

The Gendering of Cancer Survivorship

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Abstract

This article examines the relationship between gender and cancer survivorship. I argue that gender is as critical as a category of analysis for understanding cancer survivorship as it is missing from survivorship studies, particularly as concerns the identificatory basis of survivor culture and clinical studies regarding survivors' quality of life. This under-studied question of the gendering of survivorship is critical because the consequences of the social production of disease is far-reaching, from the nature of medical research to social awareness to funding to the well-being of cancer survivors themselves.

Keywords: cancer; quality of life issues; survivorship

The Gendering of Cancer Survivorship¹

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I. Introduction

Coined in 1986 by the National Coalition of Cancer Survivorship (NCCS), the concept of cancer survivorship has come to be one of the simultaneously important and problematic developments in the social and political representation of cancer. The concept's definition—as the large body of scholarship that has arisen around survivorship has shown—is widely contested, most commonly over the question of who is and who is not to be considered a survivor. Most controversially, critics express concern about the concept's focus on the living, wondering how the celebration of those still living with cancer shape our understanding of the vast numbers of cancer's deceased victims (Ehrenreich 2009). Later NCCS conceptualizations came to include family members, friends, and care givers (Twombly 2004).

In 1996, the U.S.'s National Cancer Institute (NCI) established the Office of Cancer Survivorship, “in recognition of the large number of individuals now surviving cancer for long periods of time and their unique and poorly understood needs” (National Cancer Institute). In response to the intensification and proliferation of survivorship discourse, what began as a seemingly uncontroversial coinage that was contested mainly on the basis of the terms of membership and geared primarily toward self-help (Hoffman 1996), quickly became a complicated social category that raised questions of identity and even repression. These questions included the proper disposition of the survivor (Creagan 1997), and the forms of social power that survivorship propagates insofar as survivors are located in regimes—medical as well as cultural—that were being increasingly recognized as part of unarticulated normative projects that force survivors to play certain social roles (Lorde 1997). These roles, of course, make disease a political and cultural project that often runs roughshod over the contexts in which particular survivors may locate themselves, especially at the intersections of sexuality (Arrington 2000) and race. Fast-changing developments in cancer treatment have increased the number of survivors (definitional questions notwithstanding) from three million in 1971 (when the NCI was founded) to roughly twelve million today (Valdivieso et al 2012). Accordingly, survivorship studies have developed from a loosely formed attempt to conceptualize this new population category into a highly-specialized subdiscipline standing at the intersection of oncology, sociology and other social sciences and humanities fields. For example, recent literatures have emphasized the extent to which this increased pool of survivors raise issues such as the synergy of “late-effect” and chronic conditions in adult survivors

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of childhood cancer (Oeffinger et al 2006); behavioral and health issues specific to various survivor populations (Sabatino et al 2007); the relationship between survivorship and social and legal challenges posed by unemployment (de Boer et al 2009); and difficulty accessing health care coverage (Park et al 2005). For better or for worse, disease carries with it—and is constructed through—social meaning (Sontag 1990).

This suggests that patients' decisions whether or not to seek membership in "survivorship" comes with consequences as well as potential benefits (Harwood et al 2003). At the same time, however, and crucially, the boundaries of the category "survivor" are fluid and not fixed. As such, it seems clear that survivorship can, must—or at least should—be negotiated in creative and personal ways. This essay seeks to contribute to this survivorship literature by explaining why gender is as critical as a category of analysis for understanding cancer survivorship as it is missing from survivorship studies. This is particularly the case, I suggest, as concerns the identificatory basis of survivor culture and clinical studies regarding survivors' quality of life (QOL). This under-studied question of the gendering of survivorship is critical because the consequences of this aspect of the social production of disease is far-reaching, from the nature of medical research to social awareness to funding to the well-being of cancer survivors themselves. Indeed, the stakes of *not* engaging the gendering of survivorship are high.

Given its centrality to understanding human behavior, gender—by which I mean, in essence, the performative navigation of socially-sanctioned roles of masculinity and femininity—is basic to the experience of disease. To understand the role it plays in cancer survivorship specifically, I advance my argument in three steps: First, using the well-known "ribbon" campaigns as a touch-point, I examine how gender shapes the social representations that have congealed around survivorship. Second, I evaluate the role that gender plays in shaping the narratives of cancer survivors themselves. Here, I focus primarily, though not exclusively, on how cyclist Lance Armstrong negotiated his cancer treatment in relation to his gender identifications, and then use these insights to think about gender, sexuality and the experience of survivorship. Finally, through a critique of an important collection of clinical survivorship studies—which I hold up as representative of the broader field of survivorship literature—I ask what role, if any, gender tends to play in the fledgling industry of survivorship studies. The central goal of the chapter is thus to present a broad account of the gendering of survivorship in order to explain why gender must be moved to the forefront of both clinical and social engagements with cancer.

Pinks, blues and the cancer ribbon

One of the clearest articulations of the gendering of survivorship issues from the large industry of survivor products sold by organizations such as Hope and Dreams, Personalized Cause, Healing Ribbons, and beyond. To make sense of the particular dynamics of this industry, I focus primarily on Hope and Dreams, which describes its mission in the following statement:

Hope & Dreams Cancer Awareness T-Shirt Store sells unique cancer shirts, apparel and gifts designed by cancer survivors to promote awareness for Hodgkin's Disease, Non-Hodgkin's Lymphoma, Lymphoma, Breast Cancer, Leukemia, Lung Cancer, Thyroid Cancer & Funny & Bold Cancer Shirts to inspire & empower the warrior, survivor and their supporters to fight strong.³

Hope and Dream's line of products to "promote awareness," "inspire" and "empower the warrior" utilizes a system of color-coding that many cancer organizations have utilized to "support" cancer survivors, but that seem to

³ "Cancer Awareness T-Shirts & Gifts," <http://hopedreamsdesigns.com>

contribute to the constitution of the experience of survivorship itself. A cursory consideration makes clear that the coding system advances a series of gender stereotypes, perpetuated not only by the classic “pink” of breast cancer, but a whole range of pastels and primaries for each kind of cancer. Indeed, this gendering is one of—if not the—primary way in which cancer ribbons interpolate survivors into survivorship culture. Nonetheless, keeping track of these various representations is difficult. One woman commenting on the Relay for Life web site lamented: “according to this list I have been wearing the wrong color ribbon on my purse for the last 18 months, But, I've gotten 3 different colors from 4 different websites. I am so confused” (Relay for Life). The list is striking for its apparent comprehensiveness, which amounts to an attempt at encompassing the full range of bodily vulnerabilities vis-à-vis cancer. As such, the list is also taxonomically erratic, dealing in particulars in many cases (as in kidneys and ovaries) and generalities in others (childhood, gynecological cancer). In other cases, the choices are extraordinarily literal, such as brown for colorectal and colon cancer and yellow for bladder. For missing, unspecified, or comparatively rare cancers (female prostate cancer, penile cancer, mouth cancer, e.g.), an “all cancers” category is constructed. What is clear is that the ribbon campaign is as concerned with controlling the boundaries of cancer discourse as promoting “awareness.” These boundaries are policed in large part through strict gender controls.

The coding system reveals not only the “infantilization” that Barbara Ehrenreich (2009) has called attention to, but the gendering of those infantilizations. Breast cancer gets pink while prostate cancer gets light blue, the totality of which amounts to the aesthetic of a child’s nursery. “Orchid,” the violet, purplish color afforded to testicular cancer recalls a common surgery for testicular cancer patients, the orchiectomy (often also spelled orchidectomy). Lavender is reserved for “Gynecological Cancer,” which promises to encompass by obscuring cervical, uterine, clitoral and other cancers. Finally, because of the gendered infantilization of “adult” cancers, childhood cancers are included under the general ribbon color of gold, since baby blue and pink are occupied.

Most glaring is the “½ Blue and ½ Pink” system afforded male breast cancer, suggesting that this survivor constitutes a kind of queer subject that doesn’t quite fit. Largely unknown and unspoken until recent years, increasing attention is being paid to the male breast cancer survivor, as when ABC News highlighted a North Carolina man who was denied breast cancer screening “because he was a man.” Yet, the new attention to this group is largely a reaction to years of breast cancer survivor organizing and using gender bias as a clarion call: the 2000 (on average) cases seem to have gained attention in large part because of the importance of the narrative: “I didn’t know men could get that.” Thus, male breast cancer survivors are usually treated as anomalies, but still able to work their way into the spaces opened by pink ribbon campaigns—but only if they sacrifice part of their gendered selves, welcoming in the half-pink nature of their affliction.

While the ribbon color system is not official, but the product of a cancer awareness market, its cultural reach is wide. For this reason, while the coloring of ribbons may seem fairly superficial and unimportant, the literalness of some of the ribbons points to the fact that the cultural representational order of cancer survivorship is instantiated in subtle—and often distasteful, or at a minimum, thoughtless—ways. Ribbons are merely one manifestation of the representational politics of cancer. But what kind of a representational politics do these ribbons endorse? As Ehrenreich (2009, 30) notes, “the relentless promotion of positive thinking” propagates perverse narratives that promise that female breast cancer survivors may even come out on the survivor side “prettier, sexier, more femme.” “In the lore of the disease,” according to Ehrenreich, “...chemotherapy smoothes and tightens skin and helps you lose weight, and, when your hair comes back it will be fuller, softer, easier to control, and perhaps a surprising new color.” Ehrenreich points to an American Cancer Society campaign offering beauty tips for cancer survivors and offering make-over and make-up kits donated by cosmetic companies. Even mastectomies are pitched as opportunities: “Of the more than fifty thousand mastectomy patients who opt for reconstruction each year, 17 percent go on, often at the urging of their plastic surgeons, to get additional surgery so that the remaining breast with

‘match’ the more erect and perhaps larger new structure on the other side.” In Ehrenreich’s account, cancer becomes an opportunity for starting over, perhaps from childhood, to build new, stronger and more beautiful women—warriors even.

Yet, like Sontag’s focus on the meaning of disease, Ehrenreich’s analysis only accounts for part of the story. In one sense, it doesn’t tell us much about the gendering of the “cancer survivor” as such because it is focused specifically on breast cancer which, as we have seen, has occupied the largest part of popular cancer imagination and often arrives with specific gender coordinates already in place. What it doesn’t capture is the way in which men and women are infantilized *differently*, just as reducing women to girls and men to boys provokes quite different social resonances. Perhaps, as survivorship discourses suggest, the more interesting point is that men are not infantilized at all, but are either morphed into warriors or nothing. Recall, for example, that the sublimation of aggression from infertility due to testicular cancer was the driving force of Chuck Palahniuk’s 1996 novel, and David Fincher’s 1999 film, *Fight Club*, in which the character, Bob, played by rocker Meat Loaf, eschews his testicular cancer support group for Project Mayhem, which alone can prove that “We’re still men.” In accordance with this warrior narrative, a preponderance of high profile male cancer survivors are sports stars—Brian Piccolo, Ken Griffey Sr., Lance Armstrong, Robin Cole and Arnold Palmer, among others—each of whom serves as a cultural signpost in the gendering of survivorship, even as their actual narratives tend to disrupt the simple warrior trope. In the next section, I focus on one such signpost to show how gender mediates survivorship.

II. Survivorship and the Gendered Negotiation of Vulnerability

Professional cyclist Lance Armstrong certainly ranks among the most high-profile symbols of male survivorship. Armstrong’s book, *It’s Not About the Bike*, written with Sally Jenkins, tells an uplifting story of recovery. But understanding this story is impossible without a direct and sustained consideration of gender. As Casper and Moore note in their reading of Armstrong, “The overall message of testicular cancer is that it is often silent, rarely deadly, but can have enormous implications for a man’s sense of masculinity” (Casper et al 2009, 161). Appropriately, the first page of Armstrong’s book (2000, 1) begins with a vision of a heroic, patriotic, and manly death:

I want to die at a hundred years old with an American flag on my back and the star of Texas on my helmet, after screaming down an Alpine descent on a bicycle at 75 miles per hour. I want to cross one last finish line as my wife and my ten children applaud, and then I want to lie down in a field of those famous French sunflowers and gracefully expire, the perfect contradiction to my once anticipated poignant early demise.

This vision serves Armstrong as a counterpoint to the specter of a less heroic death at the hands of cancer. While it certainly does smack of “glorious, red-blooded, American masculinity, reproduced and celebrated in the name of national allegiance” (Casper et al 2009, 176), grasping its place within Armstrong’s broader public image requires specific attention to the narratives of cancer survivorship that facilitate its gendered nationalism. The death vision, which arises in relation to cancer, provides important clues as to this relationship. At the outset, Armstrong assumes a cowboyish attitude toward cancer: “You picked the wrong guy,” Armstrong tells his disease in one of his “firm” “conversations with cancer.” But his account deconstructs itself continually as his battle-ready disposition and resolute maneuvering in a field of war metaphors falls apart amidst the reality of cancer treatment. “For most of my life,” Armstrong explains, “I had operated under a simple schematic of winning and losing, but cancer was teaching me a tolerance for ambiguities” —an admission that recalls Anzaldúa’s borderlands, where the “new *mestiza* copes by developing a tolerance for contradictions, a tolerance for ambiguity” (Anzaldúa 1987, 203).

Armstrong's narrative illustrates the potentially-subversive capacity of cancer to queer its subjects, foisting upon them a renegotiation of the terms of bodily integrity and vulnerability. At times, Armstrong's gender identification seems to decompose with his body, as though cancer treatment were a force of liberation from gender's strict controls.

Obviously, Armstrong's experience with "ambiguity"—of percentages rather than certainties, of treatments that are right for him in his particularity rather than universal "best practices"—contradict the idealized male body that has been conceptualized throughout the history of Western political thought. The cancer patient is not and cannot be Leviathan, as the masculine fantasy that sustains the bodies Hobbes envisions are undone from within by cancer and its treatment. Armstrong, like many men, begins with an idealized model, protected by youth and health. Yet, his experience of bodily vulnerability is constantly undone by his masculine self-identification. Thus, while he briefly engages the question "why me?" only to dismiss it with the realization that he "was no more or less valuable than the man sitting next to [him]," cancer still "picked the wrong guy," presumably because Armstrong sees himself not as vulnerable, but indomitable and self-contained; surely, his cancer would wither in the face of such manhood.

In other words, Armstrong's exceptional body is exempted from his otherwise questioning and open narrative. As a result, his account of chemotherapy procedures recalls the treacherous days of mega-dose chemotherapy treatments that were given to breast cancer patients by their mostly male doctors (Mukherjee 2010). However, while few women seemed to relish in the danger of being brought to the "brink of death" and then brought back, Armstrong tells his female chemotherapy nurse, "You can't kill me... Hit me with everything you got, just dump it all on me. Whatever you give to other people, give me double. I want to make sure we get it all. Let's kill this damn thing." Armstrong's protestations of toughness and invincibility, however, are met a swift rebuke: "Let me assure you," the nurse says, "I can kill you..." (Armstrong et al 2000, 108).

Armstrong's account betrays the extent to which his experience with cancer brought him to a moment of reconciliation with technology and the interrelatedness between himself and the world; in other words, he moves from a stereotype of the self-contained, self-made man to what Haraway calls the cyborg, a cybernetically-constituted hybrid of organic and machinic matter (Haraway 1995, 65). As Armstrong (2000, 288) notes "...it's a myth to say that I beat cancer. The drugs beat cancer. The doctors beat cancer. I just survived it." Armstrong's dissociation of his athleticism—bound up as it is in his valuation of his manhood—from his disease seems a pinnacle moment in understanding his particular engagement with survivorship as a gendered experience. Toward the end of his book, culminating with his failure to obtain a gold at the Sydney Olympics, the bravado is mostly gone and Armstrong's disposition is marked by a notable absence of manly individualism and a concession to the fact that his bodily and psychic integrity was not a mere product of what he did with it or put into it, but a more complex interaction with the world around him. Hence, Armstrong's survivorship is managed by his mother who he continually describes as "taking charge" and portrays as a meticulous scheduling machine, interacting with Armstrong's doctors, cooking him healthy foods and researching treatment options. Armstrong (2000, 98) recounts the difficulties he experienced turning "the driving over to anyone else."

Finally, Armstrong's death dream with which I began this discussion raises the issue of fertility. Armstrong envisions himself "cross[ing] one last finish line as [his] wife and [his] ten children applaud." Yet, as Armstrong explains in his narrative, he is sterile, limited to the reserves he deposited at the sperm bank for natural fertilization or, perhaps, adoption (though Armstrong never mentions the possibility). The projection of ten children is noteworthy for the cancer survivor, and particularly so for the survivor of testicular cancer. But this narrative of potency — against cancer, against infertility, against cycling — runs at the heart of Armstrong's story, with each step appearing as increasing ownership of survivorship identity. For Armstrong survivorship is mediated by gender

roles that in turn make surviving legible—to himself and others. Armstrong’s masculine identity proves too strong to withstand the queering potentialities of cancer.

For Armstrong, of course, there is a coda to his book’s narrative. The militant containment strategy he deploys against his sick body aligns with classical masculine dreams of purity and control. Armstrong strives (and often fails) to give up beer, fatty foods and anything else that could conceivably weaken his condition. Yet, as has been widely speculated, the Tour de France victories that stand as the heroic hallmarks of Armstrong’s triumph against cancer may have been supplemented by performance enhancing drugs. And these, in addition to the physical result of his cancer treatment itself, where, “Ironically, testicular cancer and its physical aftermath transformed Armstrong from a decent athlete into a superstar, in part by chemically resculpting his body, paring it down to perfectly meet the demands of competitive cycling” (Casper and Moore 2009, 167). This suggests that Armstrong’s post-cancer body—the cyborg that had come to terms with its intertwinedness with pharmacology and technology—was in fact superior to its pre-cancer version, but (at least in part) because it had sought sources of strength beyond inner fortitude. Armstrong’s triumph, in other words, was not only (or primarily) a mark of heroism and determination—testament to Armstrong’s character—but a story of body modification. To be sure, this fact may say little or nothing about Armstrong’s foundation’s important work for cancer awareness, research and support. But it does tell us a good deal about the gendering of survivorship, if only because (as with so many dimensions of gender) it calls into question the realignment that Armstrong supposedly went through in relation to his body upon diagnosis. It is certainly possible that Armstrong will explain his decision to take these drugs as part of his “tolerance for ambiguity,” an admission that bodies are not self-constituting, but are vulnerable and dependant. It is more likely that they will be explained as a failure of character, which will reinscribe the masculine horizons that ultimately fuel his experience with survivorship and fit more snugly in traditional narratives of gender and responsibility. Whatever the explanation, one can’t help but to ask—especially in light of what we know about the gendering of survivorship—whether it turns out that it was “about the bike” after all.

Armstrong’s narrative opens important doors for thinking about how manhood interacts with cancer survivorship. His experience also points to something more broadly associated with disease, in general, and different forms of cancer, in particular. For example, the urine pads that male prostate cancer survivors must wear, as well as the draining of a surgical incision more generally force men to confront their own “leaky bodies” (Shildrick 1997), in ways that gender studies have long embraced, in large part because of feminist classics such as Eve Ensler’s “Vagina Monologues.” Feminine care has long been branded as the antithesis of masculine order and control. In this sense, the warrior ethic that serves as the symbol of female breast cancer survivorship underscores the extent to which male survivors, who probably could benefit from a relaxing of gender norms, are instead expected to double down on their gender norms rather than transcending them. Such intransigence is obviously problematic from the perspective of the pursuit of flexible and context-bound care.

Additionally, the policing of the boundaries of gender is always-already bound up with sexual norms. Throughout his narrative, Armstrong’s heterosexual identity plays a central role in beating back the threatening backdrop of vulnerabilities that survivorship yields. Armstrong’s narrative recalls a central lesson of Audre Lorde’s *Cancer Journals*, which make clear that the gendering of survivorship is most often negotiated heteronormatively. Accordingly, Lorde portrays some of the sordid dimensions of survivorship as governed by a social imperative for survivors to perform normalcy and hide their condition for the benefit of others; this imperative became explicit when she was urged by a nurse to wear a prosthetic breast because it was “bad for the morale of the office” (Lorde 1997, 99). Lorde’s observation confirms Ehrenreich’s claim that breast cancer survivorship is encumbered by a social and medical fixation with the production of properly normed bodies. This is true, moreover, for the broad arsenal of prostheses and cosmetics that are available (mostly for purchase) to provide comfort and social normalcy

for cancer survivors of all stripes. For Lorde, the public face of survivorship is superficial: “With quick cosmetic reassurance, we are told that our feelings are not important, our appearance is all, the sum total of self.”

There are, of course, potentially high bodily and psychic costs to this cosmeticism and, as a result, survivors’ ability to work through identity issues is critical to their well-being as survivors. It is therefore significant that prostate cancer survivor Russell Windle’s discovery of an absence of support groups for gay men led him to establish a blog to provide just such a forum. According to Windle, for gay men, prostate cancer “was just another closet that they were hiding in” (Burnett et al 2010, 67). Lorde and Windle’s accounts underscore the importance of approaching gender at the intersections of sexuality when conceptualizing post-treatment support, for it is at these intersections that survivors actually experience the anxieties and alienation associated with the changed bodies that cancer yields.

Dr. Arthur Burnett notes that, “Prostate cancer is a particularly stressful disease. Beyond the physical problems...psychological ones can be extremely profound” due to “assaults on their virility and the effects on their lives and loved ones” (Ibid). Indeed, the accounts of male prostate cancer survivors are striking for their illustration of the extent to which treatments are considered in the shadow of sexual dysfunction. As Burnett (2010, 71) asserts, while the “goal of the urologic surgeon is to maximize functional recovery in all respects with radical prostatectomy...nerve preservation should not come at the cost of incomplete cancer removal in an unfortunate patient whose cancer may be locally spread beyond the prostate gland.” This balancing act is not merely a preoccupation of worried men facing prostatectomies, but seems to have pervaded the medical advice patients receive as well. Based on the experiences of fellow survivors he met through internet chat sites, Windle reports that some gay doctors seem to over-emphasize the importance of obtaining erections shortly after treatment, leading them to turn to technological fixes before allowing the restoration of natural function to take a more natural course (Ibid). In one sense, this is understandable, since sexual health is no doubt an important part of health. Yet, in another sense, many of the accounts of prostate cancer survivors raise concerns about whether the loss—temporary or long-term—of sexual function sometimes dwarf the dangers of the disease itself.

But this is only half of the story. The other half is the prevalence of men who opt for the most aggressive treatments possible or than is warranted by the disease (Bell et al 2011). These men, called to arms by the powerful word ‘cancer’, appear to accept side effects such as urinary incontinence and erectile dysfunction as a price that one must pay for removing and, indeed *surviving* cancer (Gray 1996; Oliffe 2006). That older men who tend to opt for “watchful waiting” rather than prostatectomies are an exception to this trend only serves to highlight the gendered dynamics of prostate cancer, as age operates to mediate the gendered experience of cancer treatment. These distinctions suggest that the experience of disease—and the gendering of survivorship, in particular—must also be grasped at its points of intersection with aging. More generally, however, these observations underscore a more important methodological point about survivorship, namely that to the extent which they can be useful, survivorship studies must be widely intersectional, considering not only gender, but race, class, age and ability.

A series of questions arise from these considerations. What role should gender play in clinical determinations? Should best practices be followed when they challenge or even threaten gender norms, or should the preservation of one’s gendered identity be considered part of a broader umbrella of well-being? To what extent should doctors consider these norms within particular contexts of sexual orientation? Do doctors have an obligation to help patients resist some of the more problematic effects that gender identity wields as concerns care?

III. Gender and Survivorship Studies: Critiquing the Handbook of Cancer Survivorship

In this section I evaluate *The Handbook of Cancer Survivorship*, a comprehensive text addressed to health care professionals. I do so to make sense of how its many chapters consider—or more precisely, do not consider—the role that gender plays in cancer survivorship. In light of my analysis above, I emphasize what appear to be critical absences in the *Handbook*'s studies.⁴

Throughout, the *Handbook* speaks to the universal, genderless survivor; indeed, the word “gender” does not appear in its index.⁵ Accordingly, my critique revolves primarily around the productive role that this absence plays in its approach toward survivorship. The result is that the *Handbook*'s studies tend to address a universal subject of “survivor” while acknowledging that survivors experience survivorship differently, as when Craig Earle finds that, “The ever increasing population of cancer survivors is just now being recognized as a distinct population with a lot of common health and social issues” even as “. . . the care they are in need of must be individually tailored” (Earle 2007, 19). What these accounts lack, therefore, is not an acknowledgment of difference— sex difference, after all, is acknowledged time and time again (Cook et al 2009). What is missing is a curiosity about what role gender might play in the status and behavior of the survivor, where gender serves as a key coordinate by which survivors understand and respond to their disease.

While gender does not make an appearance, then, sex does, primarily in noting disparities in outcomes and differences in well-being. For example, the study by Joan Bloom, et al (2007, 43) finds the following regarding five-year survival rates:

For men, large gains in cancer survival rates . . . were seen in cancers of the prostate, colon and kidney, and non-Hodgkin lymphoma, melanoma, and leukemia. Modest gains were found for cancers of the bladder, stomach, liver, brain, and esophagus [while . . .] For women, large gains in cancer survival rates were seen for colon, kidney, and breast cancers and non-Hodgkin lymphoma. Modest gains were found for bladder, oral cavity, stomach, brain, esophageal, and ovarian cancers and melanoma and leukemia.

Rather than disparities in survival rates, Bloom et al seek to make sense of QOL studies of survivors. Yet the common focus on QOL in the survivorship literature is largely devoid of gender analysis, not to mention the various critical intersections—race, ethnicity, sexuality, class—that one might expect when engaging such a context-bound concept, focused as it is on “complete social and psychological being: the individual’s performance of social roles, mental acuity, emotional state, sense of well-being and relationships with others” (Levine 1987, 1). More commonly, the studies describe symptoms and conditions without explaining their relevance to survivorship itself, without asking whether they alter the basic phenomenon itself to such an extent that to study the cancer survivor becomes synonymous with studying the gendering of that survivor’s survivorship. Thus, Bloom et al note that

⁴ I could have focused on a number of such texts. For example, Hewitt et al 2005, which was instrumental in putting survivorship on the scholarly map, also fails to interrogate the role that gender plays in survivorship.

⁵ The *Handbook* is similarly inattentive to race and class, though close analysis of this dimension is beyond the scope of the present enquiry.

“Concerns with sexual functioning and satisfaction are the most common issues experienced by [breast cancer] survivors...” but do not engage the gendering of breast cancer itself. There is no mention of male breast cancer or the intersections of sexuality that Lorde emphasizes.

Similarly, in their assessment of QOL studies for Hodgkin’s, Bloom et al note that women tend to experience more anxiety than men, but fail to situate this figure sufficiently in a broader context of the gendering of the *experience* of survivorship (Bloom et al 2007, 51). Surely, perhaps even more than the causes of cancer, the causes of anxiety, depression and low-QOL more generally must stem from the social positioning in which cancer survivors are located. Different cancers, after all, taken in their specific cultural positions, refract differently through gender. In this sense, it is not only “survivorship” that requires rethinking, but the utility of the word “cancer” itself, since each cancer arrives in highly specific, gendered contexts.

Much as breast cancer is treated as the quintessential women’s cancer, prostate cancer—the blue to breast cancer’s pink—occupies the preponderance of cancer discourse in scholarly and popular discussions about men. Despite the largely unknown fact that women can and do get prostate cancer, though with much less frequency, women are positioned largely in the role of supporters, helping men to cope with the wide range of sexual effects of radical prostatectomies and other common treatment modalities (Custodio et al. 2010). As we would expect, QOL discussions for men undergoing treatment for prostate cancer revolve around dysfunction—sexual, urinary and bowel. Yet, while breast and prostate cancer receive relative recognition as gendered experiences because of the body parts they affect, the more subtle and systematic gendering of cancer tends to drop out of analysis with regard to cancers that afflict men and women equally. Colorectal cancer is one notable example as its common side effect of erectile dysfunction is rarely noted in the literature. Similarly, no doubt because of a pervasive phallocentrism in both health and sexuality studies, considerations of women’s sexuality tend to be missing altogether.

The goal, then, must be to naturalize gender analysis into survivorship studies. For example, while Bloom et al’s QOL study shows that gender is often utilized in studies to distinguish different responses to and experiences in survivorship, it also illustrates that cancer treatment and post-treatment life is rarely conceptualized in a way that would *understand survivorship as a gendered experience*. Accordingly, how might we make sense of the finding that “. . . men’s focus of concern, on their sexual functioning . . . [is] not shared to an equal degree by their non-sick partners”? What do we make of the different roles that fertility—and sterility—play in different cancers, especially when fertility is mapped onto aging bodies undergoing treatment? Surely, one cannot simply treat these issues as pragmatic, genderless questions within the context of an over-broad notion of “cancer” treatment; after all, recipients of chemotherapy and radiation are not only at risk of becoming infertile, but losing some of the key social markers of gendered life, which raises the question not only of surviving, but living a meaningful life in which gender is taken seriously as a key site in which social meanings are housed. To fail to account for these contexts is to miss the phenomenology of survivorship through which QOL itself is filtered and by which it is produced.

In a study of the “long-term effects of cancer diagnosis and treatment on survivors’ family members,” Bloom et al focus on same-gender family members—the sisters of breast cancer survivors and the sons and brothers of prostate cancer survivors—a decision that no doubt serves to reinforce rather than interrogate the role gender plays in shaping QOL. These always-already gendered contexts, however, facilitate the possibility of missing gender altogether, as they do not register as contexts precisely where understanding the gendering of survivorship requires foregrounding and focus. The problem with cancer studies, it seems, is that gender is rarely treated as constitutive of experience, but is assumed to be a mere category for analysis—an appendage rather than a conceptual filter through which disease and those that “survive” it are understood. The studies, in other words, do not engage perhaps the most pressing question of all for the gendering of survivorship: can someone who “survives,” but loses the constitutive features of their gendered lives, truly be said to have survived? The common response tends to suggest

that the answer must be “yes,” because living is most important of all. Yet, this position is only purchased by devaluing gender itself. Taking gender seriously requires resisting this simple “yes” and rethinking instead what it means to live a liveable life, where the meaning of livability is constructed—at least in part—by survivors themselves.

To be sure, the QOL studies that Bloom et al (2007) and David Victorson et al (2007) analyze could be utilized in the service of a deeper understanding of gender. What is of concern, in my view, is both that they are not so utilized and that the researchers have mostly not seen fit to contextualize sexuality, bodily ability and perception within a framework of gender analysis that would capture the cancer survivor’s body in its fully lived social context. Thus, studies of Post Traumatic Stress Disorder, Mood States, Psychological Adjustment, Quality of Life, Depression, Dispositional Hope, Goal Interference, Hospital Anxiety, Impact of Event, Daily Living, Independence in Activities of Daily Living and Life Orientation, are advanced without thinking through the different situations within which people arrive at treatment and survivorship. If one were to begin and end with these studies, one might conclude that cancer foists a host of problems upon genderless bodies, as though stress, independence, depression, hope, mood and the details of everyday life were not gendered experiences, or that gender was not implicated at—or, stronger still, constitutive of—diagnosis, treatment and post-treatment identity.

Of course, these criticisms are not intended to suggest that my concern with gender should be everybody’s main or only concern. At the same time, current understandings of health outcomes rank gender among the most important predictors (Östlin et al 2003, 132). For this reason, Friedemann-Sánchez et al (2007, 148) suggest that clinical practices “tailor” their efforts to promote colorectal screening to consider gender difference. Similar studies exist throughout the clinical literature, but rarely inform engagements with survivorship, which suggests the need for bridging clinical engagements with cancer research with ongoing efforts to understand survivorship as a phenomenon with broad-based consequences for social well-being. And while it is not my purpose to re-run the numbers to find out exactly how gender analysis would inflect the *Handbook’s* studies, there are some clear cultural signposts that point us in the right direction. As regards follow up treatment, the absence of survivorship communities for men—at least as compared to those for women—point to heightened isolation. At the same time, this isolation reinforces the masculine stereotype wherein men approach even life-changing events as tests of independence and self-reliance, a point confirmed by Armstrong’s claim that cancer made him a better man. Lorde’s experience with cancer was shaped by her status as a black, lesbian, feminist poet who felt that the fetishistic attitude many breast cancer groups and survivors took toward prosthetic devices designed to preserve and maintain socially-acceptable gender positions only served to heighten the alienation she already felt from extant communities of care. Similarly, how can one understand the self-perceptions and quality of life indices of prostate cancer survivors without considering the challenge to survivors’ masculinity that is leveled by leakiness and incontinence, the experience of wearing pads and colostomy bags, navigating erectile dysfunction and sterility? These questions require new social supports, but these supports first require—as I have noted—a new epistemology of cancer. For many survivors, cancer may be the first time they are called to think critically about their gendering. In this sense, the survivor must negotiate the myriad challenges cancer presents while simultaneously negotiating changes in gender. They need clinicians armed with adequate understanding to help navigate this difficult new terrain.

IV. Conclusion

The cases I have reviewed illustrate how heightened sensitivity to gender could refocus survivorship studies on the lived, embodied experiences of cancer survivors. These considerations suggest that there is a problematic division of labor vis-à-vis the gendering of cancer survivorship.⁶ They further suggest that the bifurcation of the cancer survivor and survivors' gendered existence offer clinicians and researchers a misleading picture of the interrelations and lived experiences that will ultimately determine the QOL of cancer patients both during and after treatment. While survivors' narrative accounts tend to foreground—or at least betray a preoccupation with—the role that gender plays during treatment and post-treatment life, clinical studies tend to recoil into genderlessness. I have suggested that in so doing, they actually fail to grasp the survivor him- or herself, raising a question of what both “quality” and “life” can mean for lives conceptualized in a disembodied manner. Crucially, the role that gender plays in survivors' accounts are not merely anecdotal, but indicative of and critical to substantive health calculations, from whether or not men or women will seek medical attention; to what kind of treatment they will seek; to what counts as “surviving” vis-à-vis treatment options for individual patients; to the role psychological well-being plays for cancer patients more generally; to the question of reproduction and fertility; to broader questions of whether or not the medical services industry is properly trained and outfitted to take gender seriously as a core concern of cancer survivorship. The *Handbook* and similar such texts do not capture what is primary in the first-hand narratives, namely that the extent to which the survivor can be a survivor without sacrificing his or her dignity or social legibility is very much in question. In this sense, survivorship status is the product of a series of interpellations wherein the call that bestows and recognizes status comes not only from others, but one is called by oneself to survive in a particular—and particularly gendered—manner.

In this view, identity matters precisely because it circumscribes—if not determines—the kinds of care that survivors are likely to seek out, be offered, or encouraged to pursue. More to the point, the identity politics inherent in the gendering of survivorship remind us that treatment and post-treatment decision-making are entangled with survivors' constitution as social objects, and are not simply clinical determinations that fall outside of the social. To situate survivorship fully in this social context, therefore, is to remember what an increasing number of clinicians and scholars are recognizing, namely that “Clinical judgments—and the spending that accompanies them—are much influenced by moral and cultural politics” (Bloche 2011, 78). To be sure, all disease is potentially life-changing. But attention to gender provides a critical and focused means for grasping and facilitating these changes within a framework that prioritizes the pursuit of a fully conceptualized, hence more meaningful quality of life. This call for greater and more detailed attention to gender within the context of cancer survivorship both requires and facilitates understanding how lives are actually lived—where gender is a centerpiece of that understanding—and affords clinicians new tools with which they can help patients build robust foundations for living those lives.

⁶ To be sure, this problem persists in much health and medial research, and is not limited to cancer or survivorship studies.

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