where is it now?

—Dolores, 68, African American, stage I. She has been out of treatment for three years. She had a lumpectomy, chemotherapy and radiation.

Dr. T said that they no longer talk about cure, about cancer. They talk about remission. . . . The remission could last forever. But the possibility of recurrence is there, either of the breast cancer or something else. We don’t know what triggered—what was the triggering agent for my breast cancer. Statistically speaking, I should not have had cancer. . . .

—Rosemarie, 59, white, stage I. She has been out of treatment for five years. She had a lumpectomy and radiation.

Well, they removed it, but that doesn’t mean there’s not some cell lurking around somewhere. You can never truly be rid of it.

—Rachel, 37, Indian, two stage II occurrences. She is two and half years out of treatment. She had a lumpectomy, chemotherapy, radiation, bilateral mastectomy, and reconstruction.

Instead of thinking in a more fluid way about cancer, these survivors actually embrace standard binary thinking about cure: if one is either cured or not, these survivors have to choose “not” because they can describe plausible and probable scenarios that undermine the purity and finality of the cure state.

Survivors who think they are permanently not cured because “you never know” may be more realistic in their thinking—it’s uncertain if they are actually more prepared for the worst to happen (Cerulo 2006)—but cognitively, they also enable the uncertainty to be present in their minds.

While thought processes about cancer have no impact on what the disease does or does not do, how people think about cancer shapes how they live their lives.

Yes—I am cured

Survivors gave two dominant explanations for thinking they were cured: they trusted that their medical treatments had been complete and successful, and they chose to think of themselves as cured. For some of these survivors, their stage or type of cancer helped them think they were cured. DCIS survivors, for instance, are stage 0, now considered a pre-cancer, and many of these survivors felt cured because their cancer was not invasive. Many stage I survivors also thought they were cured because “they got it early.” But some survivors consciously chose to think of themselves as cured because they felt more control over their cancer in this way. They thought they would lead healthier and better lives by choosing to think they were cured.

I choose to think I am cured

These survivors seemed to be aware they were tricking themselves to some degree. Most were not advocating positive thinking in the way that the positivity movement does; they did not think that thinking positively would make them healthier and that thinking “negatively” would feed their cancer—a few did come close to saying this—but they mostly thought that thinking positively would put them in a better frame of mind for making the most out of their lives. They were not saying that they could will good health through their positive thinking. They knew that cancer would do whatever it wanted to do, but they could choose how much power they gave cancer over their lives by how much and in what ways they thought about it. At the same time, by saying they “believe” their cancer is cured, rather than that they “know” their cancer is cured, they reveal the space between perception and reality where uncertainty lies.

So, it’s—to me, cured is a state of mind. So if you consider yourself cancer free, you are. Even if you’re not. Because there are people I know of—I know of one case—Somebody died, and they did an autopsy on him and found that he was riddled with cancer. But he was never sick. He died, they thought, of natural causes. And the reason they did the autopsy was because he hadn’t been sick, and they wanted to know why he died. Well, the autopsy really didn’t tell why he died. He was riddled with cancer. He had all kinds of cancer. But he never looked it. He didn’t act it. He didn’t show it. There were no symptoms.

—Doris, 66, white, stage 0. She is nine years out of treatment. She had a lumpectomy.

Morgan: I don’t feel like I have breast cancer anymore. You know, based on what Dr. X said—they got it all. But the chemo and the radiation is just to make sure.

Me: How about that word, cured? Do you think it's cured—that your cancer is cured?

Morgan: Well, some days I feel that I'm cured. I usually try to say, "I'm cancer free." But I've heard—[chuckling] non-cancer patients say—Like, I have a friend. "I don't see how you can say that you're cancer free! What does the doctor know?" "Well, what do you know?"

Me: [laughter]

Morgan: You know? I chose to hang my hat on, "I'm cancer free." I'm not hanging it on, that I'm not cured.

—Morgan, age 58, African American, and a survivor of stage IIIB breast cancer. She had a lumpectomy, chemotherapy and radiation. She has been out of treatment for three years.

These survivors are bending the rules a bit by asserting their own definitions of cure: their beliefs are just as important as their doctors' statistics and opinions. Their beliefs did rest upon their doctors' reports, of course, but whereas doctors rarely say "cured," they felt being cured was within their jurisdiction to claim. The alternative, believing they were not cured, might be too anxiety producing for this group to maintain. This strategy provided more cognitive security for this group.

Trust in doctors and procedures

Many survivors felt that their cancer was "cured" if it was adequately treated by their doctors. As I discussed previously, the early detection campaign plays a huge role in convincing survivors that they will be OK. Surgery, as a medical specialty, promotes this feeling: tumors are excised from the body with "clear margins." Lymph nodes are biopsied for cancer cells. If these areas

are “clean,” cancer should not have spread beyond the primary cancer site. Blood work for cancer markers also conveys feelings of security. Full body PET scans show tumor growth. Survivors feel that after these tests, they simply need to remain “vigilant” to prevent recurrence. But vigilance does not prevent cancer; it makes cancer noticeable. Getting screened for cancer at regular intervals and paying attention to symptoms in the body can only help reveal cancer growth. Many people confuse mammography and other tests with prevention when these tests do nothing to prevent cancer. Similarly, cancer surgery, chemotherapy, and radiation treat cancer present in the body at a particular point in time. Getting cancer “early” is helpful in that the cancer has not spread, and is thus more manageable; but early detection does not prevent recurrence or even metastasis as these processes are more related to the tumor type than when it was detected.

Oh—I’m “cured.” I’ll tell you—I love the surgeon I had, and he said to me, “Okay. You don’t have cancer anymore. You’re cured.” He said that to me after he did my lumpectomy. He said, “Your lymph nodes were not affected. So we know this was the only place you had it. So, you don’t need anything after this.” But that was just his opinion. Then you go see an oncologist. Bless their hearts. They’re chemists. So what do they want to give you? Drugs. You know? That’s what they believe in. So—.

—Liz, 69, white, survivor of stage II breast cancer. She had a lumpectomy and radiation. She is six years out of treatment.

Liz was more skeptical of the medical establishment than most. She understood that specialists’ outlooks are shaped by their professional training (see Smith and Hemler 2013). Most survivors glossed over this point and were simply grateful to be alive. Most survivors were also happy to believe their

surgeons, as they often provided better news than their oncologists. Clara, for instance, believes that surgery got all of her cancer. The metaphor “getting to the root of the problem” shapes her thinking about cancer: if there is a “root” to cancer, and it is removed, then, like a weed, it will not grow again. But part of her belief about being cured is just that, a belief:

Oh, I believe, in my heart of hearts, in my particular case, I believe that it is not chronic. I believe that it’s contained. I believe that I am cured. And I’m not expecting a reoccurrence. Okay? I’m not expecting that. I think this is just something that happened, and they got to the root of it, and that’s it. I believe that sincerely.

—Clara, 52 years old, African American, stage II. She has been out of treatment for almost one year. She had a bilateral mastectomy and chemotherapy.

Clara uses other strategies I’ve discussed—she chooses to believe she is cured, she thinks her cancer was a random occurrence without reason—but her belief in being cured hinges on her trust in surgery: “they got to the root of it, and that’s it.” If that is true, then, logically, she should have nothing to fear. It makes sense to think that cancer can be excised from the body, and surgeons support this belief. Other models for thinking about cancer—particularly that cancer is an inflammatory disease or related to immune deficiency or a systemic disease—do not support this belief. Surgery treats cancer as a local problem. This belief also encourages survivors to trust mastectomy more than lumpectomy, even though results are not significantly different between procedures. Mastectomy removes almost all breast tissue (breast cancer can still grow on the chest wall) so that many survivors feel more secure with that procedure.

Yes. In my mind, I try to convince myself that the tumor is gone. My breast [tissue is gone]. I no longer need to go for mammography It's possible that the cancer [could] come back. But the fact that I scooped everything out—all the scooping—it is very unlikely that the cancer will come back. And also, to make sure, I'm taking tamoxifen. That is to deter the female estrogen—that they feel that breast cancer is caused by estrogen—too much of the estrogen is no good. . . . So, by me taking this anti-estrogen, which is tamoxifen, it stops the cancer from coming back.

—Jade, 50, Asian, stage II. She has been out of treatment for almost two years. She had a bilateral mastectomy and is currently undergoing Trans-flap reconstructive surgery.

Jade feels secure in that “all the scooping” makes her an unlikely candidate for recurrence. Taking tamoxifen is also a reassurance for her. The benefits of these treatments outweigh the side effects for her. She feels secure that she has removed the sources of cancer from her body. She has put all of her trust in these procedures and in her doctors, as others, like Bonny, have done:

Absolutely [I feel cured]. Yet. I've decided that. You know? So, absolutely. I had the best treatment that they have. Because you know—I've researched all of that. . . . Once I found out what it was that I was going to have to do, then I decided to do it. I went to the best people I could go. I went to the best place, where I felt I could be most comfortable, where I could be private and not have to talk about it and give it any life, so I could be healed.

—Bonnie, 64, African American, stage I. She has been out of treatment for nine years. She had a lumpectomy, chemotherapy and radiation.

Doing extensive research ahead of time worked to help some survivors feel secure with their decisions. (Some avoided research because it was more anxiety producing for them.) For Bonnie and others, knowing they were getting the “best” was important to their ability to feel cured (see Hudson et. al 2012). Certainly all doctors aim to be the best, as do all cancer facilities. So, getting “the best” is not necessarily related to outcome. Bonnie did not go to

an NCI-designated cancer center, for instance. But she went to the one in which she felt most comfortable and in which she had the most knowledge—Bonnie is a nurse who worked at this facility and knew the doctors. What is interesting about Bonnie’s statement, shared by other survivors, is their comfort-level with the medical decisions they made or let their doctors make for them. If they felt they had made the right choice, they did make the right choice. And this helped them to feel secure moving forward.

For now, I’m cured... for now, I’m cancer-free

One main theme that emerged despite cancer stage, type of treatment, or time since treatment, and which was present among both those who believed they were cured and those who thought they were not cured but cancer-free, is a tendency to truncate or suspend time: they concentrated on their health status at the moment so that they could save worry for a future date, hopefully one which never occurs. This allows survivors to feel cancer-free for now, which meant that they could acknowledge that cancer can recur, but also not live each day with anxiety about recurrence. Some survivors dealt with ambiguity better than others, so that some will say “cured” whereas others say “cancer-free,” but both are using the same technique of stretching and shrinking time or making each cancer a discrete occurrence rather than a chronic disease. Using these techniques, an individual cancer can be cured or eliminated even if the person ultimately cannot be cured. This type of maneuvering shows creativity, as they have determined that their cancer status does not need to be

permanent; this helps them position themselves within the realm of health, rather than existing in a quasi-cancer, liminal state:

Me: And do you feel that your cancer's cured?

Phyllis: Right now, I do. I think, you know, I'm cancer free. Knock on wood. [knocking] [laughter] So I think people can be cured of it, but I know it can also come back. So—that's what I'm afraid of, that I keep thinking about.

Me: Um-hmm. Yeah. Because there are all these words like remission or—No evidence of cancer in your body or you know, cure, or remission—And I find some of this confusing, just because they seem contradictory. You know, how can it be cured, but also come back? So, how do you think about those things?

Phyllis: I think, it's more like, you're in the moment. So in the moment, I'm cancer free. However, a year or two from now, I might not be. Or ten years from now. And that's what I am saying, like—And in remission—like, you know, being cancer free, and then when it comes back, then it's like, then you have the cancer again. So, I think it's kind of like a step-by-step thing. You're just, in the moment—"in the moment" is that terminology.

—Phyllis, 52, white, stage II. She is six months out of treatment. She had a mastectomy and chemotherapy.

While Phyllis segments cancer by time—in the moment, she is cured—other survivors treated cancer as "incidents." This helped them not only position their cancers as discrete occurrences, but they could also use this strategy to enable them to feel cured—even if just for the moment:

I think that I'm cured. I think it's gone. But I think that the possibility is always there that it could return. You know, I'm not under any beliefs or anything that I could be and clear for the rest of my life from it. . . . Do the best you can, and you know, if it returns, cross that bridge when you get to it.

—Linda, 61, African American, stage I. She is two years out of treatment. She had a lumpectomy, chemotherapy and radiation.

I don't think that you are cured. I mean, I think that you are cured from that instance, and there is always a possibility of recurrence.

—Beatrice, 71, white, stage 0. She has been out of treatment for 14 years. She had a lumpectomy and radiation.

Peggy: And you know, I asked Dr. S. I said, "Okay. Now what?" I said, "You're saying that I'm "cured," that this one's not there. Nothing's showing up." I said, "Can I get another one?" He said, "Yeah." He said, "But not from that one."

Me: So, that cancer is cured? You think it is cured?

Peggy: Yeah. But, you know—And I said, "Does that mean I'll never get another breast cancer?" He said, "We're not saying that, because we don't know why these things happen. But yeah, you could get another one, but not from this breast cancer."

—Peggy, 66, white, stage IB. She is almost three years out of treatment. She had a lumpectomy, chemotherapy and radiation.

Stretching and shrinking time and carving out cancer into discrete occurrences may both employ the bracketing I discussed in the last chapter, but what is notable in this context is survivors' ability to use time to their advantage in these strategies. Time becomes critically important to survivors because their expiration date has been made clearer to them. Survivors describe how making moments matter is important to them now, important to imbuing their life with meaning. They apply a magnifying glass to time so that present moments become huge, thoughts about the future receding into the blurry background. Thinking about cancer as cured or cancer free in the moment relies on the same tactic: the present moment is expanded, taking up mental space normally reserved for thinking about the future (or the past). Survivors can be at peace for the moment, and they use the strategies discussed in the previous chapter

in order to keep these moments going. Many survivors commented that they would worry about recurrence if and when it happened. The present is protected from worry and anxiety, even if this means being psychologically ill prepared for illness-related quandaries in the future.

Survivors who think that they are cured for the moment are exhibiting more flexibility in their thinking, perhaps even bending the rules to their favor. They might be chastised for thinking positively at the expense of realism, but their creativity in redefining “cure” as something temporary enables them to think differently about cancer: they can be cured, and then not cured, and then cured again. Some survivors discussed not giving cancer any more power over their lives by thinking about it so much. I think what they were trying to tell me is that they had a choice in how to deal with anxiety from cancer, and thinking they were cured, or unlikely to have recurrence, is not willful ignorance or denial, but a cognitive strategy that enabled them to have more non-cancer time and space in their lives.

Is cancer chronic?

If cancer cannot be cured, then is it chronic? What makes an illness “chronic”? What does it mean to live with chronic illness? When I asked survivors if they thought their cancer was a chronic illness, most of them asked me what I meant. I asked them to define it, which left survivors wondering: Does it mean that cancer’s always there? Does it mean that it can come back? Cancer researchers and doctors describe all stages of cancer as chronic because those with a history of cancer are at increased risk not only of recurrence but also of

new cancers, because survivors are likely to experience other ailments as a result of their cancer and cancer treatment, and because they will most likely also experience late- and long-term effects from their treatment—including late-term recurrence. They propose survivors receive long-term if not life-long follow-up cancer care, which often includes five to ten years of a hormonal therapy or aromatase inhibitor in addition to scheduled screenings and tests for cancer, bone density, and heart and lung functioning. Survivors, though, do not often adhere to this definition of cancer as a chronic disease.

Within my sample, I analyzed who thought their cancer was a chronic condition, who felt cured, and what kind of consequences these cognitions had for the way they lived their lives (see Table 3, below). Strikingly, the majority of early stage cancer survivors, despite stage, time since treatment, and treatment type, did not think their cancer was not chronic. Almost all survivors of stages 0 did not think their cancer was a chronic condition, and the majority of survivors of every other stage concurred. A greater percentage of survivors less than a year and ten or more years out of active treatment thought their cancer *was* chronic as compared to those two to nine years from treatment, but even those two groups mostly thought their cancer was not chronic. Survivors may be fearful until year five—five is a big marker for some kinds of breast cancers—and survivors also start seeing friends recur after 10 or so years, which may explain the slight differences: survivors may give themselves a mental break from worry after year five, but then they start seeing late-term recurrences which reignite their own fears of recurrence.

In terms of treatment type, those who had both mastectomy and chemotherapy had more survivors who thought cancer was chronic than other treatment configurations, like lumpectomy and chemotherapy and radiation, or just lumpectomy and radiation, but within this group the majority, too, thought their cancer was not chronic. Those who had mastectomy and chemotherapy thought of cancer as chronic more than other groups, perhaps because these survivors either had more advanced cancers or were more anxious about cancer, as discussed in other trends. But the vast majority of each group said that their cancer was not chronic. One might think that the perceived seriousness of cancer would correlate to thinking it is a chronic illness, but this does not seem to be the case.

Table 3: Survivors' beliefs about whether their cancer is chronic or not

	Stage					Time since treatment						Treatment type				
Chronic	0	I	II	III	total	0	1	2	3	4	total	C	M	B	N	total
Yes	1	6	6	2	15	3	7	2	0	3	15	3	2	8	2	15
No	11	13	19	5	48	6	20	11	4	7	48	15	7	14	12	48
Don't know	0	1	4	1	6	3	1	0	1	1	6	2	1	3	0	6
n=	12	20	29	8	69	12	28	13	5	11	69	20	10	25	14	69
N=67; I excluded two participants because of incomplete information. Time since treatment: 0=less than 1 yr.; 1=1-3 years; 2=4-6 years; 3=7-10 years; 4=10+ years. Treatment type: C=chemotherapy; M=mastectomy; B=both; N=neither.																

No—my cancer is not chronic

Almost all survivors said that they could never say “cured,” which I discussed above, but they nonetheless felt that their cancer was not or would not be chronic, either. They felt cancer was done, behind them, that they got it,

that they were cancer-free—and, although most acknowledged “there’s always a chance” of recurrence, most of these survivors also did not “worry” about it or “dwell on it” or even think they had a high chance of recurrence. They experience the effects of cancer treatments, the risk of recurrence, and certainly the doctors’ visits as chronic, but they disconnect these consequences from the cancer itself. Cancer is interesting in this regard. When caught early, hardly anyone has sickness or pain from cancer; many do not even feel their own tumors. Cancer is invisible to them: most survivors were told they had cancer after a routine mammogram. And then they become sick, due to the power of the medications and treatments. Survivors, therefore, describe the cancer experience as chronic or the effects of medications as chronic, but not the disease. Looking closer at these survivors, I found several patterns in their thinking about cancer as not chronic, which helped them to position themselves as “safe,” at least for the time being.

Splitting the chronic experience from the discrete disease

Early-stage survivors largely did not think about their cancer as chronic, because, to them, chronic means continual or continuous. Their cancer had been treated; many felt their cancer was “gone” and that they no longer had cancer. Furthermore, they separated the disease from any related side effects or long-terms effects they were having, whereas the medical community does not. Only a few survivors introduced the increased risk of new cancers as part of their history of having had cancer. Separating the “cancer experience” from the disease of cancer, they felt the experience of cancer is chronic, but not the

cancer itself. This enabled them to recategorize the disease and use other terminology to explain their health status:

When you say, “chronic illness,” I think of something that you’re constantly dealing with on an almost-daily basis. I don’t think of it like that, but I feel like it’s sort of like this gray cloud that is sort of always there. You’ve always got to be aware of it. You can’t just let your guard down. But it’s not like I have to actively do something to fight it every single day.

—Margaret, 50, stage II, one year out of treatment: lumpectomy and chemotherapy.

Melissa: See, to me, a chronic illness is something that you’re constantly maintaining or recovering from, or trying to balance and work into the rest of your life. . . . It’s something you will probably never recover from, and most likely, it’s the thing that will kill you. . . . Breast cancer, luckily, happens to be a cancer that they can remove and take care of and fix. So, I don’t really look at it as a chronic illness. I’m sure my friends and family probably look at it [chuckling] as a chronic illness. You know—they don’t like me to lift things anymore. They don’t like me to do things anymore. So, I guess, in that respect, it could be considered—but I don’t. By definition, I don’t view it as a chronic illness, only because it’s usually, hopefully, something that they remove from your body and you are treated for, and then it’s gone.

Me: What about the experience? Having had—

Melissa: The experience is chronic. That’s forever and ever.

—Melissa, 42, white, stage II. She has been out of treatment for six years. She had a mastectomy, chemotherapy and targeted therapy.

I was having like, a hard time breathing. I had this constant chest congestion. And it just wasn’t going away. . . . I have some left lung restrictive disease due to the chemo and the radiation, in addition to longstanding asthma that went untreated. . . . So, every day is a daily reminder. I won’t say that I have chronic breast cancer. But I have chronic effects from the breast cancer.

—Morgan, age 58, African American, stage IIIB. She has been out of treatment for three years. She had a lumpectomy, chemotherapy and radiation.

These survivors share the same sentiments: chronic means active engagement on a daily basis, or something that happens repeatedly, perhaps in short intervals. They felt cancer could be a “gray cloud,” and they felt effects were “daily reminders,” but the cancer itself was “over and done with.” Survivors could separate the experience and the disease; they maintained a new bodily awareness and consciousness of the disease while at the same time depicting the disease as gone. They are not waiting for recurrence, and do not feel that the possibility of recurrence places them in a “pre-sick” category. Even the effects of cancer do not necessarily mark them as “sick” because they view these as results of the treatment, problems they have to manage, but not illnesses that originated in their bodies.

Chronic versus discrete incidents

Most survivors said there is always a chance for recurrence, even if they thought their risk was low or unlikely. Often they acknowledged in the abstract that cancer could always recur while saying that their own cancer was unlikely to. Sometimes this was supported by testing or information given to them by their doctors, or because they felt they had done all the necessary or possible treatments; but sometimes survivors just “felt” it was unlikely to recur. Regardless, survivors who perceived themselves as being free of cancer did not perceive that their recurrence risk or other health risks made their cancer chronic. Moreover, they did not experience dissonance in thinking they

could be both cancer-free and at risk for recurrence. Similar to how they truncated time in order to define themselves as cured in the moment, survivors also split cancer occurrences into distinct cases rather than lumping them into one experience, despite the logic of recurrence:

Marissa: I think it can be chronic. I really do. If the surgical involvement has not been purported as to be complete. Mine had a beginning—identification—a middle—surgery—and an end—which would be the follow-up with the radiation. And now. That's it. I don't feel it's chronic. . . . Well, once it's done, it's done. It's kind of like, once you have your tooth pulled, it's pulled. It's gone. . . .

Me: Is cancer something that you think about in daily life?

Marissa: No. Never. Unless I'm talking to you—And I talk about cancer not as—in and of me. It's what happened to me. It's like childbirth. It happened to me then, and if I were 40, I might have another child. Yes. Do I think I'm going to? No.

—Marissa, 71, white, survivor of stage I. She has been out of treatment for almost two years. She had a lumpectomy and radiation.

Marissa expresses an interesting perspective—and one commonly expressed by my participants—that if the cancer surgeon does not “get it all,” one cancer cell could escape and cause cancer to grow elsewhere in the body, leading to metastasis. Metastasis is chronic. However, she quickly distances herself from something like this happening to her: “when it's done, it's done.” For her, even if she needs another “tooth” pulled or has “another child,” these are different events: “It happened to me then,” but “I might have another.” She thinks having another cancer is unlikely, but it would be a separate entity.

Similarly, Beatrice splits her possible future recurrences into separate instances. While acknowledging that cancer in general is chronic, she nonetheless feels that hers is not:

Beatrice: Oh, I think we know it's chronic now. I mean, we know that it's something that a lot of people have to live with for years.

Me: And what about you? Do you feel like yours is chronic? Do you feel like it's something you have to manage now?

Beatrice: No. I mean, just until the next time, [laughter] you know, this happens. But I mean, I see it as incidental each time. But I think it's realistic to know that it repeats itself.

—Beatrice, 71, white, stage 0. She is 14 years out of treatment. She had a lumpectomy and radiation.

For Beatrice, knowing that cancer “repeats itself” is not contradictory to thinking cancer is not chronic because she can split recurrences into incidents rather than lumping them together into a chronic condition. She even goes one step further, saying “you are cured from that instance,” even though she does not think one is cured once and for all. Segmenting time into discrete moments enables her to redefine “cure” as something temporary, unlike common understandings of the term, which imply finality; she can also define each cancer incidence as discrete, not part of a chronic condition, even though she says that cancer is likely to “repeat itself.”

Making comparisons

As the quotes above illustrate, survivors often thought differently about cancer in the abstract than they did about their own specific cancers. Beyond the cognitive division survivors made between general cancer and specific cancers, survivors also contrasted their cancer to other chronic diseases, like diabetes or hypertension, or to other cancers or stages of cancer. Notably, they made comparisons that enabled them to delimit the boundaries of their cancer

and think favorably of their circumstances (see Taylor and Lobel 1989). Most said their cancer was not chronic but that cancer in general could be.

Consistent with positive asymmetry (Cerulo 2006), survivors thought others might be at risk, but not them. Although the medical community compares cancer to other chronic diseases in order to get survivors to think about their disease within a similar framework, early stage survivors largely rejected this frame. Especially for those familiar with other chronic diseases, their breast cancer did not fit within the same mold:

Oh, no. I don't think [cancer is a chronic disease]. I take the follow-up medication everyday—the femara, and now I've got the generic thing. And I go in [to see my oncologist] in August. So, you know, I don't feel it's a chronic thing. You could call it chronic, I guess, in that I'm taking medication. But it's supposed to be preventive. But I have diabetes, and that's chronic, and that's—So, I can differentiate between the two. Because I take medication for diabetes, and if I don't take my medication, I can see the results because I take my blood sugar every morning, and I can see if I eat something, you know, that spikes my sugar, I can see it. I mean—I call that chronic.

—Frannie, 75, African American, stage I. She is nine years out of treatment. She had a lumpectomy, chemotherapy and radiation.

I don't see my cancer being something that I have to manage per se. I would say the prevention, or the—not even the treatment—“Care” might be a good word. Because I don't feel like I'm being treated anymore for cancer. I just feel like now, I'm caring for myself, having had cancer. But I think it goes back to, you know, like the idea of just preventative medicine—like seeing the dentist every six months. It's just kind of like—becomes part of your routine.

—Monica, 36, white, stage IIB. She is two months out of treatment. She had mastectomy, chemotherapy, and radiation.

No. No, I really don't [think cancer is a chronic illness]. [Laughter.] I think of like, arthritis as being chronic. But I think either you cure cancer, or you die.

—Liz, 69, white, survivor of stage II breast cancer. She had a lumpectomy and radiation. She is six years out of treatment.

Frannie makes an important distinction between the management of a disease and prevention of one. She feels that the pills she takes for cancer—survivors may take hormonal therapies like tamoxifen and femara or aromatase inhibitors for 5-10 years after “active” cancer treatment—are for preventative purposes, not for management of cancer. If she ceases to take her diabetes medication, she will have an immediate reaction, whereas nothing may happen if she ceases to take her cancer medication. Monica also employs the preventative frame rather than management frame that survivorship plans tend to promote. But Liz has an even stricter understanding of chronicity: arthritis is chronic because it can be managed; a person can live with arthritis. She thinks a person cannot live with cancer: they are cured of it or they die of it.

Early stage survivors also distinguish their cancers from other types of cancers, particularly late stage breast cancer. Survivors often told me that each breast cancer is different or that there are numerous different types of breast cancer, relaying the information told to them by their doctors. While the staging system presents cancer as on a continuum of severity, the understanding that each particular cancer is unique enables survivors to think that their particular case may not be like the (generalized) others. No one wants to think their cancer could progress to stage IV, but, in reality, some will. The majority of stage IV survivors in my sample were diagnosed years before with an early stage cancer. Stage IV is still taboo for earlier stage

survivors, even though management of Stage IV has improved over the past few decades. Stage IV survivors do not think of their cancers as death sentences, although early stage survivors might. They make a stark divide between their cancers and more “serious” cancers, which helps them see those cancers as chronic and their own as acute.

No [I don’t think my cancer is chronic]. I know some people have it chronic. An artist that I’ve represented for years in Philadelphia, who has become a good friend—she has ovarian. It’s chronic. And I know I’m going to lose her soon. So, it’s like my friend, Donna, with her lung cancer. It was chronic. [When I got breast cancer,] It was like, “How can I live with this disease?” [But] I don’t think of myself as chronic. I think it was a fluke.

—Peggy, 66, white, stage IB. She is almost three years out of treatment. She had a lumpectomy, chemotherapy and radiation.

I think it can be [chronic]. Um—but that goes back to that thinking of reoccurrence. And I don’t know if I’ve ever put the word chronic with my cancer. And that might just be because of the stage that I had. I guess I would view chronic more with a higher stage—where the chances of reoccurrence are a little bit higher maybe, depending on where it’s spread.

—Monica, 36, white, stage IIB. She is two months out of treatment. She had mastectomy, chemotherapy, and radiation.

That is a really interesting question to me. Because if somebody said to me, “Do you live with a chronic illness?” I would say, “No.” But it doesn’t really—in my head, it doesn’t really leave me completely. . . . I think there’s a difference, if you are talking about like—me, maybe? [chuckling] If I’m on the outside and they say, “Is cancer a chronic illness?” I would probably say, “No!” [laughter] “No, of course it’s not.” But then—so, what’s the alternative? Episodic? So then what? You have an episode, and then you may or may not have it? I think obviously if I were stage IV, it would be chronic. But I think it’s tricky.

—Heather, 45, white, stage III. She has been out of treatment for five years. She had a lumpectomy, chemotherapy, mastectomy, radiation, and oophorectomy.

It is tricky. Stage IV is clearly chronic to survivors, as are arthritis, diabetes, and other types of cancer. Early stage survivors do not think their cancers fit into the same categories as these illnesses, and perhaps they do not want to. Doing so would entail accepting other consequences of chronicity, like recurrence, metastasis, or eventual death. But many early stage survivors have chronic side effects, they will have follow-up visits for the rest of their lives, and their health statuses have been permanently changed because of their cancer history. They recognize that their lives have been altered by their cancer experience, and most survivors said something similar to what Heather says above: “in my head, it doesn’t really leave me completely.”

Reliance on treatment to be successful

Lastly, some survivors thought that because of the treatment they received, their cancer was not (going to be) chronic, similar to those who thought because of their faith in doctors and treatments, that they were cured.

Survivors of estrogen-positive cancers who chose to have double mastectomies and oophorectomies could feel that they had taken all necessary precautions against recurrence, but even others who had less “extreme” treatments felt that they had “done everything [they] could do.” Feeling that they had done all they could do left them feeling at peace: they said they did not worry about recurrence because they felt their cancer had been removed and successfully treated. Without recurrence, cancer, to them, could not be chronic (although it could also not be cured):

I’ve known several women that—it’s metastasized, and that was definitely chronic. But I think I definitely have to stay on top of it and

be alert. I guess there is always the risk of reoccurrence. But it's—for me, in my case, it's so low because they've done everything, and there's not breast tissue. You know, there's so little that, my risk at this point is lower than the average person on the street. But I mean, I still think you definitely have to be on top of that and still do exams. Because they said if it ever were to come back, I'd be the first to notice because it would be somewhere on the outside.

—Jenna, 33, white, survivor of stage IIa. She has been out of treatment for two years. She had a lumpectomy, chemotherapy, radiation, bilateral mastectomy and reconstructive surgeries.

Jenna had a double mastectomy and reconstructive surgery. She carries the BRCA gene mutation, which increases her risk for ovarian cancer, and plans to have an oophorectomy after having another child. But because “there's not breast tissue,” and because her treatments reduce her risk level for recurrence, she feels relatively safe. It is possible for cancer to come back on the chest wall or to metastasize after cancer treatment—even for those with a “no evidence of cancer” bill of health. But she trusts that her risk is very low because “they've done everything.”

Jade also relies on her sense that her treatment has been complete to set her at ease. She convinces herself, based on her interpretation of the odds, her treatment decisions (double mastectomy, chemo, and radiation), her type of cancer, and her feeling that they caught her cancer early, that “it'll be OK.” Mostly, because she found her cancer early, she feels it is unlikely to recur:

In fact, I don't think I have cancer. I think that helps. . . . Will it come back? . . . If you ask what percentage, in my mind, given the fact of what I had, very unlikely it is coming back—maybe 20%. . . . So, that's very low chance of coming back. . . . That's how I feel. I could be wrong. But that's how I convince myself: Don't worry. It be gone. It'll be okay. . . . Based on all the tests that I had done, the scans and Oncotype tests. . . . Like, the fact that the oncologist showed me that the type of cancer I had—one of favorable [types]. . . . They know how to take care of it and

how to treat them. Many studies have done to control that particular cancer. . . . I'm like an early detection. Nip it in the bud and call it a day.

—Jade, 50, Asian, stage II. She has been out of treatment for almost two years. She had a bilateral mastectomy and is currently undergoing Trans-flap reconstructive surgery.

Early detection is touted as the only real way to prevent recurrence, but, because of how cancer spreads, it is not the robust strategy most people think it is (see Aronowitz 2001, 2007). Early detection is also not an accurate description for some cancers that simply grow fast because of the type of cancer it is: survivors could be getting yearly or even 6-month mammograms that “miss” a tumor that is advanced when diagnosed. Early detection is likely to pick up tumors that cannot be palpated, whereas those that can be felt send women to their doctors. Both can be called “early detection” even though these pathways to early detection most likely result in different staged cancers. Regardless, survivors use “early detection,” receipt of extensive treatments, and odds ratios to feel that they had done everything they could to ensure a good outcome. This helps them feel safe, even though there is still much about their cancer that cannot be known.

By framing cancer as not chronic, survivors do not have to develop other strategies for coping with anxiety related to the uncertainty of cancer: this is their strategy for anxiety. For these survivors, it may be cognitively unsustainable to think of cancer as chronic because doing so would mean they would have to live with the conscious knowledge that recurrence or new cancer is possible. Most of these survivors say they do not “dwell” on

thoughts of recurrence and do not think about their cancer in their everyday life (they do think about cancer in the abstract or in terms of advocacy and involvement in cancer organizations). While they acknowledge they have a “new normal” after cancer, they use these strategies to help them separate their cancer experience from the disease of cancer. They move forward feeling they have been changed by the experience, but that they have left the illness behind. Yet, they are only able to leave the disease behind by employing the strategies discussed above.

Yes—cancer is chronic

Interestingly, survivors who did think of their cancer as a chronic condition used similar thinking to those who did not to support their position: because there is always a chance of recurrence, even if low, they considered their cancer chronic. Because there could be other cancer cells circulating in the body—cells that escaped the initial tumor, that were “laying dormant” during treatment, or that are always in the body but sometimes not suppressed by the immune system—cancer is a chronic condition. This belief led them to different strategies for managing recurrence risk:

Caroline: I do believe firmly that cancer cells are within all of us all the time, and they come and they go, and your immune system, your ability to fight them, is what’s critical. I do feel that way—that my health—you know, how I take care of myself, my eating, my exercising, my weight—all that is very important. Alcohol consumption, smoking—I think that it’s very, very important. But I feel like I am in remission from this cancer.

Me: So then, do you think cancer is a chronic illness?

Caroline: I do. I think cancer is a chronic illness.

—Caroline, 71, white, stage I. She is 17 years out of treatment. She had a lumpectomy, chemotherapy and radiation.

Jane: I have to accept that it's happened to me, and I have to do the best I can to manage this disease. It's really a chronic disease.

Me: Um-hmm. Do you think so?

Jane: Sure. It's always—you know—it will always be a concern. But, I try not to lie awake nights and worry about it. . . . chronic means that there is always a chance that it can recur. . . . So, it's just—you never know if you have a breast cancer cell that has decided to meander down to your liver or up to your brain or somewhere in a bone, and one day, it'll activate, like this one, after 18 years of nothing. Then, all of a sudden, I get a lump —and suddenly. . . . So, that's why I think it's a chronic disease. And lots of times, they do autopsies on people, and they see little cancers that sort of self-contained, didn't go anywhere.

—Jane, 65, survivor of stage II. She is one year out of treatment after a recurrence. She has had a mastectomy, chemotherapy, and radiation.

It's sort of like brushing your teeth. If you make it—if it's a part of your life and it's just like something you do because it's—I brush my teeth, I take a shower. I do that. I examine my breasts. I take my medication. I take vitamins and things like that and it just becomes a part of my life. . . . I believe cancer is a chronic illness. It isn't something that just goes away. I mean some people stay in remission for the rest of their lives and that's great, and some people don't. I've seen people who've had three reoccurrences and that doesn't thrill me, but there are worse things. . . .

—Nell, 55, white, stage I. She is 13 years out of treatment. She had a lumpectomy, chemotherapy and radiation.

Each of these survivors has a strategy for coping with the uncertainty that thinking of cancer as a chronic condition highlights. I've discussed this in the previous chapters to some extent because these strategies are part of how survivors normalize their new health status, but these strategies are different from the ones used by survivors who do not think their cancer is chronic.

Caroline feels that she is in permanent remission—she had her primary cancer 17 years ago, and she’s in her 70s now, but she still thinks cancer is a chronic state because it is related to the immune system. She focuses her time and attention on boosting her immune system in order to stay in permanent remission. She has devoted her life to healthy living and cancer awareness. She had breast cancer, her husband had prostate cancer, and her son had Hodgkin’s disease. They have all been cancer-free for a minimum of 14 years, but she still believes cancer is chronic and requires chronic active prevention measures. It pains her to think that her son has to live with a chronic disease, but she herself feels that she has overcome many of her personal fears and anxieties through her cancer experience. Jane’s strategy has been acceptance; she posits cancer as a disease she has no control over. “You never know” if a cell has migrated, but “it’s not going to do any good” to “lie awake nights and worry about it.” She thinks that there is little within her power to prevent this from happening, but, unlike Caroline, she does not think boosting her immune system will ultimately protect her—and she has come to terms with her lack of control over cancer as a disease. Nell refuses to let cancer have power over her by making it part of her routine—normalizing her relationship with cancer to the extent that caring for cancer is like caring for her teeth. She has had family members and friends die from cancer; she knows cancer “isn’t something that just goes away.” But, at the same time, she also knows that people can live through recurrences: cancer, for many people, can be managed. She tells me that if her cancer ever spreads to her bones, she has already decided how much

treatment she will endure. She believes in quality of life, and does not want to receive excessive treatment at the end of her life when all that will do is eat up her bank account and ruin the last days of her life.

These women may believe cancer is chronic because of their family histories, experience with friends, or recurrences they've had; but their stages, time since treatment, and types of treatment are relatively similar to those who do not think cancer is chronic. Some people may be able to tolerate uncertainty better than others, and some may be led to accept the uncertainty of cancer because of their background and context. But thinking of cancer as chronic and thinking of cancer as discrete incidents are strategies that give survivors a way to cognitively manage their cancer; both require maintenance and action to keep these thought systems in place. These two groups have made a decision about cancer, unlike the group below, so that their illness has defined physical or mental boundaries. By giving their cancer a definition as chronic or not chronic, they are circumscribing the uncertainty. While perhaps acknowledging uncertainty about cancer chronicity is a more flexible and realistic way to think about cancer, it may ultimately produce more anxiety, in this particular case, than "deciding" to think about cancer in one way or the other.

I don't know....

The question of whether cancer is chronic or not is complicated, and, understandably, some survivors were confused about the status of their disease. Survivors who expressed that they "didn't know" were expressing the

ambiguity of the terminology and the level of medical uncertainty about the disease in addition to uncertainty of their own possible sequela. Those uncertain about how to categorize their cancer were unsure about the boundaries of their disease: they did not know where the disease ended and their experience of the disease began, or they found themselves changing their definitions by the day. Mostly, their ambiguity stemmed from context: they found themselves confronted with new information from doctors and reminded of the seriousness of their illness by those around them. Survivors uncertain about the nature of their disease—who perhaps had not yet “decided” or been able to employ the strategies other survivors did to classify their cancer—hoped their cancer would not be chronic, but they were not sure how much stock they could place in that hope. They were not sure of how to think about their cancer in the present. Because they were using time to determine chronicity, they needed to wait for the future to reveal the true nature of their cancer:

Lili: That is another very funny thing. People know you have cancer. So, you meet somebody who you didn't see for a year or six months, and they'll say, “Oh, you look fine! You look good! How are you doing? Are you cured?” I don't know. I would never be able to tell you if I'm cured. I go through routine exams every six months, every year. No evidence found. That's all I can you.

Me: Do you feel that cancer is something chronic? Is it a chronic illness? Or do you experience it as something chronic?

Lili: I don't know. It think it's—Is it a chronic sickness? I don't know. I just feel, once I have cancer, I could never say, “I am cancer free.” You just have to be very careful, watch.

—Lili, 55, Asian, stage II. She is eight years out of treatment. She had chemotherapy, radiation, targeted therapy, and a lumpectomy.

Sometimes, I feel like it's chronic. I'm not really clear. Some days, I feel like it's gone and it's done—finished. And I think, as more time goes on, it's going to be considered a chronic disease—like, diabetes or high blood pressure, something like that. HIV. And then, sometimes, I see it as terminal, when I see friends around me dying from it. So, it depends on the day. It's weird, because I have some friends who are HIV-positive, and I'm like: How do they go through the day? Like, is it always on their mind? And now that I'm dealing with this, I'm like: How do I make it through the day? And I guess, it's just, understanding that it is what it is, but life goes on. You know?

—Vanessa, 44, African American, stage II. . She is two years out of treatment. She had a mastectomy and chemotherapy and alternative medicine treatments.

Me: What do you think—Do you think breast cancer is a chronic illness, or do you think it's something that happens and is done with after you're treated?

Ariana: Hmm. I think it's a combination of both. Because I do feel like I was done, and I was over it and I was normal again. But then, that reminder that: No. You're not done. I think that's something that I toy with in my head. Like, oh, I'm cured. Or you know: No, I'm not. I went to my doctor. "You need to watch this, this, this, this, this. You need to eat more of this. You need to take calcium. You need to do this." I'm like: Oh, my goodness. So, then, I go back, and then, I'll start to feel like I'm normal again and it's over. And then, I'll go back to her, and she'll be like, "You need to do this, this, this and this, this." I'm like: Oh, my goodness!

—Ariana, 25, white, stage IIB. She has been out of treatment for five months. She had a lumpectomy, bilateral mastectomy, chemotherapy, radiation, and reconstruction.

These survivors are in an unsettled state about how to think about their disease and illness, and they are in the minority of my study participants. Most survivors settle on one answer or another, perhaps because it is too anxiety producing to vacillate. They project their hopes into the future without secure

footing in the present (see Swidler 2001 and Bell 2010 for other arenas in which people use similar mechanisms to manage uncertainty). All survivors hoped their cancer would not come back, of course, but most closed off the future to some extent so that they did not have to think about “what ifs.” These “undecided” survivors need the future to define their cancer for them, and they switch back and forth depending on external cues over which they have no control. On one hand, they experience more anxiety in the short term because they are confronted by cues reminding them that their cancer could be serious and chronic when they have begun to consider themselves cured. On the other, if they do experience a recurrence, they may not experience as much shock as those who think their cancer is a discrete experience: they still engage with the possibility it could be chronic.

Not cured but not chronic/Chronic and not cured/Cured and not chronic

I expected that survivors would either think their cancer was cured or was chronic. They did not. Most survivors thought cancer was not cured and not chronic. The sections above show that survivors employed several techniques for maintaining these allegedly discordant positions. Their creation of new categories—cured for now, gone but not cured—and adoption of the medical terminology cancer-free and no evidence of disease—helped them develop a hybrid cognitive position. They used techniques to help them feel safe and secure about their cancer history while also acknowledging a certain amount of uncertainty within the medical knowledge about the disease. They could feel that their cancer was gone but not cured, as contradictory as that might

sound to outsiders, without feeling cognitive dissonance because they felt both of these claims were true. Indeed, cognitive researchers know that people can maintain seemingly oppositional ideas or identities by fitting them within a coherent overarching frame or schema (Festinger 1962; DiMaggio 1997) or using particular “vocabularies of motive” (see Sharp 2009). Survivors made these ideas complementary rather than oppositional through the strategies I discussed above. Those who thought their cancer was cured and not chronic or who thought their cancer was not cured and chronic had less mental work to do to make these ideas fit together, but each type needed to perform its own type of mental work to stave off anxiety and produce their “new normal.” Not cured but not chronic is a stance that engages with the uncertainty of cancer rather than forcing cancer into a dichotomous definition. Survivors who think they are cured may be shocked by recurrence, while those who think of cancer as chronic build cancer to some degree into their everyday routines. “Not cured (or only cured for now) but not chronic” may give survivors a way out of anxiety by building uncertainty into their understanding of life after cancer. They know cancer may happen again, but they can also live free from cancer for the time being.

Stage IV

I interviewed 11 survivors of metastatic cancer for this project. As such, I cannot generalize from their statements, however these individuals offer key insights worthy of description and discussion. These survivors follow many of the same trends as the early stage survivors in my sample: they try to keep

themselves healthy and their immune systems working optimally to fight cancer; they integrate cancer into their lives in order to make their lives as normal as possible; and they try to bracket thoughts that take them too far ahead in time, focusing instead on the present. But, because their cancer has passed the threshold between prevention and management, their perspectives are different than those of early-stage survivors. Their actions are directed at preventing tumor growth and spread, at preventing a situation that is unmanageable and deadly—which may be inevitable—while early stage survivors are focused on preventing cancer's return to their lives. While their prognoses are certainly worse than early-stage cancer survivors', having crossed that threshold into metastatic cancer actually makes their situation, ironically, less uncertain: some of the fear of going metastatic is gone, especially if they are managing their cancers well for the time being. Focusing on the present, they can circumscribe wellness within the moment, although they cannot bracket thoughts about mortality completely.

As earlier staged survivors compared themselves to metastatic survivors to define the terms of their existence, metastatic survivors also do the same with early-stage cancer survivors and other diseases or situations. They make their comparisons to both denote the seriousness of their cases but also to make their cancers seem less dire. Terry explains:

Terry: I didn't see what was going to lay ahead. I mean, you go through surgeries and tests and it's all very scary. You know, because you think of cancer being like—you know, a really seriously bad diagnosis. Which, it is. But when you have it, it's not so scary as it is for when you don't have it, I think. Because you're just sort of, either immune to it, or you're just used to it, and—.

Me: How do you become used to it? I mean, that seems like it's a big deal, or a big process for anyone to sort of become used to illness. Right? So can you talk about what you went through, kind of getting used to this new diagnosis?

Terry: Yeah. I don't know how I did.

Me: Do you think you're accepting of it now? Have you reached a point where it's okay?

Terry: Yeah. I mean, what choice do I have? You know? [chuckling] But I mean, I can think of a lot of worst things. You know? I mean, worse diseases, or, you know, being in a wheelchair. I would hate to do that. You know, there's certainly a lot of people that get bad—dealt bad—deals in life. You know?

—Terry, 45, white, stage IV. She was diagnosed two years ago. She continues on targeted therapy.

Her statement that, from the inside, metastatic cancer is not as scary as when you do not have it, is supported by other research: cancer is more stigmatized by those who do not have it than those who do (Katz et. al 1987; Fife & Wright 2000; Buick and Petrie 2002; Chapple et. al 2004; Anagnostopoulos and Efrosyni 2005). This is logical: perhaps people tend to skew perspectives of their own lives to best-case scenarios, whereas they tend to think of serious illness in worst-case scenario forms. For cancer, all cancer becomes the worst cases (see Cerulo 2006).

But survivors dealing with the “worst cases” use comparisons to further delineate themselves from other cases that are actually worse than theirs (see Taylor and Lobel 1989). But they also wanted to distinguish themselves from early stage cancers. All of the metastatic survivors I interviewed but one said they are living with chronic disease, which they discuss as both a continuation of earlier staged cancer but also a different disease. A few metastatic survivors

discussed this divide in detail: Irene thinks that most of the cancer societies have do not understand what the journey is like for metastatic survivors. She said a few statements off the record that conveyed her irritation at the lack of understanding of metastatic cancer, and, while she did not say this, research can attest that the focus on early stage cancer survivorship in the media and in events like Race for the Cure pulls attention and resources away from metastatic survivors (see Ehrenreich 2001, King 2008, Klawiter 2008, Sulik 2012). On the record, she said:

It's great that Komen and the rest of them find money and there is cancer research. That's great. But it really needs to be more understood that the journey for an individual in a chronic situation is *so* hard. . . . You know, [someone with early stage] went through her journey and she had to deal with her stuff. But her stuff is not like my stuff. It's not like—You should come to the session with the advanced breast cancer women. You'd find out what they deal with. They are far more courageous, far more accomplished, far more worthy of recognition I guess everybody who's been touched by this is a survivor, but some people are, you know, they're surviving every minute. . . . [I]t's impacted every phase of their lives.

—Irene, 62, white, stage IV. She was diagnosed seven years ago, after two years out of treatment for DCIS. She had a mastectomy and is now receiving continuous chemotherapy treatment.

The public's conflation of cancer stages contrasts with the division between early stage and late stage breast cancer internal to the cancer world. For her, metastatic cancer is different from early-stage because metastatic is chronic and early-stage can be left behind.

Naomi describes how the medical establishment does not discuss metastatic cancer with earlier stage survivors because they do not want to scare them. To her, this presents a false divide, because people with metastatic

cancer may have started out with early-stage cancer. She herself was diagnosed with stage IIB cancer 15 years ago, 10 years prior to her metastasis. She not only feels they are not trying to cure metastatic cancer survivors, but that they are trying to occlude them from other survivors' view:

Me: Then do you feel that because you are metastatic that you are looked at as a different kind of case—that they are not coming up [cross-talk] [with a cure?]

Naomi: Well, they're not looking to *cure* us. I think that it's only recently that even metastatic people have been addressed as a group, in terms of literature, in terms of support groups. I think there's a lot of reasons for it.

When I go to the [community cancer organization], they have primary breast cancer patients that are newly diagnosed, or maybe a couple of years. But they're all looking to be cured, and their doctors are looking to cure them, put them in remission. And the last thing that any of them want to talk about is the possibility that they may go metastatic. And that's a very frightening thing.

And I think both doctors don't want to broach that with their patients, you know, because everybody talks around it. And patients don't want to consider that that might happen to them. So, they are not pushing for that discussion. You know? It's a very frightening possibility, that you are not going to be cured. And I think most people figure, when they go into treatment for primary breast cancer—I guess that would be stages I to III—they're either going to be cured, or if they're not cured, it's probably because they're going to die. And those are like, their options. They don't think that: Well, I'll go into remission, and then I'll get cancer again. You know?

I mean—and even if they see that somewhere, it's kind of like a teenager doesn't think they're going to ever crash their car. You know? That's stuff that happens to other people. It doesn't happen to them.

—Naomi, 64, white, stage IV; she was diagnosed five years ago, which was 10 years after her first occurrence. She had a double mastectomy and chemotherapy; she is now continuously treated with targeted therapy and chemotherapy.

Naomi talks about a willingness on the part of the cancer community to deny or ignore metastatic breast cancer—metastatic cancer becomes a cognitive blind spot. Nobody thinks they are going to recur with metastatic cancer. Once

metastatic, practitioners change their treatment plan and perspective of patients. She discusses how she had a prolonged battle with her doctors and the hospital administration to receive a particular medication that was performing well in other cancer survivors but had not yet been tested with the combination of drugs she was receiving. She benefitted from the drug, but she felt that her doctors and the establishment refused to give it to her because they were thinking about her as a particular kind of case: she thinks they are not looking to cure but to maintain metastatic cancer, and, as such, are not willing to think out of the box with metastatic patients. She thinks they refused to give her the drug because it was not the standard of care, and thus they were not willing to take unapproved risks, even though it was showing benefits for others. She thinks this is an example of the cognitive narrowing that takes place even within the medical establishment in terms of how people think about metastatic survivors.

Because most of my study participants with stage IV cancer had had an early-stage primary cancer—their metastatic cancer is a recurrence from that cancer, not a new cancer, often after several years of living cancer-free—they have a unique perspective on both early stage and metastatic cancer. They know outsiders fear stage IV, but they find living with cancer like taking “control of an uncontrollable situation,” as Irene says. In other words, it is manageable, but managing it is often exhausting and reactive. These survivors know that their doctors do not aim to cure them but to keep them alive with as decent a quality of life as possible. As such, they have an interesting

relationship with the cancer establishment. Their cancers, in a sense, represent failures: proof of the inability of science to cure cancer, of treatments to prevent recurrence, and, at times, of individual doctors' missteps.

Cancer causes and explanations

The metastatic survivors in my sample give no clear attribution to cause: similar numbers of survivors say multiple causes, they don't know, family/genetics, environmental causes, and medical error. Most ran through a litany of possible causes, being well versed in cancer, before saying that none of them fully explain why they have metastatic cancer. They seem split in thinking about it scientifically (aberrant cells, weak immune system) and trying to attribute some meaning to it within the context of their life (cancer was telling me something). Because of their position in the cancer continuum, metastatic survivors often look back at cancer, through counterfactuals (Jain 2009), trying to explain what went wrong. But, beyond the seeming randomness of their cancer, they focused on the ways in which their cases are aberrations from the norm. I wondered if, in metastatic cancer, there actually is something considered a norm, since long-term survivorship for these cancers is a recent development in cancer history.

I'm a unique case

One overarching motif that did emerge within talk with metastatic survivors was their sense that they were unusual cases. While many early stage survivors wondered why they got cancer when they were ostensibly so healthy, metastatic survivors went beyond this level of wondering to describe

feeling “unique” in their cancers. They may attribute their unique situation to medical missteps or errors, and try to make the experience meaningful by situating it in the larger contexts of their lives, but their unique position as a highly functioning metastatic survivor also enabled them to perceive medicine as more of an art than a science. Early stage survivors were more likely to trust their doctors’ and treatments’ abilities to save them. Metastatic survivors do not have grandiose expectations of science, as their existence is proof of both the wonders but also the limitations of science. Because of their balanced skepticism and medical knowledge, metastatic survivors could list all of the possible reasons they have cancer, but none of them are satisfying because they can never be verified or disproven. This lack of explanation leads them to focus on the ways in which their cases are medically or statistically aberrant.

Medical mysteries

Alexis, Terry, and Irene describe similar stories about how they should not have metastatic cancer. They all defy the conventional medical wisdom about cancer—the risk profiles, the clean margins—yet prove another commonly accepted truism amongst survivors, that all it takes is one cancer cell to spread. Because there is an expected scenario, survivors are shocked when they find themselves on the other side of the odds.

You know, when I found the [primary] lump in my breast, the doctor kept saying to me, “Ugh, 80%, it’s nothing. You’re young. There’s no family history, you’re young.” He went, “Eh.” So I think that it made it much harder for me at first to even fathom it because statistically, I shouldn’t have had it. So statistically I still shouldn’t have it. I shouldn’t have had a recurrence. I, you know. . . . [Also] I have had reactions to things that no one else has had reactions to. Um, you know, I was allergic to Taxol to the first. And that’s not uncommon. But then

they challenge your system and they give you more Benadryl and more steroids and they get it into ya. And so I got the second one, I got the third one. I had an allergic reaction to the fourth one. The entire medical staff was like, “You’re joking. I mean this can’t be happening, this doesn’t happen.” Well, yeah it does. To me.

—Alexis, 46, white, stage IV. She was diagnosed one year ago, after her initial occurrence seven years prior. She had a mastectomy, chemotherapy, and an oophorectomy. She is on continuous targeted therapy.

It was [classified originally at stage] II. I had clean lymph nodes. That’s usually their telltale sign. But when I had a PET scan, it had spread through my blood into my bones. So they were pretty shocked—the doctors were. So I went to stage IV.

. . . .
And [then] I think [my oncologist] was shocked that it had such a good—I had such a good response to the [targeted therapy after it had spread]. He told me this year that the Tumor Board at the hospital considers my case a miracle, I guess.

—Terry, 45, white, stage IV. She was diagnosed two years ago and is on continuous targeted therapy.

I had a mastectomy in November of 1998, and they felt that the margins were clear, and they felt that I would never have an issue again because they felt that it was 98% certain that I would never have an issue. And so, thinking, you know, 2%—that’s a small percentage—I’m [thinking, I’m] good. . . . In 2003, I started to have a swollen arm—February 2003—and I retired in March of 2003, and got treatment for the lymphedema, and the arm wasn’t getting any better. And I had funny little odd symptoms, but nothing that was big. Long story short—it took them six months, and me pretty much jumping up and down, and they determined that I had a recurrence. . . . Even though the margins were clear, there were no sentinel nodes, no nodes removed.

—Irene, 62, white, stage IV. She was diagnosed seven years ago, after two years out of treatment for DCIS. She had a mastectomy and is now receiving continuous chemotherapy treatment.

These survivors describe their cases in terms of the statistical odds of their metastases happening, or of therapies working or not working. There is a sense within the cancer world that certain things do not happen: a patient is

not going to be allergic to the fourth treatment. Tumors are not going to spread if the surgical margins around the tumor site are clean. These are truisms that rule medical knowledge. But exceptions to these “rules” happen, which leads these survivors to question the validity of these rules as standard practices: if they exist outside the standard practices, how are those practices *standard*?

Marlene: What I’ve learned is that, they don’t know, that they classify everything, and there’s exceptions to the rules—I count me [as one of those exceptions]. . . .

Me: Okay. How do you feel about being an exception to the rule?

Marlene: I just want to know why. Like, I didn’t fit the mold. So I was like, I just wondered—if they’re just sticking to the mold and not looking outside of it.

Me: Hmm. I see what you mean. So, maybe like, they’re so focused on the majority that they forget the others?

Marlene: Um-hmm.

—Marlene, 48, African American, stage IV. She was diagnosed one year ago, after her first occurrence of stage I several years earlier. She had lumpectomies, chemotherapy and radiation. Now she has chemotherapy.

Marlene describes how professional vision causes missed cases. She feels that doctors’ understandings of cancer are skewed to the average cases, such that cases like hers, which should not have happened, slip through the cracks in their schema. She feels that they did not think she was going to recur, so they did not treat her as if her cancer might recur. The goal of standardized practices is that they work for most survivors, to help the largest amount of people efficiently and expediently. Metastatic survivors come to feel that, because their cases are outside the norm of cases, that doctors and practitioners do not fully consider them when applying practices to their

cases—but this occlusion happens well before the metastasis. Because doctors do not know which cancers are going to become metastatic and which will not, they cannot treat individual patients based on knowledge that their cancers will be the ones that metastasize. They treat based on accepted protocols.

Medical missteps

Because of their perceived uniqueness, metastatic survivors are also able to talk about the limits of medical science: if their case should not exist—if they should have been “cured” or never should have gotten cancer in the first place—then they are led to question medical science in ways that early stage survivors might not want to do. Early stage survivors want to trust that their doctors “got it all” or that the therapy did the job. Metastatic survivors are often testaments to the failures of treatments or doctors to be able to do so. Barbara’s case is particularly heartbreaking because it sounds as though one decision caused her to recur and metastasize after 14 years of no evidence of disease. While there is really no way to know when or why her cancer started to recur, her narrative lends itself to this interpretation:

Barbara: I was originally on Arimidex for 12 years. And then I was taken off of it for two years, and they believe that’s what exacerbated my cancer to start up again. . . . And I was very shocked because I just kind of woke up on Friday morning and had pain, and then by Tuesday, I was told I had cancer again. So, that’s that.

Me: So it was pain that made you kind of think—

Barbara: It was actually a pain in my back, and my lung had already collapsed, and you know, things moved very fast. I had surgery within two weeks. But had no real symptoms before that of anything. So—

Me: Right. And you were being monitored so closely.

Barbara: [in iffy kind of voice] I was. Some of the tests had kind of stopped because, you know, once you heed that five-year mark, and then, ten-year mark, you kind of get checked every maybe six months, once a year. And I had changed oncologists, and that was the reason why I was taken off the Arimidex. Because my original oncologist had retired. And then when I started with the new one, and she said, “You know, you’ve been on this medication a *long*, long time. You know, let’s take you off. Nothing has changed in 10 years or 12 years.”

—Barbara, 53, white, stage IV. She was diagnosed one year ago, 14 years after her primary occurrence. She had a mastectomy, chemotherapy and radiation and now is treated with continuous hormonal therapy.

Barbara’s case may not be a medical error as much as bad luck. Her new oncologist may not have been incorrect in her assessment that 10-12 years is a long time to be on Arimidex, but perhaps for Barbara’s particular tumor type, she needed to stay on adjuvant therapy for the rest of her life. Some medical errors are more clear-cut or blatant than others, but these experiences lead survivors to have a cagey relationship with doctors around trust. Survivors rely on doctors, but they have to be skeptical about their abilities. They realize doctors are just people.

If my oncologist had followed the directions of—the recommendations of the radiologist, the tumor that was growing in my spine back when they first were working on me would have been taken care of back at the very beginning. Instead of waiting so many years to grow to the point where it’s in my ribs and in my lungs. But the doctor didn’t follow the recommendations.

. . . .

I have all my mammograms back to the very first one I ever had Okay, I get to the surgeon. Surgeon’s looking at this mammogram and at the series I had: “Why the hell weren’t you here two years ago?” I said, what are you talking about? She goes, “I see it right here. It’s right there; here, on the mammogram, two years ago. Why the hell did you wait two years to get to me?”

. . . .

It all adds to my distrust. And, and it adds—and that is why I’m constantly questioning my doctor. I have a different oncologist now, um, and I love the man. He drives me nuts; I drive him nuts.

I: [Laughter]

R: Um, sometimes, and I’ve told him, I feel close enough to be able to tell him, I say sometimes I feel like you’re not listening to me; you’re not seeing me now. You’re thinking, aw, she’s complaining about her back again; it’s the same old issue. I said I need you to listen to me now and look at me now and not think the general Ruth, but look at the Ruth that’s in front of you.

—Ruth, white, stage IV. She was diagnosed nine years ago. She had a previous lumpectomy, chemotherapy and radiation and now has weekly targeted therapy.

Ruth can tell when her doctor glazes over and starts seeing her as a type rather than as a specific human being with very particular problems. Ultimately, though, issues of trust for survivors meld into an understanding that medicine is an art, not a science, and that people make mistakes. Ruth has gotten to the point where she and her oncologist can communicate and drive each other nuts. But when mistakes happen in one’s own particular case, they are tragic. Survivors talked about how they could perceive these mistakes and take a legal route to rectifying them—both Ruth and Alexis discussed suing—but, at the end of the day, they felt that what was done was done. They did not frame these errors within a logic of “justice” or “malpractice” or even “fairness.” They humanize doctors so that their mistakes become imperfections of them and of the system they operate in. They also feel that they simply do not have time to waste on legal actions; as such, their only choice is to accept it. As Alexis says, “it is what it is”:

I had no reason to believe that I needed to anything that drastic really either. And I’m the patient. I shouldn’t have to know, you know, what’s the likelihood this patient’s gonna recur as opposed to this patient. In

looking at it now and knowing. . . They probably should've just cut off the estrogen. When you look back at my test results, it was very sensitive to estrogen and I know better now that I probably should have done more. But how I could I know that? . . . I could probably find a lawyer . . . Is that how I want to spend the rest of my life? No. I don't want be mad. I don't want to be angry. I don't want to be questioning, I just want to do what's best and make the best decisions I can now. I can't change it. So, most of the time I'm pretty good with it.

—Alexis, 46, white, stage IV. She was diagnosed one year ago, after her initial occurrence seven years prior. She had a mastectomy, chemotherapy, and an oophorectomy. She is on continuous targeted therapy.

Hindsight is 20/20, of course. But what Alexis knows now *might* have prevented her recurrence then, had she been able to act on that knowledge at the time. Moving back and forth between past and present selves is a hazard of the counterfactual game that Jain (2009) discusses. Having to trust doctors to make decisions means putting faith in them to consider all contingencies and possibilities, which they may not if they are thinking categorically and statistically. It is clear to these survivors that their doctors are not trained to think about their cases individually, as Ruth describes, but as a type of case; and that they are aware that this type of thinking leads to mistakes:

The metastatic cancer came back to my bones, and I actually had an issue with my left thigh, that started to hurt, and I kept coming back here [to the cancer hospital], but no one did anything about it. They didn't think it was anything significant. So I never had any tests. I was going to a lot of orthopedic doctors, getting all kinds of shots and MRIs and x-rays and all kinds of things. And no one could figure out what it was. And after nine months of walking around like, literally Quasimodo, [making grunting, Hunchback noise] you know—I finally came back and I said, "Something's wrong. You're going to have to give me a bone scan." And so I had a bone scan, and I was up on the table, and they said, "Oh, my God. You can't get off the table. You have to go right to emergency surgery."

. . . .

Well, the irony of it all is that, all the orthopedic doctors I went to said, "Are you sure this is not the cancer?" And I'm saying, "That can't

possibly be, because I go to the [cancer hospital], and they didn't seem concerned." . . . I mean, they didn't do anything wrong—the orthopedic doctors. They made mistakes here [at the cancer hospital]. But—you know, I mean, I guess people are people. They make mistakes. You know? . . . I mean, I changed doctors.

—Naomi, 64, white, stage IV; she was diagnosed five years ago, which was 10 years after her first occurrence. She had a double mastectomy and chemotherapy; she is now continuously treated with targeted therapy and chemotherapy.

While reconciling current knowledge with past decision making is excruciating in medical cases, more frustrating, perhaps, is knowing something is wrong in the present and not being able to have doctors make sense of it medically. A few metastatic and other survivors had stories about being misdiagnosed or having to persist in getting a diagnosis because their doctors and other practitioners were locked within boundaries of their professions. While the path to diagnosis can be riddled with side steps for everyone, cancer survivors in particular need medical teams where doctors talk across specialties in creating medical homes for their patients. This is not the way our medical system is structured, making it very difficult for patients to arrive at critical diagnoses. Metastatic survivors, though, seemed to reconcile the medical mistakes and oversights made as human failings. Perhaps doing so enables them to maintain faith in a medical system that has failed them.

For some reason, even if unknown

As the consequences of their cancers are more immediately dire than early stage cancers, making sense of their situations can be more urgent or imperative. Not having a known cause can be more of a stumbling block for

metastatic survivors since their prognoses are unchangeable. They attached personal meaning to contracting metastatic cancer—that the cancer was trying to tell them to slow down or change their situations—as did earlier staged survivors, but their stories seem to be filled more with self-blame or regret, as if they were responsible for their metastases.

I think it's different for everybody. I know that they talk about—I've heard descriptions that, you know, the body can take three big hits, and then something develops. I'm not really sure whether it was a stress thing, or a physical illness or something—but something will trigger it off. I really—It sounds odd, but I think stress had a lot to play with it. . . . And I think things happen for a reason. . . . I think it was almost like a—Hello! Knock, knock, knock. You need to leave here. And—I mean—I don't —Like, in a way, I don't really think that that's how cancer happens.

—Allison, 51, white, stage IV, five years since diagnosis. She is on continuous hormonal therapy.

The cancer that's growing in my body may have—or that had grown in my body (because I believe that it's shrinking with this chemotherapy right now) in my mind, could have multiple causes. I was very stressed. I was very overworked. I was not taking care of my health. I made some attempts to take care of my health once I felt the lump, but it wasn't a priority. There were other priorities. . . . So, you could say, well, all the stress, run down, not taking care of oneself.

—Anika, 48, white, stage IV. She was diagnosed two and a half years ago. She is on continuous chemotherapy.

Oh, I think yeah—because of that emotional mess. I've talked about it at support groups. All the women believe that, that stuff they've gone through, you know. And the thing is [doctors say]: Oh, no, no. There's no evidence! No evidence [that links trauma to cancer]. . . . So, [the doctors] were like, telling me, “No, no, no.” . . . But then, you read all the time about how your immune system is suppressed when you are stressed and stuff like that. So, it's like, opposite ends of the spectrum. . . . It was a relief [when her sister got it]. It was like, it wasn't my fault! It wasn't something I did. Because I didn't believe it when [my doctor]

said there's no evidence. I mean, there may be no direct evidence, but we know that stress lowers your immune system. Right?

—Sabrina, 54, white, stage IV. She was diagnosed five years ago. She had chemotherapy and radiation and is on continuous targeted therapy.

Something has to have caused their cancer to turn metastatic, something worse than other, run of the mill cancers. They mostly attributed their cancer to extreme stress and not taking care of themselves. The youngest metastatic survivor in my sample is a poignant exception. Younger survivors tend to embrace the advocate survivor identity more and look for more benefit finding in cancer than older survivors (Brenner et. al 2005; Helgeson 2011). Perhaps her age inoculates her from the self-blame, enabling her to grab onto the “fight” narrative other survivors her age employ, or perhaps she's simply too young for the reasons the other survivors create to resonate:

And I don't sit here and dwell on it and try to figure out a reason. I just think, you know, I was given this for some reason. You know, I've learned a lot from it, and it made me become, I think, a strong person and a better person. So, you know—.

—Rebecca, 33, white, stage IV. She was diagnosed one year ago, after being five years out of treatment for her primary stage II tumor (which was originally classified as DCIS). She had a lumpectomy, chemotherapy, and radiation and now is on continuous hormonal therapy.

Defining “chronic”

Not surprisingly, survivors of stage IV overwhelming considered their cancer chronic: only one survivor, who described herself as having no evidence of disease, said her cancer was not chronic but its effects were. However, their understandings of “chronic” are different than early stage survivors' understandings. Whereas “chronic” denotes seriousness and progressive

illness to early stage survivors, who largely identify chronic cancer with stage IV, “chronic” to stage IV survivors denotes manageability and life longevity:

And even sometimes, I’ll say jokingly to my friends, you know, “Well, I’m going to this advanced breast cancer support group because I have stage IV cancer,” and they just kind of look at me like, “Oh, my God! You’re dying?” Like, “How many more months do you have to live?” and I said, “No. It’s not like stage IV like that.” You know? So, I think the general public still believes that once you’re labeled stage IV that you have 3 to 6 months to live, and it really isn’t that.

—Barbara, 53, white, stage IV. She was diagnosed one year ago, 14 years after her primary occurrence. She had a mastectomy, chemotherapy and radiation and now is treated with continuous hormonal therapy.

Ironically, some metastatic survivors embraced some of the strategies rejected by early-stage survivors, like comparing their illness to other types of chronic disease, which enabled them to dissipate the seriousness of their conditions:

It’s been hard for the last year trying to find anyone else who is in the same sort of place that I am. I know people who have metastatic disease but who are much further along in the path. I don’t know that I want to go to where they are. I don’t—I want to think of this as living—My doctors keep saying, think of it as living with diabetes. That it’s chronic and that it’s something that’s not gonna go away but something you can live a long time with. So, I don’t want to deal with advanced disease concerns, because that to me makes it all a little too real and I just want to be where I am right now and I don’t know many people who are where I am.

—Alexis, 46, white, stage IV. She was diagnosed one year ago, after her initial occurrence seven years prior. She had a mastectomy, chemotherapy, and an oophorectomy. She is on continuous targeted therapy.

Rebecca: I go probably like every three or four months for like a CAT scan or MRI. And all the tumors are shrinking. So—.

Me: So, does that classify you as being in remission then, or—?

Rebecca: I don’t know. Because I asked that. I said, “Well, am I technically in remission, or you know, what’s the deal?” And they say,

“Well, metastatic—.” I don’t know if they really say “remission” because you know—. They say, sometimes they think that you’re always going to live with it. It’s kind of like living with diabetes.

—Rebecca, 33, white, stage IV. She was diagnosed one year ago, after being five years out of treatment for her primary stage II tumor (which was originally classified as DCIS). She had a lumpectomy, chemotherapy, and radiation and now is on continuous hormonal therapy.

Both Alexis and Rebecca are doing remarkably well with their treatments, which enables them to compare their existence to someone living with diabetes. Early stage survivors rejected this comparison, as they preferred to think of their cancer care as prevention, not chronic disease management. From the perspective of late-stage survivors, living with diabetes is a positive comparison because diabetes is not as scary as cancer. Yet, this metaphor does not map onto everyone’s experiences or perspectives. Allison, for instance, does not like the comparison, and she does not want to dissipate the seriousness of her condition:

Because now, you know, they’re talking about how this can be a chronic illness, which—I don’t like the comparison that they make because I don’t think cancer is—the minute that it’s mentioned, it takes on a—It’s terrifying, scary—. I think it’s just—it’s not the same as diabetes, and it’s not the same as arthritis, and it’s not the same as—. But nobody tells you about, “okay, so, now, you’re going to have this, hopefully forever, and forever is going to be a really, really long time.” And they don’t talk a lot about side effects, other than nausea, if your hair is falling out, vomiting—you know, that kind of stuff. And yet, I had side effects enough that I can’t—I can’t work. When they talk about the AIs [aromatase inhibitors, a hormone therapy that stops estrogen production] being so easy—they’re not!

—Allison, 51, white, stage IV, five years since diagnosis. She is on continuous hormonal therapy.

“Chronic” illness can be manageable or debilitating. Comparing cancer to diabetes highlights quality of life within disease: while diabetes can be serious, most people can manage it successfully and have high qualities of life. This comparison glosses over all of the hardships from the treatments that cancer survivors go through, a comparison that Allison resents because it obscures her experience. She also points out that “chronic” can still mean “short” for survivors. They hope to live a very long time with chronic cancer, but she points out that some of the drugs being tested only prolong life another couple of months from the drugs currently available. At the point in the illness career where these drugs will be applied, survivors have already had a decrease in quality of life such that living another three months under those conditions may not be perceived as a benefit. “Chronic,” for Allison, still exists within an undefined (and indefinable) time frame:

Allison: But you know what’s interesting, when you read—if you read studies of clinical trials and whatnot, they talk about this drug versus this drug combination, and this one extended life 2 months versus 1.5 months. [sounding exasperated] They’re not talking years. They’re not talking— [sounding exasperated]

Me: So, that’s what’s kind of phony about the whole chronic thing you, is that—?

Allison: Well, I don’t know if it’s phony. But I mean, things can change at any time. At any time, the medicine can stop working. I don’t know. You know, you go day by day. I’ve got a good track record so far. I’ve got 4 1/2 years out of the Lupron, which is pretty good.

Chronic is the accumulation of days. “Chronic” to Terry means that cancer is not something she can leave behind, as she imagines early stage survivors can. Even though she has minimal side effects and has purposefully not told

anyone except her husband of her metastasis, she feels that the difference in cancer being acute or chronic is in being “free”:

Terry: You know, if you’re stage I, or— I mean, you go in for your sort of course of treatments, and then you’re free. [laughter] And you get to go home—or leave, you know? You just get monitored.

Me: And that’s a difference with yours.

Terry: ...It’s not so much. But occasionally, you see someone who’s graduating and gets to leave—you know, kind of thing.

—Terry, 45, white, stage IV. She was diagnosed two years ago and is on continuous targeted therapy

In the chemotherapy rooms, nurses often have “graduation” ceremonies for the early-stage survivors when they finish treatment, which must repeatedly signal to Terry the permanence and entrapment of her situation.

Ruth also compares her situation to earlier stage survivors to define their situation as *not* chronic, despite medical messaging to those survivors that all cancer is chronic. She does waver a bit: she recognizes the potential for anyone who has had cancer to have a recurrence. But, to her, these are shades of grey. There is a difference between her chronic cancer and early-stage cancer survivors’ potential for chronic cancer:

Ruth: You know, you’re clean, you’re free, although once you have cancer, you’re never clean. I don’t care what anybody says. There could always be a cell somewhere. That’s why you’re metastatic, because there was a cell somewhere that managed to fly the coop before. It can take, like they say, it can take ten years for the tumor that’s in your breast, for it to grow enough for the doctor to be able to see it. Well, that’s ten years that that tumor is partying in your breast and partying in your lymph nodes and making its way to other areas of the body before you even know it’s there. So, so anybody who has had cancer is never really cancer free. But, there’s more cancer free than other cancer free.

Me: So it’s chronic for everyone; it’s just not detectable for some?

Ruth: I don't know that you—okay, my thing now, it's stage IV metastatic. I have chronic breast cancer, which is a different disease. She [an early stage survivor] doesn't have chronic breast cancer. When I say, you know, she still has *cancer*, I mean you never know what could be down the road. But if you were stage I with a tiny tumor many years ago and you've never had any problems since, you're pretty much as free as you can be.

—Ruth, white, stage IV. She was diagnosed nine years ago. She had a previous lumpectomy, chemotherapy and radiation and now has weekly targeted therapy.

Ruth makes a distinction between metastatic and early-stage cancer based on chronicity, but she also acknowledges that early-stage cancer can lead to more serious events. However, she looks at early-stage as the best case scenario, as being as free as one can be. Early-stage survivors may not feel completely free from cancer. Naomi, because of her perspective having had an early stage primary and now metastatic cancer, thinks that early stages are just in remission. Looking back, Naomi redefines her ten-to-twelve years of being “cancer free” as “remission” rather than “N.E.D.” The cells had to have been there, she thinks, just not reaching a threshold where they were discovered, just as Ruth explains. The labels chronic or no evidence of disease do not help navigate uncertainty because they can only be applied after time and significance events have occurred. Cancer, like many diseases, can only be made coherent in retrospect.

To Naomi, her chronic status further differentiates her from early stage survivors by distancing her from the “survivor” label. As Alexis said earlier, metastatic cancer survivors are “surviving every day.” To Naomi, surviving something means that she has overcome it, that is in the past, that she, too,

gets to leave behind. Because her cancer is chronic, and her quality of life is low, she does not feel like a survivor:

Naomi: I'm not really a survivor. I would be a survivor if I was like, 90 and I came back: Oh, yeah, I survived for the 20 years or something. I consider myself still in the flames— still in the crash. You know?

Me: Still fighting?

Naomi: Yeah. I know in some senses, I am a survivor. I survived for 15 years [from the primary cancer to now]. In that sense, I'm a survivor. But I always thought of it as more of a finite thing, like, you survive when that thing is over, whenever that is. And for me, it's not over. It's ongoing.

—Naomi, 64, white, stage IV; she was diagnosed five years ago, which was 10 years after her first occurrence. She had a double mastectomy and chemotherapy; she is now continuously treated with targeted therapy and chemotherapy.

Naomi knows her cancer will not be over until her life is. Metastatic survivors are very aware that cancer will most likely end their lives. I do not know if sufferers of other chronic diseases feel that their disease will cause their death, or if they imagine that they will die of old age or other causes. For metastatic survivors, the word “chronic” can mean different things depending on how a survivor is doing at that moment in time: if medications are working well and quality of life is good, then chronic cancer can be like diabetes. If not, chronic becomes a cross to bear. In *Good Days, Bad Days*, Charmaz (1991) discusses the flow of time as measured by chronic disease: chronic disease still has acute periods and period of crisis surrounded by times of remission, stasis or peace. Time is not evenly paced. Sufferers try to stay where they are. Cancer's chronicity is like a continual ramping up, during which time treatment options narrow. As treatments stop working, harsher treatments are applied. The harshest treatments are reserved for last, which means that the future is not

something metastatic survivors look forward to. Some metastatic survivors can live a good quality of life for a prolonged period of time. But a couple of the survivors I interviewed were on their third treatment option. Chronic, for them, was about keeping on a current regimen because moving to the next one means they are exhausting an option to experience their illness as chronic. They do not look forward to a cure, even though they may hope for one, or hope that the next treatment actually works better for them—which it may, in some cases. But, underneath this hope, they aim to define “chronic” as being able to continue tomorrow as they exist today.

Living without a cure

Most of the metastatic survivors I interviewed did not think about cures; they did not feel the cancer industry was interested in curing them or actually could. One survivor I interviewed said that she was no evidence of disease. Others were miracle cases because their tumors had shrunk and had stayed that way. The others were maintaining their tumors in their current state. But “cure,” to them, was something that might happen in the future through developments in science, “like a vaccine for Polio,” as Terry hypothesized, that would inoculate people from getting cancer. They largely did not feel cancer was something that could be cured after getting it—which extended to their ideas about early stage cancer, as I discussed above. They understood their situation was not about cure but about maintenance:

Alexis: I could have chemo. I could have surgery. I could have radiation. I could have different drugs, different combos of things. Um, but I guess the way this gets managed and it is comparable to diabetes is that you—. As long as your case remains stable, they stick with what’s

working. And “when”: it’s not an “if,” it’s a “when” that changes; then they have to change the medications. And you go with that ‘til it doesn’t work.

Me: So it is a when you’re thinking—.

Alexis: It’s a when. I asked the doctor, “Will this tumor on my back ever go completely away?” And she said, “Well, that would be great. I’m not expecting it to, but as long it’s not progressing that’s a success.”

—Alexis, 46, white, stage IV. She was diagnosed one year ago, after her initial occurrence seven years prior. She had a mastectomy, chemotherapy, and an oophorectomy. She is on continuous targeted therapy.

I’ve not had any chemo. The thought is to take the least amount effective of one thing and string that on, so that when that stops, we find another thing that will work at the lowest possible dose that is effective. And rather than try to use it all at once—because it’s not a cure situation. It’s a keep-me-going-as-long-as-we-can [situation].

—Allison, 51, white, stage IV, five years since diagnosis. She is on continuous hormonal therapy.

Alexis’ and Allison’s statements echoes Naomi’s statement from above: the medical establishment is not trying to cure metastatic cancer. Irene says there is not enough research. She thinks they’re putting all the research into early stage cancer. They are aware that research is looking to cure early stage cancers so that those survivors never progress to late stage. Money is being poured into screening, as if screening can prevent metastatic. The “catch it early” campaign has somewhat convinced people that screening can prevent cancer altogether (Aronowitz 2001, 2007). The early stage survivors I interviewed also tended to believe that since they caught their cancer early, it would not progress. This may or may not be true, depending on tumor characteristics. But the lack of clinical attention toward curing metastatic

cancer, and the focus on maintenance, is what defines this type of cancer as “chronic.” While being chronic is a better state than being considered terminal or acute, having no prospects of a cure subjects these survivors to conditions of anomie unless they can use some of the strategies I’ve discussed—contracting boundaries, truncating time, focusing on the self—to be able to restrict meaning making to the present moment. Hope, though, is an important part of being able to perceive a future (Mische 2009). Metastatic survivors are cautious in expressing their hope. They do, of course, wish for the best, but the constrained language they use shows how they temper their emotions to the reality of their circumstances. For instance, Anika expresses a “cure” as something she would “like,” although she, like early-stage survivors, plays around with the definitions of cancer terminology to show how meanings have to be able to bend and expand when talking about cancer:

Anika: So, my treatment is like this: I take a treatment; I take a chemo. Well, right now, it is like this. It might change. I’ve actually met women who have had breast cancer, stage IV, who are now in remission or cured, for the—you know, for now. So, I think there’s always hope. I’d like to go there. I’d like to be there. . . . I’d like to be free of cancer.

Me: What does that mean? Does that mean no cancer anymore? Does that mean it’s cured?

Anika: Well, okay. I can be a nitpicker. Everybody has cancer cells in their body. You do, everybody has. But your immune system is capable of keeping them in check and discarding them. They say like, “Oh. Cell malfunction.” White blood cells come in. You know, the fighter cells come in and they destroy those cells. So, the misguided cell, out of control and rapidly growing, happens all the time in everybody. Right? So, if you’re thinking about it that way, everybody has cancer. So, in that way—that would be acceptable for me. [chuckling] Because everybody has that. So, that’s why I’m saying like, I’m not sure exactly what you mean by that. But I’d like to get, ideally of course, to the point

where I have no cancer tumors that are life threatening. I'd like to be out of the woods. And it would be nice if I wasn't dependent on chemotherapy or other medications. That would be wonderful. I'd like that. So, when I say I would like to be cancer free, that's what I mean. I mean, not dependent on medication and not having any life-threatening tumors in the body.

—Anika, 48, white, stage IV. She was diagnosed two and a half years ago. She is on continuous chemotherapy.

Anika expresses these hopes as “I'd like to be...” because she knows how dependent she is on the chemotherapy. She has been close to death two or three times before, once before she was diagnosed, and once when she went off her regimen to attend a naturopathic resort for survivors of various illnesses. There are cases of remission and no evidence of disease in stage IV survivors, but usually not after cancer has progressed to the brain, as it has in her case. She has had brain surgery, which removed the tumors, and is currently on a treatment regimen that makes her feel great. What being “out of the woods” means is hard to determine as stasis can only come with time. She describes at other points in her interview building her immune system back up to the point where her body can be a self-regulatory system. There are currently drugs being developed to target cancer in such a way, but they are a long way from becoming standards of care. Metastatic survivors hope to maintain their current state long enough that some of these treatments become operational, however, in the meantime, they “live day by day” and try to, as Anika continues, “find what joy today holds.”

Conclusion

In this chapter, I have examined particular ways survivors think about cancer: if it is chronic or discrete, if they considered themselves cured or not cured, and how they think about cancer causes. All of these ways that survivors think about their cancer are cognitive strategies for managing anxiety and uncertainty, as medical science cannot comment on what causes cancer at the individual level, which cancers will recur, and which can be cured, other than to offer statistical analyses of risk factors related to tumor composition. Survivors largely decide for themselves how they are going to define “cancer-free” and “chronic”; they may start with the medical definition of these terms, but they imbue these terms with their own meaning. Early-stage survivors do not think about these elements in dichotomous terms: they may not be “cured,” since cancer is not curable, but they largely do not think their cancer is “chronic,” either. They do not find sustaining these seemingly contradictory ideas unmanageable as they employ methods, like bounding time, to harmonize these positions. Similarly, metastatic cancers stretch time by comparing their illness to other types of chronic illness or even other metastatic survivors. While “cure” is not in their future, focusing their attention on smaller segments of time can expand the meaning of those moments, making time feel qualitatively richer and slower. Survivors employed other methods to manage the ambiguity of “not cured but not chronic” or “chronic but longevity undetermined,” as noted above. These

strategies are attempts to solve the problem of cancer's ambiguity as much as they are ways to emotionally manage an uncontrollable situation.

The crux of cancer's ambiguity is its lack of determinant cause. As survivors repeatedly told me, there can be no cure without a cause. I am not sure this is true, but this sentiment is part of the discourse surrounding cancer. Beyond cure, not having a theory of cause also disables survivors from making sense of the event and incorporating cancer into one's life narrative. Ville & Khlat (2007: 1009) note that this lack represents an "absence of link" that survivors need to bridge one area of their life to another in creating a coherent and meaningful narrative. Without an explanation of what causes cells to go awry, survivors may pose what Ville & Khlat call "fantasy causality" to help them link cancer to previous or future parts of their lives. Ville & Khlat find that creating a coherent narrative may remove some of the emotional aspects of the event whereas an absence of link may disable the person from attributing meaning to the event. Being able to craft a narrative helps survivors make sense of their illness experiences and reshape their sense of self (Williams 1984). Sense of coherence can also mitigate the stress associated with disruptive life events (Richardson and Ratner 2005). Having a sense of cause also enables survivors to take direct action, maintaining a better sense of control over cancer (although, depending on personality type, these actions themselves can perpetuate anxiety (Miller 1986)).

In the previous chapters, I have discussed cancer's potential disruptiveness, its effects on identity, and variations in how survivors

incorporate cancer into self-concept. I have also described the strategies and practices survivors employ in creating a new normal, carrying forth their old normal, or merging the two. This chapter shows how survivors conceptualize cancer as a disease and illness experience, but it is also about how they manage ambiguity and uncertainty. How they move forward with, after, or beyond cancer is defined by how they position themselves in relation to these terms. “Cure,” “chronic,” and “cause” are not factual, scientific qualities of cancer but ways of making sense of cancer. Survivors fit their lives within these frameworks, or they fit cancer into their life, based on their definitions of these terms. These basic elements provide survivors a basis to their narrative about cancer that they can then use to make decisions about the future, what is meaningful, and the role illness will continue playing in their lives.

CONCLUSION

The moral imperatives of survivorship: illness as opportunity for self

You know, because there is a dilemma. Like, you know, once you face death, how do you go back and do the simple things? They're just not important anymore.

—Dawne, 64, African American; she was diagnosed with DCIS and had a mastectomy 13 years ago.

In the preceding chapters, I have described some of the cognitive strategies and social practices survivors employ in living with, after, or beyond cancer. Breast cancer is often but not always a disruption to women's lives, destabilizing their sense of self and plans for the future. Depending on perceptions of disruption, survivors may enact particular kinds of identity work, imagining or creating new identities, foreclosing others. These experiences influence how they incorporate breast cancer as a disease, illness identity, and survivor identity into their lives: survivors integrate, compartmentalize, and/or r/eject these components of breast cancer to differing degrees. In addition, survivors may frame cancer as a chronic, incurable disease, as not chronic but also not curable, or as cured, at least for the moment. How survivors employ these strategies matters for how they “move on” following cancer: these conceptualizations help survivors to maintain life “as normal” or to define life as a “new normal”—with, after, or beyond cancer. The “new normal” may be one defined by physical and cognitive limitations from treatment effects, but it is also one largely defined

through a new consciousness or perspective on life. Most survivors in my sample discussed the positive aspects of this new consciousness: they described ways in which they used this new consciousness to improve themselves and their lives.

I have noted that many survivors emerge from breast cancer treatment with a desire to focus their lives on their selves. They use cancer as a catalyst or justification to redraw boundaries and redefine what is meaningful to them. These desires are defined by a particular context in which illness has become defined as an “opportunity,” and illness identities as sources of strength. As I noted in the opening chapter, adaptation of the term “survivor” and the existence of breast cancer identities are recent developments; “survivorship” is a phenomenon enabled by medical developments and molded by cultural factors. Imperatives to use breast cancer as a particular kind of growth experience can be traced to developments in breast cancer history as well as broader socio-historical trends.

However, the type of empowerment and self-affirmation that women express through breast cancer survivorship also points to the limitations and deficiencies they feel in the other structures that currently guide their lives. Women may need breast cancer to present an opportunity for empowerment if current structures constrain their subjectivities and leave them feeling depleted rather than empowered. Without a feminist movement that can direct women and survivors to other sources of empowerment, breast cancer survivorship culture may be the most visible and vocal outlet for women. Women who

conform to normative social standards can experience empowerment and carve out space for the self through breast cancer culture.

The generalization of trauma and expectation of empowerment

Before discussing the ways in which breast cancer survivorship is a unique case, I want to offer the perspective that there is nothing intrinsic to breast cancer that would make it more or less an opportunity for growth and empowerment than other types of experience. In fact, breast cancer is an unlikely candidate for empowerment: breast cancer is invisible, unpredictable, and currently understood to be incurable. According to medical understandings, one cannot exactly “overcome” cancer, and it is odd to think of “surviving” a chronic or ill-defined disease, especially as no other disease employs this frame. When survivors talk about surviving, they discuss the horrific treatments or the uncertainty—for these experiences, “survive” may be an appropriate term. But they acknowledge that cancer is lived with, even if they feel the disease is gone (but not cured).

Embedded within a common discourse of survivorship, though, breast cancer culture draws upon general notions of empowerment through its relationship to other events. Some of the strategies and practices breast cancer survivors employ in “moving on” or creating a new normal after cancer are not that different from those of other types of survivors. Researchers of childhood sexual abuse describe these survivors’ recoveries in similar terms: survivors go through an “increasing sense of visibility, congruence, and connection,” “emerging sense of self-definition and self-acceptance,” “A shift

in worldview,” “A sense of regret over what has been lost,” “A sense of resiliency and growth” (Philips and Daniluk 2004). Survivors of rape and natural disasters also experience ruptures in ontological security that may ultimately empower them, but so, too, might individuals experiencing more commonplace, everyday events (see Becker 1997; Swidler 2001; Frances and Harvey 2015). Survivors seem to go through similar processes of identifying themselves as survivors. Even in the case of community-scale events, these processes can be largely individualistic (see Erikson 1976). For example, Rebecca DiMartino, a survivor of the Boston Marathon bombing, described her post-bombing life in much the same way as the survivors I interviewed described their lives after cancer diagnosis:

Boylston street is such a big part of our lives now and there was so much left there that day and there’s a part of us that’s always going to be there. . . physically. . . and emotionally, I left my sense of peace and security. And now, the only choice that we have is just to try to make the best of everything and not let us be weak and instead be, you know, the popular phrase ‘Boston Strong’” (NPR 2014).

These similarities between type of survivors are not surprising:

“survivorship,” as a concept, is about moving from victimhood to some sense of triumph over the previous trauma. It is a narrative of *individualized* empowerment, even within a collective—of mobilizing the self against loss to claim a new life. The generalization of trauma as a type of experience that should lead to personal growth connects these types of experiences.

The imperative for individuals to actively use these kinds of experiences—whether as “post-traumatic growth,” “empowerment,” “self-improvement” or the like—is one of the most interesting (and new) aspects of

breast cancer survivorship. This imperative may stem from therapeutic culture (Stein 2011). Research implies that traumatic events are defined as those that rupture one's taken-for-granted life assumptions (Kauffman 2002, Janoff-Bulman 1992). The role of therapy is to help the individual reconstruct a sense of security in order to recreate a cohesive self: if trauma ruptures the self, healing the self means creating cohesion, overcoming fragmentation. Reckoning with one's mortality should, we have come to think, lead to some kind of epiphany or understanding of the self—but these are largely cultural beliefs as trauma could just as easily leave an individual in a state of disrepair. Traumatic experiences may, of course, promote self-reflection and growth independent of the demand to do so; trauma blocks the flow of normal life, often forcing people into deliberate thought—and this itself might lead individuals to make life changes. But therapeutic culture's emphasis on growth and self-exploration, combined with larger political forces, like the “expressive individualism” and neoliberalism fostered in the 1970s (see Cowie 2010), has resulted in a climate of individual-level responsibility for the self. Transforming the self into a “project” (Giddens 1991), individuals become entrepreneurs of their own experiences—crafting their experiences into opportunities for self-improvement. This emphasis on the self occurs in differing domains, but it is particularly strong in mental and physical health as those domains capture mind and body.

Many scholars perceive this emphasis on the individual's responsibility for his or her health as part of the neoliberal project: “neoliberalism calls for

the individual to enter into the process of their own self-governance through processes of endless self-examination, self-care, and self-improvement” (Petersen 1996: 49). Armstrong (1993) argues that the “new public health” contributes to the rise of a neoliberal subject who is responsible for self-surveillance and regulation. Rose (2007), among others, argues that maximizing one’s health has become a moral obligation in the 21st century. The “success” of the breast cancer movement and the development of the thriver/warrior breast cancer survivor identity is an outgrowth of these larger cultural shifts in how we perceive the self. Imperatives to use illness as a source of empowerment dovetail with cultural shifts in perceptions of personhood. If the self is a project, logic holds that health would become a domain for self-development and illness, a source of empowerment.

Some scholars are weary of criticizing the new paradigm of health too much, as it has had some positive consequences for women (Griffiths et. al 2014). Feminism and women’s health movements have long demanded women’s involvement in their health care, as doctors have overlooked and patronized their health concerns. Feminism and the women’s health movement may have inadvertently contributed to the rise of the “neoliberal subject” in health, but the trade-off has been that women have increased control over their own bodies, an active role in managing their health, and a proactive role in preventive care. These efforts increase women’s relative power, although they also increase their complicity in self-surveillance and self-regulation. As activated, consumer patients, individuals discipline their own bodies according

to medicalized regimes, which has implications for the extent to which health care and pharmaceuticals manage conceptions of health, the body, and self-improvement. Women, survivors included, tend to participate in these structures in order to feel empowered as players.

Cancer, however, illustrates how little control we actually have over our bodies. Screening practices, harsh treatments, and adjuvant therapies attempt to “tame” the body but ultimately cannot. The responsibility individuals have over their health actually undermines them: cancer is a breach in one’s ability to control the body and, by extension, the self. As such, cancer has to be reframed as an experience. Cancer becomes a “wake up call,” a chance to reclaim ownership over one’s body and life through redrawing boundaries around their selves and social spaces, through taking control of eating and health practices, and through conscious meaning construction. Cancer survivors reappraise cancer as a positive force in their lives, and positivity becomes a way to take control over cancer. But these kinds of narratives would not be possible without cultural emphasis on the self as a project.

The uniqueness of breast cancer as a case

Turning to the singularity of breast cancer: why is it that breast cancer should become a collective identity centered on empowerment? How is it that breast cancer has turned into a positive critical moment for women’s selves? The imperative to craft breast cancer experiences into something useful and beneficial for the self is relatively new, an outgrowth of the social trends I outlined above and throughout the dissertation. Breast cancer is more than

cancer as the culture surrounding it exists almost independently of the disease. And it is different from other types of post-traumatic growth experiences because of this culture, even as it shares many attributes with them. Breast cancer's position as a female illness and a collective identity for women also cannot be understated. While uterine and ovarian cancers may be as harmful, and other diseases, like fibromyalgia or depression as feminized, breast cancer tapped into the social movement and philanthropic field before these others with resounding success. There may only be enough bandwidth in people's minds for a few major causes at a time.⁷ Breast cancer was able to mobilize and unite women around a collective identity unlike other diseases and even unlike other types of female experiences because of the number of women affected, the success of its marketing and fundraising, and its non-normativity yet ability to be uncontroversial. Breast cancer has been able to evade the moral stigma attached to other diseases (or outgrow its own peculiar moral stigma) and has capitalized on its associations with motherhood, femininity, and womanhood. Women with apolitical and normative orientations to the status quo can identify as survivors without feeling like they are challenging the systems that support them, and they gain social acclaim for doing so.

Breast cancer has also become perceived as an opportunity for survivors

⁷ In philanthropic circles, donors are said to have three causes they can support before their attention and donations start to dwindle (I learned this working for a philanthropic development firm); in a different field but for similar reasons, Markovitz and Hellerman (2001) theorize that soccer never caught on in the U.S. because the "sports space" was already saturated with three "American" sports—they theorize that these sports fill attention, leaving no room for a forth major sport.)

because of the extent to which women are constrained by their other social roles. The self has become a project—an important prerequisite—but many women find it difficult to carve out space and time for it. The older women in my study described the survivor-oriented classes and support groups as rewarding because these activities were time they could take to focus on themselves. Younger women found a mission or calling in breast cancer. Against the backdrop of raising children, caretaking for parents, and juggling demanding careers, “focusing on the self” becomes its own reward. Some survivors found breast cancer useful because it actually enabled them to take time out for the self. This comment by Barbara about how cancer has changed her life is not atypical but, given her status as having stage IV breast cancer after 14 years of being cancer-free, perhaps unexpected:

[sighing] I think it’s—I want to hope to say that it’s made me a better friend, a better mother to my children, a better wife. I think because I’m taking time for myself now and doing everything I can for myself, that maybe I’m helping my family too. And you know, I think I’m a better person now. I’m reaching out more to other people that I never did.

....

So, I feel that I’m fortunate now, that I do have extra time, and I can do all this—things for myself, things for my friends, for my family. You know? I think I’m there for people now. When you’re working 40 hours a week and then coming home and you know, just making dinner—you know, you don’t have a lot of time.

Barbara’s comments may seem shocking to those of us on the outside: she has stage IV cancer yet she says she is “fortunate” to have the time now to do things for herself, be a better person, focus on her family. She has the time now because she left her job when her metastasis was discovered. She is focusing on the silver lining in her experience, but she is also giving herself

permission to carve out space and time in her life for the things she did not have before. Sulik (2011) would agree with my assessment that breast cancer gives women the “permission” to focus on their selves and change their lives in ways that create meaning for them. She argues that the caretaking role women play in “normal” life actually primes them for their role in self-care in breast cancer, although they may vacillate between feelings of guilt over their “selfishness” and justification in taking the time and space for the self. I find that women need this space—and that it is a sad comment on women’s lives if an illness provides the rupture to structures necessary for them to access suppressed parts of themselves.

The necessity to use cancer to better one’s self, to give oneself agency and power—but in a way that does not challenge the status quo—has interesting implications. If women need to be empowered through illness, then they are not already empowered. If an event like cancer needs to transform consciousness, then people must not be living consciously until they have an experience like cancer. Breast cancer ironically creates a space for “the self” in some women’s lives where it did not exist or was not prioritized before, if only by rupturing the routines and patterns of everyday living. Yet, also ironically, survivors have to contend with the colonizing discourse of breast cancer culture in order to make this space work for them, to individualize it to their needs and desires. And they have to cope with the disease of cancer, as well. Survivorship culture has been criticized for being for and about early-stage survivors with good prognoses. This may be one of the reasons why.

Being empowered from breast cancer depends on being able to leave the disease behind while retaining the new consciousness enabled by cancer's disruption: the permission to be "selfish" about one's life and self.

A survivor responding to Barbara Ehrenreich's critique of breast cancer culture, featured in *Harper's Magazine*, wrote: "What she would not see—and what she did not see in the activities she scorns—is why we do this" ("Cult or Culture?" 2002:5, cited in Gardner 2006: 216). I would guess that this survivor would say that survivors participate in pink-ribbon culture to commemorate others, ward off fear, and create a supportive community. However, I add that survivors also participate in this culture because survivorship is one of the few mainstream opportunities for "the self" in a larger culture that demands a lot of women but provides little room for them to feel empowered. Women feel that they have been through a battle with breast cancer in a war that never ends; they want recognition for their struggles in breast cancer and beyond. We have defined cancer with these metaphors; it is not surprising that survivors want something to collectively commemorate their efforts and experiences as women and as survivors.

What the case of breast cancer reveals

I began this research thinking about how people move on after a rupture in ontological security. What cognitive strategies and social practices do they employ in redesigning life after a disruptive event? How do they reconstruct conceptions of the self and identity after such a rupture? I thought that breast cancer would be a fruitful case study for investigating these questions, that I

would be able to abstract from survivors more generalizable understandings about these questions. Obviously, this is both true and not true. As I discussed at the beginning of this conclusion, there are ways in which breast cancer is similar to other traumas or disruptive events. But there are also ways in which the case of breast cancer presents a unique perspective on these questions, a partial and biased understanding. Breast cancer answers these research questions in particular ways because of what breast cancer is and means culturally and to individual women.

A large number of the women I interviewed said they did not return to normal after breast cancer. They did not regain ontological security fully. But they found themselves in a context in which they could use ontological insecurity in particular ways. Breast cancer survivorship presents survivors with a social script and an identity immediately upon diagnosis. Advocacy groups created survivorship so that sufferers would not get lost in the disease: they could have structures and practices to help them reclaim life after diagnosis. Survivors use terms like “new normal” to describe the health ramifications of treatments and existential awareness that now permeates life. But this understanding is crafted within support groups and self-help books. The term gives them an ability to feel settled within conditions of unsettledness, which individuals outside of such strong and cohesive cultures may have to develop more on their own.

As survivors define their cancer experience, changes to their selves, and conceptions of normality within the context of breast cancer culture, their

experiences of cancer are as much about the larger cultural and medical understandings the disease as they are about survivors' willingness to participate in this particular culture. A survivor defines her experiences in relation to "survivorship," even if by rejection. Survivorship gives a person a special status and a new identity. Having social scripts and a survivor identity can be helpful to women coming out treatment. But this identity is predicated on cancer not being normalized and survivors not returning to life as normal. Resistance to the normalization of cancer—either through treating cancer like diabetes or other chronic diseases, or perceiving cancer as just a "rite of passage" (Ehrenreich 2001: 49)—highlights the uniqueness of the experience and preserves the possibility for survivorship to be an identity.

Normalizing cancer, treating it as a chronic disease like diabetes, removes the special status assigned to cancer. Survivors want breast cancer to be destigmatized but not normalized. They want their experiences to be marked and socially acknowledged because of the intensity of the treatments and the general reputation of cancer as a deadly disease. If medical research can distinguish between threatening and non-threatening types of breast cancer, and develop less toxic treatment modalities, at least for non-threatening types, this will have a resounding effect on the breast cancer illness experience. If certain types of breast cancer are normalized in this way, then there will be no need for a survivorship identity around these kinds of cancers. Survivors resist normalization now because of the harsh treatments but also because of what the cultural category of survivorship does for them.

Ironically, the survivors who try to normalize cancer the most are ones with metastatic cancer, as the survivorship mentality does not fit their experiences.

Desiring the goals without the means

While survivorship is largely for and about early stage survivors with good prognoses, it is important to consider who, within this group, *can* take advantage of breast cancer as an opportunity for empowerment. The breast cancer movement has always been predominantly white, middle/upper class, and heteronormative. These women have access to the resources needed to transform the experience. Bower et al. (2005) found that women with household incomes over \$100,000 reported higher levels of positive meaning and vulnerability, theorizing that these women “may perceive cancer as being more threatening and may also be better positioned to accrue the positive consequences of stressful events” (243). They also found African American women reported higher levels of “positive meaning” but not vulnerability from their cancer experience in comparison to white women, consistent with prior research; they linked this finding to the role religiosity/spirituality may play in post-traumatic growth (ibid). Pathways to growth may be different depending on levels of vulnerability. But, to a large extent, it is a privilege to be able to frame cancer as an opportunity and to harness the existential uncertainty felt in order to make life-affirming changes.

While, from a Foucaultian-Rose perspective, the need to be empowered by breast cancer is conceived of as a type of social control, being able to be empowered by illness also reflects other conditions. Women’s ability to

harness existential uncertainty in order to make life changes is perhaps what Lorde (1980) means when she discusses the distinction between “self affirmation” and “superficial farce.” Self-affirmation, like in Maslow’s hierarchy of needs, depends on having one’s foundational needs addressed first. Many women do not have the necessary psychosocial resources and social and financial support to use cancer as an opportunity.

The imperative to be a particular kind of survivor, to beat cancer and be empowered, might force survivors who cannot translate breast cancer into a growth experience into a worse psychological state than they would have been otherwise. However, this may only be the case for those who *want* to follow these injunctions, who believe in their cultural underpinnings—in other words, those who conform to the social messages surrounding survivorship. For example, Margaret, who I introduced in previous chapters, ended her interview in tears, feeling:

Like, I’ve just got to keep moving, keep moving, keep moving, keep moving. And I don’t have time to reflect the way I ought to I guess. There are things in life that I’m a little more frustrated with, I think, because—I don’t know why. Maybe because I went through all of this, and I realize that—how quickly things can change. . . .

But at this point, there’s not a whole lot I can do. I still feel a little unable to make changes.

Margaret, even though she works five minutes from a breast cancer organization that provides information and support services, does not benefit from its existence. She wants to be able to make positive changes in her life—she feels she “ought to”—but does not have the support at home, the time off from work, or the personal resolve to tap into the services she wants. Not

everyone has the psychosocial tool kit to be able to take advantage of cancer as a growth experience or derive meaning from these types of experiences—but not everyone frames cancer in this way, either.

The importance of living the examined life that Lorde emphasizes, of finding one's "own internal sense of power," may not be an available and realistic model of existence for all people, and not every survivor needs or wants to make their cancer experience into something meaningful (Kernan and Lepore 2009). James Jasper, in theorizing how "moral shocks" can open people's field of vision, leading them to act in particular ways, acknowledges that "responses to moral shocks vary greatly. Most people, in most cases, resign themselves to unpleasant changes" (106). The difference in cases like Margaret's, though, is that she wants to make changes and benefit from taking survivorship classes—she just feels unable to do so.

Interventions for harnessing insecurity

While many of my participants wanted to use cancer as a catalyst for self-growth or change across life domains, certainly not all of them were able to do so. Survivors who want cancer to be transformative but cannot make these transformations on their own are a critical population. As Merton (1968[1957]) outlined decades ago with his theory of strain, conforming to cultural goals but not having access to the right means can produce psychological strain. Survivors who follow cultural imperatives but cannot fulfill them may be left in more vulnerable positions than those who ignore or defy them.

Survivorship programs are usually the first response to survivors in need, but, as is shown in Margaret's case, the demands of survivorship are overwhelming. Survivors like Margaret need help negotiating the demands of survivorship itself. More "groups" are not the answer—at least not immediately for these kinds of survivors. Groups like Komen exist to advocate for the survivor identity; the spaces they design are not ones in which survivors can learn how to embrace their vulnerability and make it work for them—they are ones that ask survivors to overcome vulnerability. Support groups are designed to help survivors with their psychosocial needs, but, being subject to the dynamics of group members, these spaces are hit or miss in terms of helping survivors learn to harness their ontological insecurity.

The Institute of Medicine (Hewitt 2003) recognizes that many survivors are lost after treatment; once survivors leave the "safety net" of treatment, they often feel that they are doing nothing to manage or prevent cancer. Behavioral researchers have been focused on the transition from active care to follow-up care, debating when the best time for psychosocial interventions might be: after diagnosis is too early, after treatment may be too late as survivors disappear for months from medical surveillance. They acknowledge that survivors need continuous and dynamic attention to their concerns throughout the course of survivorship, but funding this kind of research and implementation is limited when grants are geared toward biomedical research.

However, assessing how and what survivors think about cancer, not just their positive or negative "adjustment" to cancer, and how they want to move

forward—with, after, or beyond cancer—would be an important first step in designing interventions. As I have discussed, survivors employ different strategies for keeping life normal, returning to normal, or creating a new normal. These strategies are predicated on if they think about cancer as chronic or discrete, if they perceive cancer as disruptive, and if they want to use cancer as a catalyst for self-transformation. These domains need to be assessed in one-on-one interviews by existentially minded cognitive therapists in between their follow-up visits or in tandem with visits to their oncologists' offices. While it may be a limitation of my ability to think outside of therapeutic culture, and perhaps problematic to suggest a therapeutic solution to a problem partly created by therapeutic culture, survivors were overwhelmingly positive about participating in my research. I gave them a space to talk about issues they had not been able to discuss before—with family, friends, social workers, support groups, and especially not their oncologists. I also attributed importance to their stories. Simply listening to them, giving them the space to construct a narrative about their particular survivorship experience, was useful to them. One-on-one work with someone who is trained to help survivors address existential questions can help them harness the uncertainty they feel instead of allowing it to become paralyzing or debilitating.

Many survivors become involved in community cancer organizations, advocacy efforts, and lifestyle groups because these are sites that allow them to tap into—and not ignore or deny—the uncertainties and insecurities they

feel. They have the personal resolve to participate in these groups without feeling overwhelmed or burdened by additional demands. Other survivors may be able to address the ontological insecurity they feel on their “own,” with the support of family and friends. But the group of survivors I am discussing here needs help framing ontological insecurity as a resource to employ, not something to move beyond or deny. They need a safe space in which they can acknowledge these uncertainties as part of their new realities. Learning how to harness the ontological insecurity they feel, and being given the support and resources to be able to do that, is important for these survivors. Breast cancer culture presumes that survivors will be able to empower themselves by overcoming cancer. Survivor groups can provide support, but they enact their own demands on survivors. Helping survivors understand the nature of their goals and perhaps push back against the demands of breast cancer culture and these groups can help them retool their cancer experiences in ways beneficial to their individual experiences.

Appendix A

Methodology

For this project, I conducted 80 semi-structured, in-depth interviews with female breast cancer survivors. My sample is not random, but purposive. I interviewed survivors of all stages of breast cancer from three community cancer support-based organizations and one NCI-designated cancer center support group, all in New Jersey. I also recruited participants through snowball sampling, asking these participants to hand my information to others they thought may be interested and through asking my own social network to reach out to their friends and colleagues about my research. In addition to interviews, I volunteered at several cancer events held by different organizations, including the ones from which I recruited volunteers, so that I could understand more about the breast cancer community and breast cancer activism. I had several informal conversations with survivors about my research at these events, which informed my thinking about various topics. During the beginning of this project, I also worked at an NCI-designated cancer center, learning about breast cancer from within the world of cancer research and outreach.

Because of how I recruited participants, my sample holds some selection bias. People who belong to community organizations or support groups have the desire, self-assessed need, and available time and resources to attend, and thus represent a certain kind of person: they are invested in their cancer identity or in promoting cancer research; they want to belong to a

community of cancer survivors—which involves hearing and sharing experiences; and they have the support from their family, friends, employers to attend. The women who joined my study volunteered—they contacted me—because they wanted to promote cancer survivorship and have their experience make a difference: they wanted to tell their stories in hope that they could fill voids they perceived in the cancer literature, address gaps between medical and life worlds or even between professionals within the medical field, and help others suffering with or through breast cancer. These women had attended meetings, workshops, support groups or events in the past or continued to do so, or they had signed a listserv for information about these things through one of the organizations I contacted. Because of their involvement or desire to be involved in these organizations, participants' narratives were shaped by the information received and the forms of talk produced at these venues to differing extents. I analyzed the interviews with this in mind. However, I wanted to recruit breast cancer survivors who had thought about what cancer meant to them, had “worked on” processing their experiences, and who could be descriptive in informing me about the emotional and existential cadences of their experiences. Starting with members of these organizations and then sampling their friends and contacts (and my own) ensured that I would hear richly detailed, thoughtful—although not necessarily coherent or smooth—narratives. I want to emphasize, though, that many of my participants were not active members in community organizations or support groups; many had signed up at one time, perhaps

early in their treatment, and were still on listservs even though they no longer attended events and meetings.

I have worked on other studies on cancer survivorship as an interviewer and/or data analyst (Hudson et. al 2012; Friedman et. al 2012; Balasubramanian 2010) and have noticed little substantive difference between survivors who use support groups and those who do not in terms of their medical experiences, how they thought about their illness, or what they wanted out of life moving forward: the trajectory of experiences were common between breast cancer survivors regardless of whether they attended a group or not, as were many of their appraisals of and feelings about their experiences. Support group use becomes vital when individuals do not have the individual coping skills or support network to help them. Because of location, my sample (as well as these others I worked on in the past) was skewed toward high-income, highly educated women. Most of these women did not “need” to belong to a support group—they had support networks, research skills, financial resources—but they wanted to go. The reasons for going ranged from looking for camaraderie to wanting to stay abreast of new research findings to wanting to find a way to give back to the community or support other women. I found that the cancer survivors who were active participants in community groups may have been more *outwardly* engaged in their survivor identities in everyday life than those who were not, they may have been more invested in therapeutic culture, they may be more assertive in getting their needs met, or cancer may be more central to their thinking about

themselves than those who do not belong—or they may not be. People who do not join community organizations may feel just as deeply about their experiences and identity but look to other, more individualistic outlets for information and support. Importantly, involvement and intensity in cancer identity and survivorship organizations vary across one's illness career and in relation to particular cues and events so that what a person wants now may not be the case months later.

Just as the reasons and motivations for group involvement vary, so do reasons for not joining or being highly involved in these organizations. The survivors I interviewed for this study who did not participate in survivor groups at the time of interview tended to not belong for four main reasons: they felt they had other, adequate support networks; they perceived support groups to be based on emotional support rather than the medical knowledge they wanted; they did not want to “give more time to cancer” or were in the process of transitioning out of “cancer survivor” as their main identity (see Howard 2008). One person told me that she wanted to be more involved but did not have the time; and another survivor of metastatic breast cancer felt out of place at the multi-stage survivor group she sometimes visited. All of these reasons have been discussed in cancer research, but I mention them here in order to discuss the potential bias of my sample. Most people were at some point in their illness careers involved in a cancer-organization or group or participated in cancer fundraising events. A few expressed skepticism about

pink-ribbon marketing and groupthink. But all were open about their cancer identity, divulging their cancer to coworkers, family members, and friends.

More important than group membership in terms of potential sample bias, I find, is the desire to talk about cancer experiences to a social science researcher. Participants knew I wanted to talk about their experiences and cancer identity but also their thoughts about cancer, medicine and science. They knew I was not a therapist or counselor but a researcher. They wanted their experiences to be translated into a message that could help other women. This motivation set the tone for the interviews and helped us discuss difficult material. Telling painful stories had a “selfless” purpose: I was there to analyze and translate their personal stories in order to help someone else, not to offer advice or therapeutic support (although I do think the telling and retelling of one’s story has therapeutic effect no matter whether the listener is a therapist or researcher). This kind of self-selection bias did seem to help provide a candidness and richness to the interview content. I let participants guide the discussion toward topics they felt were important as long as we addressed my key questions. As my project is about how people think about cancer, I wanted to select people who have consciously engaged with this inquiry. In addition, because I am not trying to generalize my findings across all cancer survivors, but want to discuss strategies for grappling with questions about ontological security and practices of creating a new normal, sampling from community and support groups ensured that I interviewed people who were mentally engaged in their cancer management. As I only interviewed

people finished with their active treatment or, if metastatic, were at least a year past their diagnosis date, these individuals had had time to think about what cancer means to them and to create a working narrative for moving on with or beyond cancer.

In reviewing other scholars' published qualitative studies, I recognize many of my participants' sentiments in their participants' quotations, which also supports the idea that there is a common foundation to the survivor experience. Survivors have lived through an intense illness experience; they have transitioned into or are in the process of transitioning into acceptance of cancer as a chronic condition for which they will need lifetime monitoring.⁸ Unlike recently diagnosed, active patients, survivors have embarked upon an "illness career" (Kleinman 1988); they have already spent some time processing new information and experiences, incorporating changes (or resisting them) into their previous schemas, understandings, and practices. Over time, survivors' illness careers may include recurrences or bouts of new cancer, or they may be medically uneventful but psychologically and socially challenging. As such, survivors' status as chronic disease managers—while by no means ensuring a monolithic illness experience across them—positions

⁸ This is by no means the only definition of "survivor," but it is similar to that espoused by the National Cancer Institute: "One who remains alive and continues to function during and after overcoming a serious hardship or life-threatening disease. In cancer, a person is considered to be a survivor from the time of diagnosis until the end of life" (National Cancer Institute 2009). Membership groups often embrace a broader definition of "survivor," including active patients and family members or caretakers – anyone experiencing cancer as an illness if not directly as a disease. While this broader definition is useful for coalition building and political activism, my intent in studying survivors is to study them as chronic disease managers.

them for several rounds of cognitive “grappling”: They may reach different “understandings” of cancer at different points in their illness careers, revising understandings in relation to new medical or self knowledge. In addition, as breast cancer has become positioned as a chronic disease by the medical field due to a variety of factors—more screening and earlier detection, more and earlier treatment, greater number of survivors or early-stage breast cancer—survivors may vacillate in how they think about their illness: worst-case-scenario fear competes for space with more manageable (even if severe or troublesome) health concerns like lymphedema, bone deficiency, and heart problems. Focusing on the effects of treatment or on the pacing of extended follow-up care may distract survivors from thinking about recurrence and death from the disease. Thinking about cancer as a chronic disease, akin to diabetes or heart disease, may diminish or suppress some of this threat, as well. The survivorship of cancer has enabled the disease to enter shared metaphorical territory with other chronic diseases. This matters in terms of how cancer is thought about as it is incorporated into the life course and the strategies people use to move forward after diagnosis.

Research Design

Demographic Data for Study Participants(N=80)		
Characteristic		
<i>Age</i>	Mean = 54 Range = 25-75	
<i>Race</i>	%	n
White	72%	57
African American/black	21%	17
Asian	6%	5
Latina	1%	1
Ashkenazi heritage	9%	7

<i>Household Income</i>	%	n
<60K	21%	17
60-99K	26%	21
100K	46%	37
DK/NA	6%	5
<i>Education</i>		
High School	18%	14
2-year degree	8%	6
College	38%	30
Advanced	38%	30

Cancer Characteristics of Study Participants (N=80)		
<i>Stage</i>	%	n
0	15%	12
I	24%	19
II	36%	29
III	10%	8
IV	14%	11
	1%	1
<i>Time Since Treatment</i>		
< 1 yr.	29%	23
1-4 yrs.	41%	33
5-9 yrs.	18%	14
10+	12%	10
<i>Treatment</i>		
Mastectomy	49%	39
Lumpectomy	55%	44
No surgery	3%	26
Chemotherapy	65%	52
Radiation	70%	56
Surgery, chemotherapy and radiation	46%	37
<i>Recurrences</i>	6	
<i>Second breast cancer</i>	4	
<i>Recruitment Site</i>		
Cancer center	9%	7
Community organization	70%	56
Snowball sampling	21%	17

Sampling Frame

Participants were female survivors of breast cancer; 18 years of age or older; English literate; and physically, cognitively and emotionally able to participate in a 60- to 90-minute interview. If early stage, participants had to be finished with their active cancer treatment (initial surgery, chemo and/or radiation but not adjuvant or hormonal therapies that are considered part of their follow-up treatment) for at least three months; if metastatic, patients had to have been diagnosed at least one year prior to participation in the study.

I recruited survivors of early stage as well as metastatic breast cancer in order to maximize variation of type of treatment and intensity of medical intervention into the daily lives of survivors during both their active treatment and survivorship periods. Type of cancer and type of treatment may predict intensity of medical intervention. Interviewing breast cancer survivors of various types of cancer and types of treatment will allow me to ascertain whether cognitive strategies for disease management vary widely or are similar depending on cognition of cancer and/or intensity of medical intervention.

As individuals volunteered for this study on a rolling basis, it was not possible to guarantee specific numbers of participants based on specific social and demographic characteristics. However, I monitored recruitment to maximize diversity, paying attention to variables of interest to my analysis: race and ethnicity, age, income, education, type of cancer treatment, location of treatment, intensity of medical intervention, and years from diagnosis. I

aimed to capture sufficient diversity of these variables in order to cluster participants into subgroups of sufficient size to use in analysis. My intent was not to make generalizations for particular subgroups from this study but to explore topics deeply within them, noting any differences across subgroups that should be explored more in future research.

In writing about my participants, I gave them all a random pseudonym. I list their “active” treatment—meaning the treatment they had while under active care of their oncologist. I did not list any adjuvant therapies survivors take during their follow-up care, but most survivors take a hormone therapy, like Tamoxifen or Femara, or an Aromatase Inhibitor for five to ten years after active treatment.

Recruitment Strategy

I procured participatory agreements with three community cancer survivor organizations and one NCI-designated cancer center support group in central New Jersey. Because of the location of these organizations, the average income and education of members is higher than the national average; however, each organization was selected for its ability to attract diverse populations to my study: one group has a “youth” branch, for women under 40; one group is specifically for African American women; and one group has tailored meetings for survivors of metastatic breast cancer (women with metastatic cancer often report feeling unwelcome in groups for all stages of cancer or that these groups do not suit their needs). The three community organizations offer support services and educational resources for cancer

survivors and hold various activities and benefits where members congregate. To recruit participants, I placed an announcement in a newsletter and email blast for one organization, spoke at well-attended meeting for two of the organizations, and had the program directors and social workers introduce my study during support groups. Participants called or emailed me to enroll in the study. After conducting interviews, I asked participants to refer me to other cancer survivors they know. I thought this would accomplish two things: a more diverse sample and also a sample of non-support-group cancer survivors. I gave every survivor a thank-you package that included a tin of Tazo® green tea, a thank-you note, and a flyer for the study.

Interview Protocol

Interviews lasted between 45 and 150 minutes, most being 60-90 minutes. I conducted interviews in person at the participant's home, my office or designated space at the community organization, or a location of their choice that offered sufficient privacy. Participants were assured of the confidentiality of their interviews and personal data. I read the consent form with each participant in person, asking her to initial each page before signing the complete consent form. I provided each participant a copy for her records. I assured each participant that she could skip any question she did not want to answer and that she could withdraw from the study at any time. I also created a list of information with social support and cancer support services ready to offer any participant if she seemed distressed by the content of the interview, although use of this was never necessary.

Interviews focused on three domains of the cancer survivor's experience: entry into the world of cancer, understandings of cancer as a disease, and conceptualizations of self across the illness experience. I asked about their abstract thoughts about cancer; their experiences of diagnosis, treatment, and post-treatment survivorship; their experiences of the medical field during each of these phases; and their cognitive and practical strategies for managing cancer as a chronic illness. My interviewing style allowed the conversation to veer into areas the participant deemed important. I veered back to questions as they seemed relevant to the conversation, making sure we covered the content of all question areas during the interview. I started each interview with a short survey of demographic and health-related information. Please see Appendix B for the interview schedule.

Data Analysis

The audio recordings and verbatim transcripts of interviews, my field notes – which I recorded after the interview – and any other correspondence I had with interview participants, like follow-up emails or phone calls, comprise the original data for this project. I used an immersion/crystallization approach for analysis of interviews, which consists of cycles of reading the transcripts, summarizing themes, and rereading the interviews again after creating this list of themes to code throughout the interviews (Strauss and Corbin 1998; Crabtree & Miller 1999; Denzin and Lincoln 2000). I ascertained themes by the prevalence of similar sentiments across interviews and by the “weight” attributed to particular quotations or sentiments by the participants themselves.

I broke these themes into components in order to code segments with more specificity.

Following this method, I derived codes mostly through deductive analysis; however, I did use several inductive codes related to specific questions asked during the interview. For instance, I was particularly interested in whether or not survivors perceived cancer as a chronic disease or illness. I created a code for “chronic” to mark passages where participants discussed this aspect of cancer. An example of a deductive code that arose from the data is “new normal” as many participants either used that phrase or described this state during their interviews. These findings form the basis for my chapter design.

I entered all transcripts and audio files into Atlas.ti software (Scientific Software Development 2010) in order to be able to filter codes by demographic data and cancer-related variables obtained in the first part of the interview. I filtered pertinent codes according to the survivor’s membership categories—i.e., stage of cancer, type of treatment, years since active treatment, race/ethnicity, age—in order to analyze differences between groups in terms of cognitions and experiences. I sorted and sifted the quotations attached to the particular codes into the themes presented in each chapter.

Appendix B

Interview Schedule

Opening:

First of all, let me thank you for agreeing to participate in this study on cancer as a chronic illness. This study is part of my dissertation research in sociology at Rutgers University. I am interviewing about 60 participants about their experiences with cancer from diagnosis to the present.

As you know, the purpose of this interview is to talk about your experiences with cancer – how you think about and manage cancer, what your experiences with doctors and the medical field have been like. Please be assured that I will keep this interview confidential. You’ve been assigned a code so that your name will not be linked to your comments here today. I will be recording this interview but will delete any information that could identify you to other people. I will not use your name in any reports or publications.

For the interview, I’m going to start by asking you some basic background questions about yourself and your cancer treatment. Then I am going to ask you some open-ended questions. Interviews usually last around 60 minutes. Please know that you may skip any question that makes you uncomfortable; however, it is important to the study that all participants answer each question as fully and honestly as possible. Again, no one else will have access to your name in relation to anything you say here today.

Do you have any questions before we start?

Great, let’s get started. I’m going to turn on the digital recorder now.

Part 1: SURVEY PORTION

This first part includes some basic background questions about you and some basic questions about your cancer history. Please remember that you may skip any questions you choose.

1. What is your age?
2. What is your current marital or relationship status?
3. What was your marital or relationship status at the start of your treatment?
4. What is the highest grade of school or year of college you completed?

5. Are you currently employed?
☐ Full-time ☐ Part-time ☐ Not employed ☐ Retired
☐ Seeking employment
6. Were you employed during your diagnosis and treatment?
☐ Full-time ☐ Part-time ☐ Not employed ☐ Retired
☐ Seeking employment
7. If applicable: What field of employment do or did you work in?
8. Do you currently have medical insurance?
9. Did you have medical insurance at the time of your diagnosis?
10. What was your household income last year, approximately, before taxes?
 [“Household” includes all income that contributes to household expenses.]
☐ less than \$20,000 ☐ \$20,000 – \$39,000
☐ \$40,000 – \$59,000 ☐ \$60,000 – \$79,000
☐ \$80,000 – \$99,999 ☐ Over \$100,000
☐ Don’t Know ☐ Chose not to answer

These next couple questions are about your cancer history:

11. What stage was your cancer?
12. What treatment(s) did you have for cancer?
13. Where did you receive your treatment(s) for cancer?
14. When was your last active treatment for cancer (i.e., surgery, chemotherapy or radiation treatment?)
15. [I know that you participate in programs here at _____, but do you belong to any other] [Do you participate in any] support groups or cancer-related events? Which ones?
16. Have you participated in any [other] support groups in the past?

PART II: INTERVIEW

Theme A: entry into medicalized system for cancer

Now we are going into the open-ended part of the interview. I want to let your experience guide our conversation, but I do have a few questions I may ask you. First, I would like to hear about your experiences getting diagnosed and treated for breast cancer.

1. Can you tell me about what led up to your diagnosis of breast cancer? What caused you to seek medical attention at that time?

Did you or anyone close to you think something was wrong? (Were you having any symptoms?)

Did you suspect cancer was a possibility at this time?

Whom did you seek care from? How did you know what doctor(s) to seek out for your cancer care?

2. Did you know anything about cancer prior to your diagnosis?

Did you have any “medical” knowledge about cancer?

Did you have any personal experience with cancer? Did know anyone who had had cancer? Had anyone in your community/circle of friends ever talked to you about cancer? What did they say?

Had you noticed media coverage on cancer, like TV or magazine articles or ads? Do you remember any examples in particular?

3. Do you remember what your doctor told you when you were diagnosed?

Do you remember how s/he described the cancer?

How did you decide what treatment you were going to receive? (what did you have?)

Where did you get your information from? Did you do a lot of your own research?

4. Can you describe what happened during your cancer treatment(s)?

Where did you go to have [treatment]? What was it like there? How did you feel being there?

How did you feel about the medical equipment used in your treatment – what was your experience of that?

How much technology was involved in your treatment?

Was your cancer treatment generally what you had expected, or did you envision that your experience would be very different?

5. How easy or difficult was it talking to your doctors about cancer?

Did they use medical or common language to describe what was going on?

Did you have to learn new information to be able to talk to your doctors?

6. How did you balance other aspects of your life with your cancer treatments?

7. Do you feel you ever got back into your “normal” routine when treatment was over?

How involved were your doctors at this point?

Did you experience any difficulties or challenges at this time?

Did you have any thoughts or expectations about what life would be like after your treatment ended and recovery began?

8. How often do you see doctors and others in the medical field now?

What do you do in terms of caring for your cancer now?

Do you have any cancer-related issues you see doctors for now?

How do you feel about the role doctors and medicine play in your life?

Do you feel comfortable in medical spaces, like doctors’ offices, clinics or hospitals?

Theme B: Health/Medicine/Technology

I want to now ask you some questions about how you think about health, your experiences with medicine, and your interactions with doctors and others in the medical field.

9. How did you think about your health before you were diagnosed with cancer?

What kind of patient would you say you were? Would you go to doctors as a preventive measure, like for an annual exam, or only if you felt something was wrong? Did you do anything outside of doctors for your health (like take vitamins or medications, exercise, “alternative” health care, etc.)?

Before diagnosis, did you feel that health is something people need to work at or that health and sickness are things that just happen to people?

Has the way you think about health changed as a result of having cancer? How so?

10. Did you spend much time around doctors or in hospitals before you were diagnosed?

Did you have regular appointments with any doctors?

Did you or someone close to you ever require any extensive medical attention?

Can you recall any vivid experiences with doctors or medicine? For instance, do you remember getting blood drawn for the first time or getting a shot? Do you recall how you felt about doctors or medicine at this time? About the medical equipment or tools?

11. Did you have any particular impressions (good or bad) of the medical field before you were diagnosed?

What did you think about doctors, for example – did you respect doctors? Were you disappointed by doctors? Did you think doctors were trustworthy or “quacks”?

How did you feel about medicine and medical technology before you were diagnosed? Like, did you ever avoid certain kinds of medications/treatments? Did you feel that western medicine is a godsend or potentially harmful?

Has any of this changed since having cancer?

12. Has your perspective on the medical field – doctors or medicine – changed since having cancer?

How comfortable are you discussing things, medical or personal, with doctors now as opposed to before?

Do you react any differently to medical equipment that might need to be used in exams now? For example, how do you feel about needles now? Latex gloves? Big machinery like mammography or MRI machines? X-ray machines?

Theme C: Cognitions about cancer/chronic illness

Lastly, I want to ask you some “abstract” questions about cancer in general and what having cancer means to you.

13. Can you describe to me how you think about cancer?

What is [type of] cancer?

Do you have thoughts about how one “gets” cancer?

Do you think cancer is a chronic illness?

Do you think you still have cancer?

Do you think cancer can be cured?

14. What does “having cancer” mean to you?

What do you think of the term, “cancer survivor”?

15. How often do you think about cancer?

When do you think about cancer the most? What usually triggers your thinking about it?

Do you think about cancer differently now than when you were first diagnosed?

What kind of thoughts do you have when you think about cancer?

16. Has cancer changed the way you think about the future?

17. At this point, how would you say having cancer has impacted your life?

Is your daily life any different now, after being treated for cancer?

Have your relationships changed as a result of having cancer?

Do you think about yourself differently since you were treated for cancer?
How so?

Do you think about your body differently now than before you were diagnosed?

Do you think about illness any differently since cancer?

18. My last question for you today: a lot of people talk about things they've learned – good or bad – through having cancer. What “life lessons,” if any, has cancer taught you?

Has cancer changed your outlook on life?

Thank you very much for your time and for answering these questions as fully and honestly as you did. I appreciate your time and help. Before we end, I wanted to ask if there is anything you would like to add that I have not asked you.

Do you have any questions about this study, now that you have finished the interview?

I did want to ask you some questions about your involvement in the study:

Would it be OK with you if I contact you if I have any follow-up or clarification questions?

I also wanted to ask you if know any cancer survivors who you think would like to participate in this study.

Would you be able to tell them about this study and have them contact me, or perhaps make an email or phone introduction for me? Can I follow-up with you about this contact if I do not hear from him or her?

Thank you again for all of your help. I wish you all the best.

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