

PINELOPI TZOUVA

Breaking Free of Cancerland:  
Changing the Stories We Tell About  
Breast Cancer



DISSERTATIONES LITTERARUM ET CONTEMPLATIONIS COMPARATIVAE  
UNIVERSITATIS TARTUENSIS

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Press

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# INTRODUCTION

## A Certain State of Affairs

“Memoirs have been disgorged by virtually everyone who has ever had cancer, been anorexic, battled depression, lost weight. By anyone who has ever taught an underprivileged child, adopted an underprivileged child or been an underprivileged child. By anyone who was raised in the '60s, '70s or '80s, not to mention the '50s, '40s or '30s. Owned a dog. Run a marathon. Found religion. Held a job” (Genzlinger, 2011, no page).

No moment has been more opportune than the present one for those who want to share their story. From start-ups and small businesses to big multi-national corporations to organizations of every ilk and color, people reach out today with a narrative of their own, sharing their history and vision, identifying with specific values, and constructing a clear and memorable image to serve their entrepreneurial goals (Salmon, 2010). Far from being limited to the professional world, the storytelling boom of our times (Mäkelä et al., 2021; Mäkelä & Meretoja, 2022; Georgakopoulou, 2022) has been particularly relevant to individual life-narratives. Beginning in the period around the 70's and evolving in a gradually intensifying way, historical conjunctures and socio-economic developments have determined that people would feel the need to put their life-experiences in a narrative form and present themselves to the world through a story. This seemingly irrepressible tendency, leading to a massive production of memoirs and taken to stand for a natural and healthy urge of the human species, has made one of its strongest manifestations among the ill. Illness memoirs, or auto-pathographies, commonly perceived as functioning in healing and restorative ways on one's identity and life (Price Herndl, 2006; Peterkin, 2009), have long established themselves as a separate and flourishing subfield of autobiography with those narrating the experience of breast cancer holding a very prominent position, and constituting a massive cultural phenomenon in the U.S. today.

Notably, all that takes place within a socio-economic system of inter-connecting structures, objects, practices, and meanings (Latour, 1993), which, having evolved in time, have come to make us view the construction and re-construction of self(and illness)-narratives as a fundamental part of being a person in a cultural setting that perceives the self as “a perpetually rewritten story” (Bruner, 1994: 53), and promotes the writing of life-narratives as a *psychologically healthy* and even *ethically responsible* way to live. “How, indeed, could a subject of action give an ethical character to his or her own life taken as a whole if this life were not gathered together in some way, and how could this occur if not, precisely, in the form of a narrative?” (Ricoeur, 1990: 158; see also: Schechtman, 1997: 93–119).

In this context, illness/breast cancer narratives are believed to be useful, or better, essential, not only to anyone interested in the experience of illness, but primarily to the patients/narrators themselves (Pennebaker and Smyth, 2016;

Atkinson, 2018 and 2022; Avieson et al., 2019). They are thought to perform an act of re-remembering and to restore a sense of self and of a unitary identity from the pieces that have come apart (Becker, 1999; Price Herndl, 2006), as well as a sense of control (Couser, 1997), which is lost after the shock of the diagnosis, the subjection to a debilitating treatment, and the threat to life. In this sense, illness stories are not merely seen as an expressive practice that communicates the experience of illness and its effect on the ill person, but also as transformative and even therapeutic (Peterkin and Prettyman, 2009). The narrator deals with the physical and psychological trauma of her experience through language, reassesses the past and reinvents herself by reenacting a drama of mental and bodily survival that leads to an empowered and coherent subject position (Henke, 1998). Putting facts, thoughts, and emotions in the form of a coherent, well-ordered story<sup>1</sup> presumably helps people re-built a sense of identity – after their, supposedly consistent, identity was disrupted and fractured by illness – and accept potentially major life-changes by incorporating them in a revised life-narrative, better suited to their current state. By writing an account of their experience, the women can negotiate emotionally what happened to them and reclaim their agency, therefore, getting again on top of things, and joining once more the group of the productive. Finally, breast cancer/illness narratives have been shown to perform a function of belonging and encouragement (DasGupta and Hurst, 2007). The authors recast themselves as members of a community of women and as helpers who offer support to other sufferers (Price Herndl, 2006). From a now more empowered position of recovery, they put forward a model for coping with breast cancer. They give advice and try to inspire other women to adopt an active and positive attitude that will get them through and back on track.

Against this ideological background, the crafting of breast cancer memoirs and illness stories more broadly has been intensely promoted in the last couple of decades by various powerful stakeholders (scholarly orientations/knowledges, a remarkably thriving mainstream psychology and spirituality, a book-and-affect selling network) and their respective discourses, processes, and practices. One of them is a *specific publishing market* (embedded in the broader breast cancer market, which includes all products and services connected to breast cancer). That is, a conglomeration of publishing businesses thriving on the construction and consumption of memoirs while fostering neoliberal values, such as individualism and self-responsibility. Within this area of commercial activity, people are encouraged to compose their stories of dealing with illness and trauma based on specific story-telling patterns made available in the form of manuals by the very publishers who then bring to the market autobiographical illness stories, as we

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<sup>1</sup> I am not maintaining here that narrative, or writing one's autobiographical illness narrative, is per se a bad thing. Not all illness narratives are well-ordered and coherent, either. What I am describing is the contemporary general tendency (expressing itself through various channels, as we shall see further on) to direct ill people to write a certain type of stories, which is the reason way the problematic issue of having such big numbers of this specific variety of stories published in the U.S. needs to be addressed.

will see in more detail later on in the introduction. Another actor under the influence of which the current excessive production of memoirs of healing takes place is an all-pervasive<sup>2</sup> self-help *therapeutic culture* (Furedi, 2004; Ward, 2015; Rimke, 2017 and 2020). Employing a language of sentimentality/spirituality and popular psychology, therapeutic culture has become a fundamental element of the broader cultural imaginary in the Anglo-American world and beyond (Nehring et al., 2016), creating and sustaining an economy of personal confession and affect (Illouz, 2008; Karppi et al., 2016). Therapeutic culture (including reading and writing for healing), which seems to have emerged since the late 80's, foregrounds and prioritizes – essentially constructs – people's "inherent" vulnerability (Chandler and Reid, 2016; Ciccone, 2020), currently constituted as the defining feature of individual psychology, and invites us to engage in a variety of practices of ever-lasting healing and self-improvement. These include various wellness/yoga/meditation retreats, as well as numerous alternative therapies for relaxation and stress relief/prevention, all of which are targeted to middle/upper class people who can afford them, and, most certainly, to women with breast cancer. Finally, a third and very important agent which I will very briefly introduce here and examine in the following chapter, is *Narrative Medicine*, an area of medical humanities, reading illness narratives as valuable testimonies from which health practitioners can learn and offer better services, and authors can empower themselves and restructure their shattered identities after the event of illness, thus, linking the production of these stories to a certain social change.

The majority of them are linear, coherent, and well-ordered stories written predominantly by professional, white, heterosexual, middle/upper class women. They begin and end with the individual, her illness and shattered identity, the "journey" of her treatment and recovery – finally, her survival: a gutsy winner, and a stronger and (often) more beautiful woman now. In their pages, breast cancer takes the form of a novel of education, a *Bildungsroman*: a narrative genre linked to neoliberalism and liberal individualism (Moretti, 1987; Slaughter, 2011; Walker, 2016; Moenandar, 2017; Bristow-Smith, 2018), and a story-type that has seeped into and heavily influenced almost all kind of storytelling of our times. The majority of breast cancer memoirs of perseverance and triumph, massively crafted and widely circulated in the U.S., are greatly determined by various socio-cultural dominant tendencies shaped by highly neoliberal settings, and powerfully forming the entrepreneurial individual in ways that facilitate the current economic and socio-political arrangements (Rose, 1990; Moenandar, 2017).

Against this background, mainstream breast cancer narratives, tending to minimize negative emotions – such as anger, fear, or despair – and to emphasize

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<sup>2</sup> In our therapeutic culture it is not just people who need to heal, but also, among a multitude of other things, cities (Bates, Imrie & Kullman, 2016), architecture (Codinhoto, 2017), the economy (Matthaei, 2001), politics (El-Sayed, 2020), and even the museum (a recent initiative in Ghent where I live was "Healing the Museum", taking place at S.M.A.K., the Municipal Museum of Contemporary Art, and including three workshops: introduction to mindfulness, slow art looking, and deepening meditation, <https://smak.be/en/exhibitions/grace-ndiritu>).

a specific type of heterosexual femininity entangled with pink ribbon culture notions of womanhood, describe breast cancer as a battle and a test for the character, and function in ways that divide the world into winners and losers. They frequently follow a *Bildungsroman* pattern of coming-of-age and moral growth, as the protagonist learns important life-lessons, and ultimately saves, thanks to her own will-power, her life. In these majoritarian stories, the ill subject-author does not question the dominant economic and political structures that determine health and well-being nor does she exercise critique of any kind, but takes complete responsibility both for becoming ill and for her healing. Breast cancer is presented as a matter of personal transformation and spiritual self-development, a situation you simply have to go through with determination and positive attitude, or even as a treasured experience the authors would not have chosen to miss if they could. Healing is up to them and up to how good fighters and warriors they are, so that they can win this “battle” and emerge victorious and powerful.

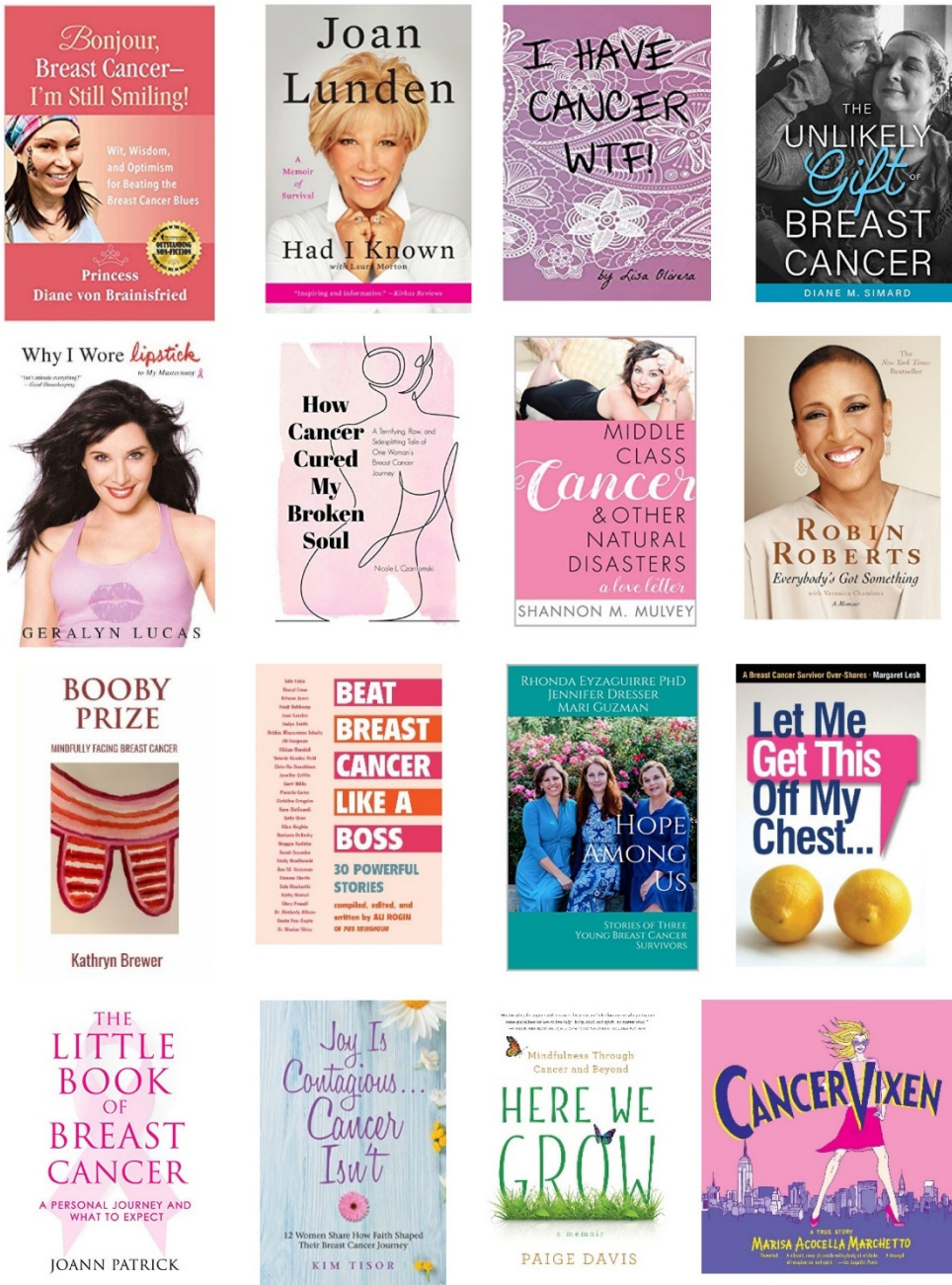


Picture 1. Stock images found on the internet.

This unshakable positivity finds expression in books with mostly pink or pastel-colored covers, frequently featuring pink ribbons and flowery patterns and sometimes also the authors themselves, smiling happily with whitened teeth. Covers that exude a certain freshness and cleanliness, reminiscent of soap bars that you can almost smell. These books bear titles such as *Bonjour, Breast Cancer – I’m Still Smiling!: Wit, Wisdom, and Optimism for Beating the Breast Cancer Blues* (Diane Young Uniman, 2019), or, *Cancer Kickin’ Warrior: The Ultimate Feel-Good Cancer Survivor Book* (Inez Whitehead-Dickens, 2010), and many more, in a similar vein. Their positivity manifests itself through varieties of somewhat different shades but with the main features of the content described above unchanged. Sometimes, the memoirs are more on the affective/sentimental side, like Leslie Reilly’s *When Cancer Calls, Love Answers: A Story of Miracles, Defying the Odds, and Spiritual Transformation on the Big Island* (2021), whose “powerful pages will fill anyone’s heart and soul with Peace and Hope, no matter the stage, grade, or kind of breast cancer” (amazon.com description). Or Vero Lemay’s *When Cancer Calls, Answer: A Story of Acceptance, Resilience and Self-love* (2020), in which the author “(shares) her healing journey of **acceptance, resilience, and self-love** (and) hopes to inspire others to take “**response-ability**” for their health and **thrive** in the face of cancer” (amazon.com description, bold in the original). Other times, women’s testimonies are more of a managerial/entrepreneurial character, grabbing the bull by the horns. Like, for example, *Beat Breast Cancer Like a Boss: 30 Powerful Stories* (2020) by the award-winning journalist, Ali Rogin. The author, “[d]rawing from first-hand interviews of successful, high-profile women from myriad industries and perspectives” helps us “[l]earn how preeminent actresses, musicians, politicians, journalists, and entrepreneurs faced a formidable disease and put it in its place” while successfully managing “the work/life/cancer balance” (amazon.com description). Oftentimes, one also encounters memoirs that make getting breast cancer look like a perfectly normal thing – although, more or less all of them do that – which has its own confirmed place in the order of the world. Such as: *Everybody’s Got Something* (2015), by the Good Morning America host, Robin Roberts, “in which she recounts the incredible journey that’s been her life so far, and the lessons she’s learned along the way” (amazon.com description). Or, articulating perhaps even more clearly breast cancer’s embeddedness, *Middle Class Cancer and Other Natural Disasters: A Love Letter* (2019) by Shannon Mulvey, with the author in a picture, on the otherwise two-thirds-pink cover, lying on a sofa in a black, tight dress and playfully smiling out at the reader. Which brings us to the memoirs that boldly take a hyper-feminine, sexualized tone, like the comic book *Cancer Vixen: A True Story* (2006), by Marisa Acocella Marchetto, a cartoonist for The New Yorker. Marchetto begins as follows: “What happens when a shoe-crazy, lipstick-obsessed, wine-swilling, pasta-slurping, fashion-fanatic, single-forever, about-to-get-married big-city girl cartoonist (me, Marisa Acocella) with a fabulous life finds: A LUMP IN HER BREAST?!? She kicks its ass, of course – and does so in killer five-inch heels” (ibid:1, capitals in the original). This last story, apparently for its expected appeal to a wider audience, has been optioned to be made

into a film starring Cate Blanchett, just like the memoir *Why I Wore Lipstick To My Mastectomy* (2004), by the Columbia educated journalist Geralyn Lucas, which came out as a television film in 2006. Lucas' memoir begins with a section titled "The Lipstick Manifesto: Have Courage, Wear Lipstick", which the author closes as follows: "And maybe applying red lipstick is a simple act of courage – to imagine yourself as someone or something you never thought you could be, and somehow, in a carefully applied swipe of beeswax, to become her. Maybe wearing lipstick is the beginning of a revolution inside your head?" (ibid: xv). But my very brief overview of mainstream breast cancer memoirs would be surely incomplete if I didn't mention the, gaining more and more prominence, spiritually inclined offspring of the genre. These are books that emphasize the importance of spiritual practices and, specifically, mindfulness, in order to learn valuable skills that help one survive breast cancer. Such as *Here We Grow: Mindfulness Through Cancer and Beyond* (2018) by the mindfulness facilitator and meditation teacher, Paige Davis, who gets a breast cancer diagnosis at thirty-eight, "quickly realizes, however, that cancer is not her crisis point but a landing pad of experiences that's inviting her to integrate her mind, body, and spirit" (amazon.com description). Or the book *Booby Prize: Mindfully Facing Breast Cancer* (2019), in which the coach and business consultant, Kathryn Brewer, "tells her personal story of becoming more resilient with self-compassion and humour, and draws on the science of *positive psychology* and *mindfulness* to help you face your new role as breast cancer patient" (amazon.com description, my italics).

All these majoritarian responses are nothing extraordinary for cancer under neoliberalism, which promotes what boosts and backs it, and transforms everything under it into a presumable opportunity for growth to be seized and made use of by the responsible, autonomous, entrepreneurial individual. As Audre Lorde's first sentence goes in *The Cancer Journals* (1980): "Each woman responds to the crisis that breast cancer brings to her life out of a whole pattern, which is the design of who she is and how her life has been lived".



Picture 2. Breast cancer autobiographical narratives.

## What's Wrong with All That, or, Why Should We Care?

The present-day more general storytelling boom (Mäkelä et al., 2021; Mäkelä and Meretoja, 2022; Georgakopoulou, 2022), operating in affective/disciplinary modes infused by neoliberalism and neoliberal individualism (Foucault, 1988; Illuz, 2007; Fernandes, 2017), distracts and diverts, also in the context of breast cancer, from efforts to change an oppressive and unjust society (King, 2008; Jain, 2013) hitting the hardest the most vulnerable (see: [breastcanceraction.org](http://breastcanceraction.org): “Disparities in Breast Cancer: Through the Breast Cancer-Care Continuum”), and serves, instead, to access and, ultimately, change the self (Freeman, 2014). Having been crystallized into a taken-for-granted social expectation, and under the guise of self-care (Illuz, 2008; Ward, 2015), which, in a broader context of spirituality and emotional well-being, skillfully conceals its character of discipline and control (Arthington, 2016; Purser, 2019), the “change/improve your self through storytelling” directive is currently addressed to absolutely everyone with common sense, who, “naturally”, cares for their constant growth (Rose, 1996; Houghton, 2019). Branded as a process which is, moreover, restorative and healing (Pennebaker and Cohen Chung, 2007; Atkinson, 2018; Avieson et al., 2019) it is aimed even more strongly at people dealing with illness, trauma, and suffering, such as women with breast cancer.

This state of affairs is highly problematic for several reasons. By following trajectories of steadfast optimism, perseverance, and self-help leading to triumph (Stacey, 1997; Ehrenreich, 2001 and 2009; Segal, 2007 and 2012; Conway, 2013; Staneva et al. 2018) in a context that foregrounds and advocates individualism, self-reliance, and self-improvement (Jain, 2013; Waples, 2013 and 2014), the mainstream narratives present the patient as the one who will be held accountable or turned into a “hero” (Stacey, 1997), and overlook all context and systemic injustices causing suffering and disease. By looking only at the individual, they obliterate community and shared responsibility (King, 2008; Sulik, 2011), thus, precluding the formation of activist fronts, especially needed in the case of diseases that have taken the form of a real epidemic, such as breast cancer. By being aligned with the pro-cure cult “cause-marketing stories” (Strach, 2016: 5), they emphasize “awareness over information. They promote individual over collective solutions. They enable and empower individuals. They frame issues around marketable emotions (like hope). And they are consensual, positive, and seemingly apolitical” (ibid). In functioning this way, the master narratives mask and obscure rather than reveal, “producing and maintaining ignorance about breast cancer” (Segal 2007: 4), while an ever-flourishing market has turned it into a charitable cause. This masking and obscuring, as well as disguising/passing of a terrible disease for something it is not (something normal, soft, and even good; a chance to learn and improve yourself and become more beautiful) happens on at least two different levels. First, on the level of the devastating effects that breast cancer and its treatment can actually have on people, and even more so on already vulnerable social groups (Bassett and Krieger, 1986; Kasper, 2000; Bowen et al. 2013; Conroy et al. 2017). Second, on the level of how things operate in a broader,

all-encompassing, profit-oriented system, in which conventional, individualist breast cancer narratives – for all the things they exclude – are but a functional, sustaining element. As Anne Boyer writes in her Pulitzer Prize winning critical essay/breast cancer memoir, “[b]reast cancer’s industrial etiology, medicine’s misogynist and racist histories and practices, capitalism’s incredible machine of profit, and the unequal distribution by class of the suffering and death of breast cancer are omitted from breast cancer’s now-common literary form” (2019: 10). Precisely so, the mainstream stories, oblivious to broader socio-economic mechanisms and violent necropolitical structures – seemingly operating beyond their authors’ white, upper/middle-class world – do not touch upon any of the various injustices that cause and exacerbate suffering. Such issues, remaining outside the authors’ sphere of concerns (but not outside of their actual lives), do not feature in their majoritarian stories of achievement, which present their experience as typical of all women, and render all other realities invisible.



**Picture 3.** Charity initiatives by the Susan G. Komen Foundation, and events organized by S. G. Komen.

The conventional narratives surrounding breast cancer, in line with a broader neoliberal culture that shapes our understanding of the disease, often encourage individuals, particularly women, to adopt more entrepreneurial, productive, spiritual, or feminine personas. These narratives, however, fail to address the alarming numbers of women who die each year from breast cancer in the United States, or the disproportionately high mortality rates among women of color, the impoverished, the uninsured, and those living in toxic environments (Saini et al., 2019; see the article “Air Pollution and Breast Cancer” on the Breast Cancer Prevention Partners website). While major institutions like the Komen Foundation and the National Breast Cancer Foundation amass significant funds through donations, the vast majority of these resources are allocated toward “awareness” and “the cure,” with little directed towards research on prevention or the exploration of involuntary environmental exposures (Moffett, 2003; Brown, 2007; Richter, 2019; Ohayon et al., 2020). Moreover, corporations that profit from the sale of products containing toxic ingredients – substances likely or certainly contributing to the onset of breast cancer – frequently market themselves as supporters of the cause (Kasper and Ferguson, 2000; Jain, 2007; Sulik, 2011; Horne, 2013).

Within mainstream breast cancer discourse, there is a conspicuous absence of any mention of the fossil fuel industry’s connection to the breast cancer crisis, nor is the industry’s role in exacerbating the climate crisis addressed (Korsh et al., 2015; Turner et al., 2020). The emissions of greenhouse gases such as carbon dioxide and methane, two primary contributors to global warming (see the article “Understanding Global Change” on <https://ugc.berkeley.edu/background-content/burning-of-fossil-fuels/>; see also: Houghton, 2005; Al-Ghussain, 2018), are ignored, as are the risks associated with nitrogen dioxide (NO<sub>2</sub>), a toxic pollutant linked to an increased risk of breast cancer, whose effects are worsened by heatwaves and drought (see the report “The Climate Crisis and Breast Cancer” on [www.bcaction.org](http://www.bcaction.org)). Similarly, the increasing frequency of wildfires in the United States, driven by climate change and the burning of fossil fuels (Dunne, 2021), and the associated release of harmful pollutants such as hydrocarbons, have been linked to breast cancer risk (Popovich and Katz, 2021; see the article “Biggest Fossil Fuel Firms Responsible for a Third of Western Forests Burned,” 2023, on the Yale School of the Environment website). These pollutants are further compounded by the use of flame retardants and “forever chemicals” (PFAS), which are known to damage the endocrine, immune, and reproductive systems (Lerner, 2018; Beans, 2021). Additionally, extreme weather events, such as hurricanes, tsunamis, and intense rainstorms, which have become more frequent due to the warming of the oceans, lead to the contamination of water supplies with cancer-causing chemicals, such as PCBs, which have been banned in the United States since 1976 (Flavelle, 2019). These complex, large-scale environmental and health issues are often overlooked in the best-selling breast cancer memoirs, which focus instead on individual, personal narratives of transformation and survival.

This selective portrayal of breast cancer and its aftermath contributes to a culture of individualism, rather than fostering collective awareness or solidarity.

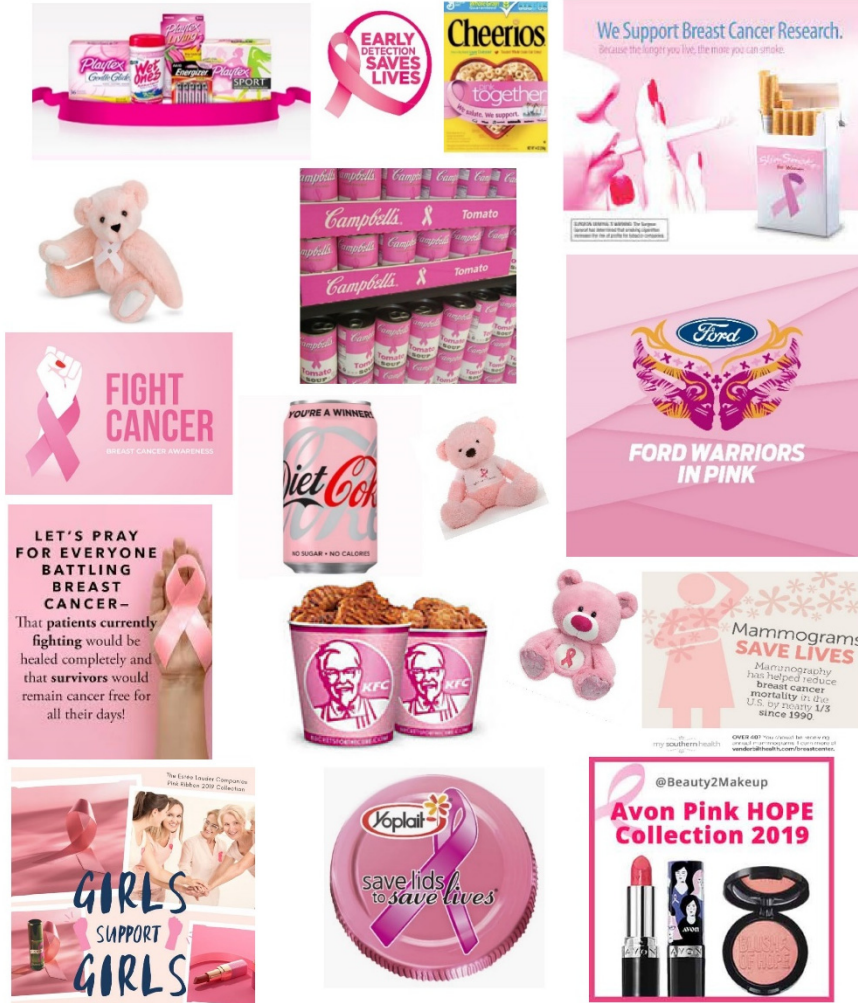
While these narratives may celebrate personal triumphs, they fail to acknowledge the broader systemic factors at play – namely, the corporate structures that profit from the disease. These structures promote an image of breast cancer as a heroic, life-affirming journey, even as they perpetuate death and suffering. As Gayle Sulik aptly summarizes, the breast cancer marketplace is rife with “the ultra-feminine pink kitsch,” “teddy bears and tote bags,” and “sentimental support” that ultimately mask the true violence of the disease and its treatment (Sulik, 2011: 4–5). By framing death and mourning in terms of “survivorship” and “creative self-transformation,” these narratives neutralize the political and ethical dimensions of the disease and, instead, turn the tragedy of breast cancer into a marketable commodity.

As such, death, dying, and mourning – crucial aspects of the breast cancer experience – are co-opted by the very corporate entities that profit from the disease. This commercialization is further evidenced by the “cause marketing” strategies that brand breast cancer as a hopeful, uncontroversial cause, often paired with corporate-sponsored events such as walks and marathons (Strach, 2016). These efforts not only obscure the environmental causes of cancer but also perpetuate the idea that breast cancer is an opportunity for self-reinvention, rather than an issue requiring systemic change (Ehrenreich, 2001). In this context, the corporate-driven narrative relegates death and mourning to the realm of “heroes,” “survivors,” and “lost sisters,” commodifying these deeply personal experiences and erasing the possibility of meaningful, collective action against the environmental and social factors that contribute to breast cancer.

Ultimately, the failure to address the environmental determinants of breast cancer – despite mounting evidence linking environmental factors to the disease (Steingraber, 2000; Seager, 2003; Brown, 2007; Gray et al., 2017) – reveals the true priorities of the breast cancer industry. This industry, valued at an estimated \$12–16 billion annually, spans a range of sectors, including surgery, chemotherapy, radiation treatment, mammography, and pharmaceuticals (Ehrenreich, 2001: 51). These profit-driven motives overshadow any genuine efforts to combat the root causes of breast cancer, further entrenching the power of the corporations and institutions that benefit from the status quo.

“The cancer industry consists of corporations, organizations, and agencies that diminish or mask the extent of the cancer problem, fail to protect our health, or divert attention away from the importance of finding the causes of breast cancer and working to prevent the disease. This includes drug companies that, in addition to profiting from cancer treatment drugs, sometimes produce toxic chemicals that may be contributing to the high rates of cancer in this country and increasing rates throughout the world. It also includes the polluting industries that continue to release substances that are known or suspected to be dangerous to our health, and the public relations firms and public agencies that protect these polluters. The cancer industry includes organizations like the American Cancer Society that downplay the risk of cancer from pesticides and other environmental

factors, and that historically have refused to take a stand on environmental regulation” (<https://bcaction.org/the-cancer-industry/>).



Picture 4. Stock images found on the internet.

These issues remain largely unaddressed and the focus is primarily placed on individual responsibility, maintaining a positive attitude, and making appropriate lifestyle choices (Ehrenreich & Brenner, 2001), in addition to encouraging regular mammograms, which are claimed to “save lives.” While big institutions manage annual budgets amounting to millions of dollars in donations, the funds allocated for research aimed at the actual prevention of cancer are minimal, a fact

which is also true for federal breast cancer funding (Richter, 2019, p. 4). Karuna Jaggar, Executive Director of Breast Cancer Action, aptly asks: “If Komen is committed to funding research on the causes and prevention of breast cancer, why do they allocate less than 4% of the \$1.9 billion (yes, billion) they have raised to these areas?” (<https://bcaction.org/2011/09/28/more-questions/>).

In this context, the experience of dying becomes commodified, fueling an industry that perpetuates the cycle of harm while inundating the public with images of heroic battles, smiling survivors, and empowering narratives. Dissenting voices find no space within this framework as they are actively suppressed – women’s objections being deemed as pathological, and women themselves as in need of urgent counseling (Ehrenreich, 2001, p. 50; see also Ehrenreich’s *Bright-Sided: How the Relentless Promotion of Positive Thinking Has Undermined America*, 2009). Emotions labeled as “negative” by our culture of toxic positivity, such as anger, indignation, or outrage, which would serve to expose injustices and inspire collective action (see *Sister Outsider*, 2007, by Audre Lorde; *Talking Back*, 2015, by bell hooks; *Eloquent Rage*, 2018, by Brittney Cooper), are dismissed, despite being entirely justified.

Notably, in *The Cultural Politics of Emotion* (2014), Sara Ahmed discusses the constructive potential of anger in her section titled “Feminism and Anger.” She links anger to what she terms the “politics of pain” which, drawing on the consciousness-raising groups of the 1970s, allowed women to make connections between their personal experiences and the structural relations of power, thereby transforming pain into collective resistance (Ahmed, 2014: 172). According to Ahmed, pain alone is insufficient to provoke social and political change; it requires the accompanying anger to recognize the wrongness of the pain, to view it as an injustice, and to demand action (ibid: 174). Ahmed also refers to Black feminism and Audre Lorde, who in *Sister Outsider* (1984) writes, “anger expressed and translated into action in the service of our vision and our future is a liberating and strengthening act of clarification... Anger is loaded with information and energy” (Lorde, 1984: 124, 127). Anger, in this context, empowers individuals to identify social injustice and motivates them to challenge and change the social and political structures that perpetuate oppression. As Ahmed suggests, “If anger energises feminist subjects, it also requires those subjects to ‘read’ and ‘move’ from anger into a different bodily world. If anger pricks our skin, if it makes us shudder, sweat and tremble, then it might just shudder us into new ways of being” (Ahmed, 2014: 175).

While emotions such as anger are restrained, emphasis is placed on the ultra-feminine aspect of breast cancer, specifically on maintaining a pleasant appearance throughout the physically and emotionally taxing ordeal, as well as promoting initiatives like the “Look Good... Feel Better” program by the American Cancer Society. This program offers beauty workshops and free cosmetic kits to women undergoing cancer treatment. However, the emphasis on appearance diverts attention from the larger issues at play and undermines the urgency for meaningful action. Moreover, the beauty products distributed in these kits often contain carcinogenic substances (<https://bcaction.org/2015/10/08/what-toxic->

cosmetics-are-in-this-look-good-feel-better-bag-and-also-on-a-store-shelf-near-you/).

In this context, proud and cheerful women conform to the mainstream narrative of *Cancerland* and are celebrated as “survivors” while simultaneously being at risk of dying from metastasis at any point in their “journey”. At the breast cancer marketplace in the U.S. dying of breast cancer has been stripped of its significance. The dead are relegated to the background, their deaths normalized. The mourning process, far from serving any purpose of social transformation, is reduced to a shallow and sentimental display, as Ehrenreich observes in *Welcome to Cancerland*: “They are said to have ‘lost their battle’ and may be memorialized by photographs carried at races for the cure – our lost, brave sisters, our fallen soldiers. But in the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the ‘survivors’ who merit constant honor and acclaim” (Ehrenreich, 2001: 48).

Ehrenreich further illustrates this point an expression of which she witnessed at a fundraising event where survivors, dressed in pink and adorned with medals, paraded to loud music and public announcements of their years of survivorship. In this context, she wonders: “At what point, in a downwardly sloping breast-cancer career, does one put aside one’s survivor regalia and admit to being in fact a die-er?” She reflects on the dead and recounts a deeply unsettling image: “For the dead are with us even here, though in much diminished form. A series of paper bags, each about the right size for a junior burger and fries, lines the track. On them are the names of the dead, and inside each is a candle that will be lit later, after dark, when the actual relay race begins” (ibid: 53). This kind of memorialization of the deceased strikes one as superficial, coarse, and ultimately disrespectful, encapsulating the commodification of mourning in the pink-culture landscape. It is an example of how mourning can be reduced to a sentimental or utilitarian process that fails to challenge the intersecting necropowers responsible for widespread death and destruction, as Radomska, Mehrabi, and Lykke assert (2020: 95).

In summary, as statistics show, breast cancer claims the lives of thousands of women each year, particularly in the U.S., within a persistent context of systemic inequities that disproportionately affect the most vulnerable populations. However, its normalization, aestheticization, and instrumentalization within dominant discourses and societal narratives remain predominant, shaping the mainstream response. Ethico-political positions that focus exclusively on the individual prevail in a neoliberal culture that has turned this major epidemic from a complex, multi-leveled, medical *and social justice* issue, into an opportunity to become stronger, into a charity poster-child (an expression I borrow from the breast cancer activist Barbara Brenner, speaking in the documentary *Pink Ribbons, Inc.*), and a “popular item for public consumption” (Sulik: 2011). The major narratives surrounding breast cancer fail to address the unethical profit motives, environmental injustices, health inequities, and the roles of class, race, and social status as active forces shaping the breast cancer crisis. Instead, dominant stories foreground the individual’s personal battle, journey, healing, and ultimate

victory, which is framed as an act of self-improvement. Consequently, we may infer two key points: First, the prevailing narratives serve as vehicles for perpetuating an oppressive, profit-driven system – neoliberalism. Second, without an appropriate response to these dominant tendencies, no meaningful change will occur.



Picture 5. Images from the 2011 documentary *Pink Ribbons, Inc.* by Léa Pool.

## Looking at the Network of Connections and at Different Stories

Under this light, my dissertation, *Breaking Free of Cancerland: Changing the Stories We Tell about Breast Cancer*, seeks to understand and critically examine the interplay of different actant forces that constitute the ideological, material, structural, and emotional landscape which engenders the production of such narratives, and to seek and discuss counter-narratives and their potential for social change. These, in my project, are stories debunking the political-economic interests, as well as the culture of toxic positivity served by the majoritarian narratives, and making minoritarian points and claims, while being written, not by women one would commonly consider as “in the margins” (colored, working class, uninsured), but by an outgroup inside the dominant group: white, middle/upper class women who write and draw their protest, complicating the Bildungsroman plot, as well as the relationship between center and margins. Most importantly, the stories I study are not highly acclaimed works belonging to a counter-narratives’ canon, or having emerged in the cultural/social space without leaving

any doubt for their activist character. On the contrary, they have been viewed with suspicion, they have been questioned, or they have been totally dismissed. My intention in choosing this type of narratives is threefold. Firstly, I want to shed light on the fact that minoritarian (and minor) voices may not be many, but they are still more than we think, as well as of a wider variety than what we are accustomed to. Secondly, I aim to argue that training ourselves to see beyond the expected and cultivating more openness to accounts of mixed tendencies might reveal that micro-processes of transition to different states are already in motion. Thirdly, I want to propose that part of achieving social change has to do with recognizing voices of resistance as such and talking about them, bringing them to the foreground, so that they can be heard and multiply, and join forces with other voices speaking about more types of oppression and violence.

The “Cancerland” of my title is a term coined by Barbara Ehrenreich, a journalist, social critic, and political activist, in her 2001 award winning report, “Welcome to Cancerland: A Mammogram Leads to a Cult of Pink Kitsch”, published in Harper’s Magazine. Ehrenreich wrote this report when she got breast cancer, and by “Cancerland”, she refers to the broader cultural landscape surrounding and giving shape to breast cancer as a cultural phenomenon in the U.S. Popular beliefs and attitudes, social imaginaries and outlooks by individual stakeholders and big anti-cancer institutions that determine what we think breast cancer is and how we should react to it, and that she found insulting and shocking. But also, crucially, things, objects of an instrumental, of a defining character, inextricably involved in processes and practices that, in their whole, define breast cancer in the U.S. today. Things that do not only form the background for action, but facilitate, encourage, trigger, prompt, provoke both the thinking and the performing of breast cancer, such as wigs, teddy bears, scarfs, cards with poems full of nauseating sentimentality, and all the endless pink products offering themselves to be consumed both as ideological signposts and as commodities for corporate profit. In the 2011 documentary “Pink Ribbons, Inc.” by the director Léa Pool, based on the book *Pink Ribbons, Inc: Breast Cancer and the Politics of Philanthropy* (King, 2006), Ehrenreich explains herself: “When I was being treated for breast cancer in 2000 and 2001, I did a strange thing: I wasn’t... did not research the science. I became fascinated more by... this breast cancer culture that I was encountering on the Internet and in other forms at that time. So, I became more... I turned sort of into an anthropologist, I think, “What’s going on here?” You know? What is it with all these pink ribbons and everything?”

Precisely this, and more, is the Cancerland I examine. The specific neoliberal, socio-ideological space of which I hope we can break free as we collectively, collaboratively raise awareness, not anymore for breast cancer as a medical issue, but – in and beginning from the cultural context of breast cancer – for the necropolitical, cancerous ways we exist as citizens, storytellers, and ethical beings. Thus, Cancerland, in this dissertation covers more than the territory of a particular biomedical condition and the dominant cultural assumptions and tendencies around it. It also refers to and deals with – as part of its research problem – the deeply neoliberal grounding of current notions of self and selfhood

and it critiques the highly problematic socially prescribed ways to be a consumer-entrepreneur self in the West today, in a world of human and non-human others, and in a commonly shared planet<sup>3</sup>. As the anthropologist Lochlann Jain explains regarding their book *Malignant: How Cancer Becomes Us* (2013), “understanding how our society makes sense of cancer, a subject that has so carefully been segregated from the massive institutions that have constituted it in its current form (as if cancer were a separate subject that comes to these institutions and ideas fully formed), enables us to better understand not only cancer, but also the broader common sense ideas that inform our everyday lives, and the broader ways that violence (one of whose forms is cancer) underwrites our self-and national-understanding” (Jain and Stacey, 2015: 3).

### **So, How to Go About It?**

How to go about it, then? How to start breaking free of Cancerland – as I have defined it? That is, to change our understandings and the meanings we communicate. How to raise awareness regarding the social, political, and economic factors that produce and sustain Cancerland: neoliberalism, dominant perceptions of breast cancer as a normal thing in a woman’s life, and neoliberal performances of selfhood built on ideologies that maintain the circle of death, among them? Can one of the possible answers be storytelling, but *of a different type*, since this is the primary way we interpret and communicate the whole of existence?

Indeed, a closer look reveals that the toxic-positivity imbued narratives of individual triumph – as I have mentioned earlier – is not all there is out there. There are counter-narratives, as well, challenging and talking back to the majoritarian stories in a real battlefield of competing meanings, or, as Richard Delgado argues in his text, “Storytelling for Oppositionists and Others: A Plea for Narrative” (2000): “there is a war between stories. They contend for, tug at, our minds” (ibid: 64). Granted, oppositionist articulations and voices in the context of breast cancer narratives are few and far between. They do exist nevertheless among the majoritarian narratives, and they testify for the active presence of a minority: women who don’t think of their lives along (almost purely) Bildungsroman lines, who are not thankful for getting breast cancer, and who complain and protest, such as Audre Lorde (1980), and, among the white, middle-class women, Christina Middlebrook (1996), and more recently, Anne Boyer (2019). These women write stories that do not affirm the status quo but

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<sup>3</sup> This all-encompassing sounding phrasing serves here to underscore the fact that breast cancer (for all its incalculable human toll) is but one manifestation of a bigger system of being in the world, which takes its toll on many other levels as well, beside the human. While the goal of this dissertation is specific and limited (to examine critically mainstream neoliberal breast cancer stories and promote alternative narratives), understanding breast cancer itself is key to the alternative ways people can look at it, so that subsequently can give different accounts. And understanding breast cancer needs to be done within the bigger context to which it belongs. This is what I have tried to do in my study.

interrogate and denounce it. Defined by negativity, critique, satire, irony, and refusal (but also humor, creativity, in-betweenness, denial to be fixed in a specific box), they stubbornly fail to comply with the norms (Halberstam, 2011), and queer many central concepts of our society while exposing its hypocrisy and complicity. Unsettling the ways we perceive and perform the self, and the ways we relate to the sick, mutilated, and dying bodies of others, these counter-narratives question fixed forms of storytelling, continuity, and the whole, and honor the marginal and the fragment. They offer different understandings of the world and performances of selfhood that do not conform to a discourse of friendly cooperation and placid acceptance, and make crucial statements about breast cancer as a socio-cultural phenomenon. In this sense, they are stories of resistance to oppressive world-and-narrative structures and to injustices. Some of them are clearly activist in content and style, making statements in ways that are unambiguous and militant. But there are also instances of micro-activism: activist gestures on a minor scale, on the level of the everyday and of the seemingly inconsequential that sometimes we fail to see (Manning, 2016; Svirsky, 2010). The stories of (partly) outsiders and underdogs pointing towards more ethical alternatives, but in ways subtle enough to go unnoticed or even be misconstrued as aligning with the status quo, rather than posing a direct challenge to it.

All these accounts dispute what Richard Delgado describes as “[n]arrative habits (and) patterns of seeing, (which) shape what we see and that to which we aspire. These patterns of perception”, he argues, “become habitual, tempting us to believe that the way things are is inevitable, or the best that can be in an imperfect world. Alternative visions of reality are not explored, or, if they are, rejected as extreme or implausible” (ibid: 62). The way to undo this or “[t]he cure is storytelling”, that is, “counterstorytelling” (ibid: 61). The stories of “outgroups, groups whose marginality defines the boundaries of the mainstream, whose voice and perspective – whose consciousness – has been suppressed, devalued, and abnormalized” (ibid: 60). The need for such resistance *against* and *with* storytelling has been emphasized in more, and crucially relevant scholarly texts, such as work from the field of Critical Medical Humanities (Woods, 2011; Costa et al., 2012; Woods, Hart, and Spandler, 2022), Literature and Narratology (Rimmon-Kenan, 2002 and 2006), Queer Studies (Halberstam, 2011), and Queer Death Studies (Lykke, 2019; Radomska, Mehrabi, and Lykke, 2020), acutely addressing the hushing up of structural violences and injustices through status-quo aligned types of narrative, and suggesting alternative forms of storytelling as a means of countering the hegemonic discourses. Critical feminist studies have shown that there are different ways of narrating the self, transgressing the limits of coherence and defying conventional narrative expression. The authors of the volume *Beyond Narrative Coherence* (Hyvärinen, Hydén, Saarenheimo and Tamboukou, 2010) challenge the idea of narrative coherence as a gauge of a good life story, which gained currency in narrative studies of the 1980s-90s, by showing “how the coherence paradigm privileges middle-class conventionality and marginalizes the experiences of artistically creative as well as politically traumatized people” (ibid: 2). In her chapter on traumatic testimonies (Hyvärinen

et al., 2010), Molly Andrews refers to our reluctance to accept that “there are no heroes” and “no lessons” in these stories and that suffering “did not resolve itself to a better world” (ibid: 163). However, Andrews maintains, these stories may serve as a point of access to “a wider social context” (ibid). Siding with this critical and politically engaged scholarship, and looking to subvert normative thinking by foregrounding different articulations and alternative stories I will examine three such counter-narratives, which nevertheless have not been acknowledged always as such. Three stories by women who eventually died of breast cancer, each waging her own oppositionist’s war in a U.S. neoliberal setting, against different forms of oppression and abuse.

## **Two Oppositionists, Three Stories, and One Context**

The narratives I study in this dissertation are: “Eurydice in the Underworld” (1998) and “The Gift of Disease” (1997) by the avant-garde writer and multimedia artist Kathy Acker (1947–1997), and *Cancer Made me a Shallower Person: A Memoir in Comics* (2006) by the best-selling, self-taught comic book artist Miriam Engelberg (1958–2006). What these two quite different authors/artists have in common is that both of them in their account(s) of their experience with the disease speak in an honest way about their confrontation with their mortality and about the social and medical attitudes that exacerbated their emotional toil. They write about the polluted environment in which they live, the neoliberal, persisting emphasis on personal responsibility, their excruciating physical pain, financial hardships, depression, mastectomy, and being infantilized by the medical context and treatment. Both authors/artists are women with strong political attitudes, while they come from worlds and they have created in contexts that differ considerably from each other. Acker wrote postmodernist punk literature, while deeply involved in a bohemian downtown New York and San Francisco art scene. She was a rock-star of American letters and a literary provocateur, living a life of constant movement, without any long-term commitments. Engelberg was a married San Francisco woman, artistically inclined and with a sharp critical spirit, combining a part-time office-job as a computer trainer in the non-profit sector with comics-making and motherhood. Both artists, as well, performed in public. Acker gave numerous public readings-performances of her texts, and also collaborated with the British punk rock band, the Mekons. Engelberg, in her earlier days, did stand-up comedy together with a friend, performing autobiographical texts in theaters in San Francisco. Also, they both drew images to go with their text. Obviously, Engelberg much more so than Acker, since she worked in the genre of comics, and had decided – after an unsuccessful collaboration with a friend who was a professional illustrator – to draw her own images. But Acker, too, frequently made drawings to go with her writings (see: *Blood and Guts in High School*, 1984; *Pussy, King of the Pirates*, 1996; *In Memoriam to Identity*, 1990), which is also the case in one of the stories I examine here: “Eurydice”. Notably, however, and regardless of any other similarity, it is above

all the minoritarian quality of their stories raising voices of dissonance in the pursuit of social change *in ways that might not be readily visible* that bring them here together.

Engelberg's graphic memoir has been the subject of several research articles and academic publications within the field of medical humanities. It has been recognized as a significant contribution to the emerging discipline of Graphic Medicine: a field that bridges medicine and the humanities by examining illness narratives rendered through the medium of comics in order to understand the experience of illness, healing, and healthcare. Nevertheless, while mostly celebrated, Engelberg's joking, satirical tone has been also a point of contention and taken to be, in essence, a normative element betraying a narrative without genuine anti-conformist intentions. The artist has been suspected of mainstream tendencies, such as advocating for resilient, smiling cancer patients who don't lose their sense of humor despite their ordeal. Such misrecognition is not uncommon when it comes to counter-narratives operating in a minor key, and it is the reason why minor gestures of resistance oftentimes take place without being acknowledged as such. Engelberg's dissident voice, though, has gone unacknowledged in a much lesser degree than that of Acker.

To begin with, there is little to non-existent work within the medical humanities focused on Acker as most scholarly engagement with her oeuvre emphasizes its feminist and avant-garde dimensions. An additional and – in the context of my thesis – important reason why “The Gift” at least (if not “Eurydice”) has been entirely overlooked is because of a certain awkwardness it must have caused. Acker presents there a specific choice (turning to spiritual healers for help) and a journey (learning from them lessons that healed her cancer). Both of these elements, in resembling normative narratives, do not seem to correspond with her persona as a fierce critic of the status quo, and could describe her as aligning with majoritarian ways of thinking. Both of these, as well as the fact that she emerges a person with deeper insight and self-knowledge at the end of the story after having learned to address the traumas that caused her cancer, must have been very far from what was expected of Acker.

In my analysis, I take what has been potentially considered in “The Gift” as major to be an instance of the minor – a minor gesture of resistance, which, precisely because of its subtlety (sometimes ambiguity), can be hard to identify and easy to be mistaken for something it is not. In this sense, the innovative value of my dissertation lies in two research choices. First, it addresses a gap in existing literature by making an original contribution to the study of two important but understudied texts by Acker (“The Gift” and “Eurydice”) from a medical humanities perspective. Second, it pays attention to stories of resistance (counter-narratives) which, *unlike widely acclaimed and celebrated breast cancer stories* (such as *The Cancer Journals* by Audre Lorde, and *The Undying* by Anne Boyer) might not be readily or unanimously (as it has happened with Engelberg) identified as such because they reside in the realm of the minor.

We will get back to Acker and Engelberg in the ensuing chapters of the dissertation. Perhaps only, very concisely, to note here one important thing. Operating

from certain margins and employing a logic of fragments that challenges the dominant and the central and disturbs linearity and coherence, Acker and Engelberg affirm the subversive power of oppositionists and counter-storytellers offering accounts markedly different than the master narratives. Nevertheless, despite their uncompromising, subversive attitude, they are not complete outsiders, but stand somewhere in-between outside and inside. Despite their irony and non-compliance and clear political agenda, they are not completely without Bildungsroman/majoritarian traits (with the exception of “Eurydice”, in which at least I couldn’t make any such connection), and rather seem to mix elements of a *Bildungsroman* protagonist and a *picaro*. A trickster who doesn’t care about self-development and only struggles to survive, and is, in Bakhtin’s typology, the main character of the exact opposite narrative genre. A closer look at these stories shows them to be hybrids, moving in-between categories, a fact which, nevertheless, does not cancel or compromise them as minoritarian activist alternatives, but adds to their complexity and places them in a space where interesting tensions are allowed to exist between antithetical tendencies. For example, the need for belonging and the introspective hero who scrutinizes every aspect of their being, go together with a scathingly critical attitude towards the wrongdoings of a toxic, hypocritical society that puts all the responsibility on the individual and accepts none of its own (Engelberg, 2006). The need to be acknowledged as a person, to look inside oneself and resolve lingering emotional issues, coexist with a clearly articulated output on what needs to change urgently in western medicine, concerning particularly the doctor-patient relationship (Acker, 1997). So, while these counter-narratives are very far from being soothing stories of sisterhood, patience, and perseverance seeking to inspire by suggesting a model for coping with breast cancer, they are at the same time part of the same lifeworld in which we are all shaped as people. Being a non-conformist outsider and a wanderer looking for one’s own way somehow concurs with being very much part of a community and having a few important things to say about it. Ultimately, and for all their in-betweenness, in the breast cancer memoirs’ predominantly pink and pretty landscape, these stories are three ugly monsters, queer tricksters and truth-tellers gesturing towards more ethical ways of existence. This is particularly significant in the U.S. context to which I came as the research process unfolded.

The choice of the specific context followed, rather than preceded, the choice of the actual case studies. At the time of selecting the narratives of Acker and Engelberg, I did not necessarily prioritize the U. S. as a focal area. However, shortly after initiating my research, I became so fascinated by what I was learning that the U.S. as an area of study for this particular topic emerged as the option I would have certainly taken had I started the other way round. Sometimes, to know one thing you need to see it in contrast with its opposite, and in the U.S. the contrast is vast. What is described as problematic in this dissertation – inequalities, toxic positivity, neoliberal notions of selfhood, a quest-story for everyone, and a society that values nothing as much as constant growth and profit – is a reality almost everywhere today, but nowhere quite in the way it happens in the U.S. These problems exist in the rest of the world, as well. But in the U.S., one

of the major strongholds of individualism and neoliberalism, the birthland of the American dream and the idea that we can all make it if we try, the place where so many people don't have basic health insurance even as others publicly celebrate survivorship in highly visible, costly, and performative ways, we are confronted with a different situation. Being brave in the face of obstacles and looking your best despite everything, coping and rising from your ashes, being invincible because you want it and because your sheer will makes it "possible", all that in the U.S. takes a whole new dimension. This is not the place to compare in detail the U.S. reality to that of other places. It is, however, I think, recognizable, what I am talking about, as well as the reasons why the study of the specific manifestations of breast cancer as a cultural phenomenon and as a topic of autobiographical narratives in the U.S. context makes sense and is necessary today.

## Scholarship For Community

My project, looking at the issues outlined in this introduction under a title clearly expressive of its position and politics, begins from scholarly research and from a critical examination of the sources, with curiosity, openness, and respect for the contributions of others whose efforts have greatly facilitated and guided mine. However, given the unmistakable presence of harm and injustice already identified by valuable work that has long preceded this one, it aspires to be more than an academic text in a university program context. Beginning as a theoretical investigation, it assumes a community-engaged character and is ultimately addressed as a micro-political gesture and a call for action. In this sense, it is inspired by other researchers' practices of bridging the activist-academic divide (Eschle and Manguerra, 2006), of knowledge production for social justice (McGregor and Knox, 2017), and of creating community-university alliances (Bourgeois and Palmer, 2022). Such work has critiqued and undermined past dichotomies between academic output and social intervention (Autonomous Geographies Collective, 2010; Hoofd, 2010), particularly in fields traditionally dealing with oppression and inequities, such as feminist studies (Felski, 1989; Atkinson and Standing, 2019; Findlay, 2022; Sobande, 2018; Wånggren, 2018), critical race theory (Delgado, [1995] 2000; Sonn and Quayle, 2013; Pulliam, 2017), black studies (Rojas, 2010; Andrews, 2020) and disability studies (Davis, 2000; Pearson et al., 2016; Liasidou, 2014) to name but only a few. It has moreover found expression not only in articles, books, book series, and journals that systematically publish such work (eg. *Anthropology in Action: Journal for Applied Anthropology in Policy and Practice*; *Studies in Social Justice*; *Social Justice Research*; *Journal of Critical Race Inquiry*; *Race and Class*; *Environmental Justice*), but also in websites and blogs ("Justice Everywhere: a blog about philosophy in public affairs", run by a cooperative of political theorists and philosophers and in collaboration with the *Journal of Applied Philosophy*; "Transforming Society: a space where research, evidence and critique can create positive social change", in collaboration with Bristol University Press and Policy

Press, and many more) bringing academics' perspectives on social justice matters to a non-academic public. Beginning with this project on breast cancer autobiographical narratives, I wish to keep doing research that is politically and socially engaged also in the future, finding this to be a quality that, particularly in contexts of oppression and violence, makes academic work truly meaningful, regardless the object of study.

## Perspectives

Moving from the singular to the plural, though, and from stark neoliberal individualism to a critical-creative ethics and politics for a community, is not something that can be done only from one specific standpoint, one discipline or area of expertise. Indeed, not even with the combination of two. Acknowledging this fact in relation to more current social justice issues, a growing number of theorists from areas such as feminism, disability studies, queer theory, and crip theory (Garland Thomson, 1996; McRuer, 2006; Kosovsky Sedgwick, 1992; Sandahl, 2003; Clare, 2015) suggest a teaming up of different fields in order to give a joint answer to the coming-together of oppressive discourses that strengthen each other. Similarly, and in the realm of purely practical action, it has been suggested that “the breast cancer movement could forge links with other social justice movements, such as the anti-globalization movement, the peace movement and the environmental justice movement” (Moffett, 2003:287). Following this fundamental understanding, I will attempt reading and interpreting breast cancer memoirs – themselves also formed by and reflecting a coming-together of various culturally dominant discourses – employing a combination of approaches, including narrative studies, anthropology, cultural studies, feminist research, queer (death) studies, and social justice studies. Having made this choice, nevertheless, I consider my interdisciplinary perspective as bearing a strong anthropological element, since anthropology's broad spectrum covers all aspects that, individually, consist each of the aforementioned fields' central concern.

An anthropology and ethnography of books, then? Of texts? Is this all I've got to access the life-world I study? Ehrenreich at least can claim that she did participant observation, having gotten breast cancer herself, and being there, in a U.S. context, experiencing everything first-hand. My own experience with a neurological condition – a chronic illness I live with for the past twenty-four years – and my experience as a working-class female patient in a neoliberal world is definitely something I (in)directly draw from, but is that enough? Anthropological/ethnographic knowledge has been historically represented as “diverse from, and even opposed to, that which results from documentary research” (Cunha, 2005: 36, cited in Lowenkron and Ferreira, 2013), and so “the task of *ethnographing documents* may still seem strange and obscure to most ethnographers, in contrast to the allegedly self-evidence of the expression “participant observation”” (Lowenkron and Ferreira, 2013: 81, italics in the original). And how can one's research be valid if it “does not guarantee the same strategies of

authority derived from the certainties (if not of objectivity, at least of controlled partiality) produced by the experiences of direct contact and dialogue with the persons who inhabit ethnographic narratives”? (ibid). But perhaps being there is not the only way to go about it.

Lowenkron and Ferreira (2013), who, similarly to me, have made texts the objects of their research, in their article, “Anthropological Perspectives on Documents”, observe a certain change in things. They remark that “[t]he “post-modern” view of ethnography as text has led anthropologists to turn their attention to other textual genres that had either been set aside or regarded as less important once anthropology moved away from the “armchair” and gained “scientific” authority and legitimacy through malinowskian fieldwork” (ibid: 78). In this context, Lowenkron and Ferreira, whose research does not center on literary sources but focuses on legal documents and bureaucratic writing, propose another approach to the study of texts. That is: “moving anthropological self-representations away from ethnography as “participant observation” or as writing, toward ethnography as modes of reading” (ibid: 82). They advocate expanding the ethnographic work done on documents and “analyzing them as producers of knowledge, relations, effects and affective responses (Stoler, 2002 and 2009; Cunha, 2004; Navaro-Yashin, 2007; Gupta, 2012; Ferreira, 2013) or even as artifacts whose material, aesthetic and formal properties, as well as social life (or socio-technical processes) can no longer be easily ignored (Latour and Woolgar, 1979; Riles, 2006, Reed, 2006; Hull, 2012b)”. This perspective suits my case.

In brief, my intention is to examine how texts function as circulating and disseminating discourses, and therefore, as producers of knowledge around success and failure in a material-semiotic network, composed by various processes, physical objects, and symbolic representations/meanings. Moreover, how they gather upon them and return back to the social, amplified, because condensed and therefore more powerful, dominant belief systems and structures of thought that determine our bigger structures of life. As I am summarizing what we have just looked at – a network of interconnecting elements – I can’t help thinking of Bruno Latour arguing in *We Have Never Been Modern* (1993) that the separation between nature and culture, or science and politics is not a valid one. While these distinctions are defining of modernity, in reality phenomena cross these lines, proving the modern modes of interpretation incapable of reflecting the practical ways in which we actually live. The general attitude “seem(s) to say, let us not mix up knowledge, interest, justice and power. Let us not mix up heaven and earth, the global stage and the local scene, the human and the nonhuman” (ibid: 3). The social world, however, is constituted by hybrid objects, “monsters, cyborgs, tricksters” (ibid: 47), in-between categories: quasi-objects and quasi-subjects, assembled through a certain work of mediation, a mediation which such divisions render “invisible, unthinkable, unrepresentable” (ibid: 35). These omnipresent hybrids include, among many other things, “the hole in the ozone layer”, “computer chips”, “Monsanto”, and “AIDS”, making Latour ask: “Can anyone imagine a study that would treat the ozone hole as simultaneously naturalized,

sociologized and deconstructed?” (ibid: 6). So then, can anyone imagine so breast cancer?

Breast cancer, too, is such a quasi-object, a hybrid constituted by the things I have mentioned above, plus much more, acting concretely in the social world and forming it (breast cancer) as the hyper-complex, hybrid phenomenon that it is: biopsy results, chemotherapy injections, news items, toxic substances in food, air, and daily use products, yoga retreats, mega-corporations, wigs, breast prostheses, narrative genres, meditation, support groups, grassroots activist organizations, pink ribbons, marathons for the cure, laboratories, scientific articles, and manuals on how to write your own story of healing. Each of which are, in turn, hybrid objects, and “productions of natures-cultures” or else, “collectives” (ibid: 106–107). Each of which have agency (the agency of objects being a question on which Latour returned with *Reassembling the Social: Introduction to Actor-Network-Theory*, 2005) and are co-producers of society and of breast cancer, not because they can cause action on their own, but because they “make a difference in the course of some other agent’s action” (ibid: 71). Because they “might authorize, allow, afford, encourage, permit, suggest, influence, block, render possible, forbid, and so on” (ibid: 72). Since I rely quite a lot on Latour’s thought in order to understand my subject, I will quote him here more at length:

“Let one of the representatives talk, for instance, about the ozone hole, another represent the Monsanto chemical industry, a third the workers of the same chemical industry, another the voters of New Hampshire, a fifth the meteorology of the polar regions; let still another speak in the name of the State; what does it matter, so long as they are all talking about the same thing, about a quasi-object they have all created, the object-discourse-nature-society whose new properties astound us all and whose network extends from my refrigerator to the Antarctic by way of chemistry, law, the State, the economy, and satellites” (1993: 144).

Reading once more this passage from Latour’s book, I realize that I have come across a similar way of thinking in Anne Boyer’s Pulitzer prize winning critical essay/breast cancer memoir, *The Undying: A Meditation on Modern Illness* (2020). Her memoir is in fact very little about her own individual case and very much about the far-and-wide extending multitudes of things, human and non-human, that constitute the conglomeration, the “collective”, in Latour’s words, which is breast cancer. The Himalayan yew tree from which one of the author’s chemotherapy drugs is harvested, endangered since 2011; YouTube videos by patients with triple negative breast cancer sharing their experience; the Susan G. Komen foundation; computer screens, servers, and “detectors with names made of letters: MRI, CT, PET” (ibid: 15); “quiet technicians, loud clatters, warmed blankets, cinematic beeps” (ibid); the difficulty of doing the dishes when treated for breast cancer; stock phrases, such as “attitude is everything”; class, race, and gender in a neoliberal world. Boyer traces a network of inter-connecting quasi-elements, involved in and co-creating, as Latour remarks, injustices, social hierarchies, and inequalities (2005: 72). All that is also reminiscent of the book

*The Body Multiple: Ontology in Medical Practice* by Annemarie Mol (2002), who draws on feminist theory, medical anthropology and, notably, science and technology studies, to discuss atherosclerosis as a complex blend of object-subject relations, hospital structures and practices, medical tests, consultations, and so on. Mol's work, based on detailed observations of a hospital setting, and inspired by thinkers like Bruno Latour and Donna Haraway, emphasizes that reality is not pre-given but actively produced through practices. It brings to the foreground a plurality of realities as well as the interplay between materiality, discourse, and practice, and challenges the authority of biomedical science as a singular arbiter of truth, advocating instead for an appreciation of the multiple ways in which health and disease are enacted.

Inspired by Latour, Jain, Boyer, and Mol, I will analyze minoritarian (and minor) breast cancer narratives as life documents and as cultural-material artifacts within this network – communicative, affective objects that occupy a certain, distinctive position in a group of similar objects, performing a series of (seemingly) reactionary, status-quo-aligned acts, but also subversive, activist gestures, in a broader, predominantly conformist context. I will look at how a specific type of autobiographical-literary texts reflects and reproduces a neoliberal world, while other, minoritarian, dark, and disobedient counter-narratives can undermine, expose, critique, and lead to a change. My thinking is informed by actor-network-theory and by the rest of the fields (of research and activism) mentioned in this section. My actual analysis of the texts, however, does not employ an ANT methodology, but takes more the form of close reading and makes use of a strongly descriptive mode, which is characteristic of ethnographic research. As such, it emphasizes detailed, narrative-rich, and context-specific descriptions of the works and of the relationships between the different elements in them, but also examines genre, tone, and (literary) aesthetics. It attempts to capture the behaviors and nuances as they occur in each of the case studies, not only presenting the inter-actions taking place but also interpreting the cultural meanings behind them (what Clifford Geertz calls “thick description”). It also involves immersive observation sometimes including the researcher's reflections, and recognizing their influence on the interpretation and understanding of the material.

## Outline

This dissertation is structured in three parts. The first part consists of a theoretical chapter presenting aspects/elements of the broader social/scientific/political/material network within which mainstream breast cancer stories proliferate, and engaging in dialogue with research that is relevant to the understanding of the issues involved. My inquiry includes a discussion of the practice of Narrative Medicine, a section tracing the emergence and development of illness narratives from the 70's until the 90's, and an examination of the systematic propagation of a specific story type (triumph over tragedy) as a model for people's illness and

trauma narratives by publishing companies and recovery-oriented health-care structures. The chapter continues with an analysis of the ways neoliberalism has evolved from an economic system to an ontological issue defining the ways people think and exist in the world, as well as of the entanglements and inter-relations between neoliberal ideologies and the *Bildungsroman*. Subsequently, I turn my attention to spiritual/alternative practices (the ways they have been appropriated by neoliberalism and the ways they exercise control), then to master and counter-narratives (mainstream, dominant stories and dissident, alternative accounts, opposing each other and at the same time linked to each other), and finally, to the activist practices of refusal and resistance.

The second part is an examination of the counter-narratives “The Gift of Disease” (1997) and “Eurydice in the Underworld” (1998) by Kathy Acker. In the first case, I investigate how the minoritarian and (elements from) the majoritarian interact, with Acker rejecting mainstream western medicine to seek help from spiritual healers and enter with them a “school of the self”. A point after which she follows a *Bildung* (education) according to which illness is caused by emotional traumas and people are responsible for their own recovery. I argue that the text, in its whole (including clearly activist-critical sections in the beginning *and* the time Acker spent with the alternative healers), addresses dehumanizing aspects of medical care in the U.S., and breast cancer as a type of business. In the second case (“Eurydice”), I understand Acker’s account as a textual performance in-between genres, an activist-poetic piece making a point against necropolitical structures that victimize the vulnerable. I consider it as a story that queers binaries of self-other (involving directly the reader and blending the author’s self with those of other precarious women), and even life-death (presenting us with a type of death that is vibrant, powerful, and even a space from which people can still speak, be heard, and exert influence). I analyze “Eurydice” as an ethico-political gesture of mourning, making mourning public and powerful, and as an act of female defiance to male sovereignty. My study of the text links and compares it to the age-long Greek oral poetry tradition of *moirologia* (laments), mournful public rituals performed by women until recently in rural areas of Greece when a death occurred in their villages. I find that the counter-cultural practice of *moirologia*, in terms of structure, content, and functions, bears significant resemblances to “Eurydice”, which justifies a comparative look helping recognize Acker’s story as a counter-narrative of female opposition.

The third part of the thesis studies the graphic novel “Cancer Made Me A Shallower Person: A Memoir in Comics” (2006) by Miriam Engelberg. In this chapter I explore, among other things, the tensions that come at play between *Bildungsroman* and picaresque elements in a testimony that resists normative narratives of success and failure, refuses to participate in socially prescribed ways of dealing with breast cancer, and employs humor and satire as a powerful means to expose injustices and undermine the authority of master discourses. Engelberg opposes meditation, yoga, mindfulness, journaling, and toxic positivity while critiquing social expectations towards breast cancer patients to become wiser, nobler, and more spiritual as a consequence of their “journey”. She claims that

her cancer made her actually shallower and, giving her comic book an episodic structure (like that of a picaresque narrative), she presents her graphic avatar passing from situation to situation, debunking oppressive beliefs, and speaking about the environmental causes of breast cancer. Engelberg is a character who will not learn lessons or become better at the end of the story. The dissertation draws to a close with a few pages of conclusive remarks.

# CHAPTER 1. BREAST CANCER UNDER NEOLIBERALISM

## Narrative Medicine

“In writing and reading, a touch of salvation is possible... some kind of not being lonely, the balm of world-making words” (Atkinson, 2018: 11).

“narrative medicine [...] privileges the patient’s voice and a move to bring the patient’s first-hand bodily, human experience back into the clinical encounter in a nuanced, empathic manner” (Hinson, 2018: 520).

Illness narratives or (auto)pathographies, first-person narratives describing the author’s personal experience with illness and medical care (Kleinmann, 1988; Frank, 1995; Couser, 1997; Henke, 1998; Brody, 2003), emerged as a subgenre of autobiography in the late twentieth century, and evolved into a currently booming area of narrative production, as well as a massive cultural phenomenon of our times. This phenomenon has become the focus of a now major field of scholarly studies, the medical humanities, including disciplines like anthropology, sociology, and literary studies, and focusing on issues at the intersection of humanities/social sciences, and medicine. Illness stories, then, have been the object of analysis for the last 25 years (Garro, 1994; Charon et al., 1995; Charmaz, 1999; Docherty and McColl, 2003; Kokanović and Flore, 2017; Barker, 2017; Lucius-Hoene et al., 2018) from a perspective between medicine and literature, Narrative Medicine. This perspective advocates the integration of narrative in the practice of medicine (Schleiffer and Vannatta, 2013), emphasizes the importance of patients’ stories in research, education, and clinical practice, and promotes the systematic study of narratives that convey the experience of illness. Its goal is to produce reconsideration of existing medical practices and ethical attitudes, to illuminate the nuanced and concrete reality of illness from the viewpoint of the patient, and to enable the medical practitioners to learn from the patients’ stories and gain insights towards an ethics of empathic care (Charon, 2006).

Narrative Medicine (Charon and Montello, 2002; Mullan et al. 2006; Parsons and Hooker, 2010), was introduced in 2000 by Rita Charon and is currently established as part of the curriculum in several prominent medical schools in the U.S. (Columbia University Medical Center, Ohio State University, University of California Irvine). In its context, medical students study literary texts (canonical works of realist fiction and autobiography) and learn to analyze them with the employment of literary techniques (Lanphier, 2021) by doing “close reading”. This means training “readers (medical students/professionals) to identify frame, form, time, plot, and desire” so that they can “mobilize their considerations of the enduring narrative features of medicine and of illness – temporality, singularity, causality/contingency, intersubjectivity, and ethicality” (Charon, 2006: 126). In layman’s terms, the main goal is to understand how the events unfold in time, the order in which they are presented by the “author”/ill person, and the causality and

meaningful connections that are made. After the close reading of the literary texts, students write down their own reflections regarding their experience with the text, and finally, close reading and discussion of the students' texts is performed in the classroom together with their teachers. The aim of this process is to equip students and medical staff with "narrative competences" in order to do a close reading of their patients' narrative during the consultations (which is also thought to assist them in making a diagnosis) and treat them as human beings with individual stories rather than purely based on symptoms (Chu et al. 2020). This goal reflects the primary reason of the work of narrative medicine, namely, to re-humanize medicine, and reconstitute it, from its reduced current state of an impersonal, professional gesture, back to a dignified human encounter and a journey to healing (Marini, 2016). Rita Charon in *Narrative Medicine: Honoring the Stories of Illness* (2006; see also: Charon et al., 2016), explains that this is "medicine practiced with the narrative competence to recognize, absorb, interpret, and be moved by the stories of illness" (2006: vii). Nevertheless, this specific engagement with narrative, traced to the post-war rise of humanist and "holistic, person-centered approaches, often including attention to individual case studies, biographies and life histories" (Squire et al. 2013), has received some valid criticism.

Scholars have argued that it is questionable whether we can actually teach empathy through the study of literary works (Macnaughton, 2009) and that things look very different in the classroom than in the real-life practice of the medical profession (Nuland, 2010: 272). Others object the utilitarian approach to narrative as a method of collecting "medical data" and making the right diagnosis (Willis et al., 2013: 68). Yet others advocate the expansion of the definition of narrative to include experimental forms and non-literary modes of expression, opposing the dominant tendency "to treat narrative as synonymous with verbal, if not literary, expression and to define it in terms of linearity and coherence" (Bolaki, 2016: 6), and pointing out that "mainstream medical humanities criticism [...] still revolves around the influential models of Brody, Couser, Frank, Hawkins and Charon" (ibid: 9). Finally, "[d]espite the importance that the Narrative Medicine approach is acquiring in biomedical and health sciences", its "scientific value" and "effectiveness" has been evaluated by "just a few studies" (Fioretti et al., 2016: 2).

To my understanding, promoting the study of stories that communicate the personal experience of illness as a way of increasing doctors' empathy in a culture literally saturated in neoliberal-cult-of-the-self narratives, makes Narrative Medicine really not all that critical and innovative as an approach, and, to an extent, rather complicit in a massive storytelling economy that trades in affect and distracts from real solutions, particularly in the case of breast cancer. I fail to see how medical students' close reading of literature, then writing and reflecting on what they have read through their own subjectivity, then doing close reading on their own texts, can help breast cancer patients by leading the future medical professionals to a moment when, during a consultation, they will nod and say: "I understand how you feel". I wonder how it can be helpful to breast cancer pa-

tients, many of them coming from highly challenged socio-economic backgrounds, if “[t]he physician, too, is engulfed by sadness as she listens to her patient” (Charon, 2001: 1897). If “[t]he physician grieves along with the patient, aware anew of how disease changes everything, what it means, what it claims, how random is its unfairness, and how much courage it takes to look it full in the face” (ibid).

I do not intend to sound dismissive of Narrative Medicine. And even if a little bit of extra empathy can be cultivated in young doctors’ minds in today’s corporate-like conditions of work at the health sector in the U.S., that’s already a gain. But the gain (this very badly needed gain and change) can be so much greater if legitimate criticisms directed at the work and function of Narrative Medicine are addressed and constructively employed to make its practice more discernibly aligned with goals of social justice. O’Mahony writes:

“I would argue that the study of medical humanities should provide hinterland and perspective. These are unquantifiable attributes. By *hinterland*, I mean a connection with broader culture, a connection with the world beyond the medical school and the hospital. By *perspective*, I mean an understanding of the place of medicine in society, the historical forces that have shaped it, and the challenges it will face in the future” (O’Mahony, 2013: 617; italics in the original; my underlining).

I second this suggestion. I think that this “connection with broader culture” and “with the world beyond the medical school and the hospital” should emphasize the study of critical texts that can make students and practitioners aware of the current socio-political arrangements affecting health and the ways we understand and deal with illness. I would propose that strong connections be made between literature/empathy on the one hand, and health equity, community, and communal responsibility on the other. That courses such as “Narrative, Health, and Social Justice”, and “Advocacy and Organizing: Narratives of Activism, Social Justice, and Community Health”, from the master’s program in Narrative Medicine in Columbia (which, notably, are not core courses/mandatory, of which only one involves the themes of community and activism), be given a place at the forefront of what Narrative Medicine is and does. What I suggest is actually already a part of the Narrative Medicine master’s program, embedded in the curriculum. Browsing the webpage we see that titles such as, “Race, Narrative, and Medicine: Describing African American Bodies” and “Illness-thought-activism: From HIV/AIDS to Covid-19” are present. But they are not given an important enough position. What is central and defining of the character of Narrative Medicine is acquiring narrative competences (by reading, reflecting, writing, discussing) and listening in an empathetic manner that honors (perhaps fetishizes?) the perspective of the patient offering a safe space for self-expression, but no critical probing or change.

In fact, I would imagine Narrative Medicine more aligned with (or inspired by) the goals and methods of Narrative Therapy, which is *also* part of the Narrative Medicine MA curriculum, but only as an elective. Narrative Therapy is a social justice approach developed by Michael White and David Epston around the same period as Narrative Medicine started emerging in academia (White and Epston, 1990; Epston and White, 1992), and draws from poststructuralist philosophy (most prominently Foucault’s concept of modern power<sup>4</sup>) and social science<sup>5</sup>. Narrative Therapy works by means of a collaborative effort of therapist and service-user aiming to expose dominant discourses that shape people’s understandings of reality. Narrative therapists use questions to guide the patients towards the awareness that there are cracks and gaps and blind spots in what we take for “truth” or for “just the way things are”. This happens by paying attention to events or points in the life of the patients as narrated by them, which discredit the dominant paradigm. The agency of the patients is acknowledged, and it is through their own skills and wisdom that they reach the possibility to develop “multiple story lines that speak of multiple possibilities for people’s lives” (Combs and Freedman, 2012: 1038). This fact along with the question-based structure and the goal of evaluating the validity of “reality” is reminiscent of the Socratic method. Socrates, a notorious social critic of his times, used a very similar technique to question common knowledge and assist people in disposing of false ideas about the world “as we know it”. Additionally to what Socrates did, narrative therapists connect people with similar issues who can then “both contribute to and partake of a growing body of insider knowledge [...] [A]s people join their voices together, they are more likely to be heard in the larger society. They are less marginalized. This linking of lives through shared purposes is one of the fundamental and recurring ways that narrative therapy supports social justice” (ibid: 2012: 1035).

The teaching and practice of Narrative Medicine can also draw inspiration from the Narrative for Social Justice Initiative (N4SJ) (<https://www.thenarrativesociety.org/n4sj>), founded by the Diversity, Equity, and Inclusion Committee and by members of the International Society for the Study of Narrative (ISSN). The N4SJ Initiative is committed to the making of public scholarship and to bringing together scientific research and community engagement. Interestingly for this thesis project, and linking N4SJ to Narrative Therapy, its main goal is to see “how narratives of any kind, be they fictional or non-fictional, can challenge discourses circulating in the public sphere that fuel inequities and social injustice” (ibid).

Narrative and storytelling have immense potential to assist both individual (Price Herndl, 2006; Ramirez-Esparza and Pennebaker, 2006; Peterkin and Prettyman 2009; DasGupta and Hurst, 2007) and community healing (Sharratt, 2016; Chioneso et al., 2020; Saul, 2022; McNeil-Young et al., 2023) and to bring about transformation and social change. There are, as we have seen, uses of

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<sup>4</sup> See Foucault: 1965; 1975; 1977; 1985.

<sup>5</sup> Mainly the work of Gregory Bateson (1980).

narrative that do precisely that, in ethical, politically engaged, and socially sensitive ways. There are, nevertheless, opposing tendencies, as well (a profit-making storytelling boom operating within the neoliberal self-help, writing manual-assisted, entrepreneurial recovery-oriented economies of affect), which need to be countered. And there are still areas, such as Narrative Medicine, that can be improved, renewed, or even radically updated in their core to face the challenges of our times from an alert and politically responsible position. We could be all surprised by the results. But how did all this evolve in time, to reach the point at which we are today?

## Types in Time

The healing and restorative properties of illness narratives are manifest in the work of many theorists who wrote in the period around the beginnings of the illness memoir explosion, which, interestingly, coincides with a more general rise of storytelling, namely, the 60's and 70's (Smith, 2012: 4). Arthur Kleinman's book *The Illness Narratives: Suffering, Healing and the Human Condition* (1988) underscores the significance and necessity for patients to give expression to their experience in the form of a story, and for medicine to "record this most thickly human dimension of patients' and families' stories of experiencing illness" (ibid: 28). Anne Hunsaker Hawkins in *Reconstructing Illness: Studies in Pathography* (1993), coins first this term (pathography) and, together with Kleinman, pre-figures what we now know as Narrative Medicine, claiming that "[p]athography restores the person ignored or cancelled out in the medical enterprise [...] places that person at the very center (and) gives that ill person a voice" (ibid: 12). This process "involves the discovery of patterns in experience, the imposition of order (and) the creation of meaning – all with the purpose of mastering a traumatic experience and thereby re-establishing a sense of connectedness with objective reality and with other people" (ibid: 24). Following the emergence and evolution of illness stories in the second half of the twentieth century, the author notes that "[a]s a genre, pathography is remarkable in that it seems to have emerged *ex nihilo*; book-length personal accounts of illness are uncommon before 1950 and rarely found before 1900" (1993: 3; italics in the original). She remarks that breast cancer specifically is overrepresented in illness narratives (already from the end of the 1980's), and presents three types of pathographies that mark the development of the genre's character in time, clearly indicating how the genre arrived to the point at which it is today.

In the late 1960's and in the 1970's, the dominant type is mostly *testimonial pathographies*. These are mostly didactic and with the intention to help others – very much like most contemporary breast cancer memoirs – an example is *Living and Dying Gracefully*, by Herbert Conley (1979). Stories in this category "are like religious "testimonies", public professions of faith that are meant to bear witness to the truth and strengthen other believers by relating an experience of *spiritual trial or conversion*" (ibid: 4, my italics). The goal of these stories,

according to the author, was to give expression to the ill person's thoughts and feelings while the general attitude towards medical practices is one of acceptance and trust. Evidently, however, this type of stories did and do much more than that: they express a certain political attitude. They perform an ethical positioning that informs current neoliberal accounts taking breast cancer as a personal test the successful coping with which will make the patients better people (trial and conversion).

Illness stories written at the end of the 1970's and in the 1980's seem to demonstrate a major change in disposition and purpose, albeit in a minor scale. These are what Hunsaker Hawkins identifies as *angry pathographies* (ibid: 5–8), stories that were then – as they are still today – rather few and “really not characteristic of the genre” (ibid: 8). In these narratives, confidence in doctors and trust in medical procedures has collapsed, and so has people's faith in “several of midcentury America's favorite cultural myths”, such as “that of the medical encounter as comforting and reassuring” and “that of medical science as invincible in its march to eradicate disease” (ibid: 5). Main features of these stories are the patients' outrage at objectifying and brutalizing mainstream medical processes, and their turn to alternative treatments. Their principal objective was to denounce dehumanization in conventional medicine. Examples include: *Heartsounds: The Story of a Love and Loss* (1980) by Martha Weinman Lear, and Jean Craig's *Between Hello and Goodbye: A Life Affirming Story of Courage in the Face of Tragedy* (1990). We cannot help noticing, though, that the titles of these pathographies, classified as “angry”, do not really reflect much anger, but remain rather sentimental and positive in tone, just like their predecessors, the testimonial pathographies.

A third type of illness narratives that boomed in the 1980's and in the 1990's, and which, unlike the angry pathographies, is still burgeoning in contemporary times, is that of pathographies advocating *alternative modes of treatment* (Hunsaker Hawkins, 1993: 9). These accounts, although critical of a strictly biomedical approach, do not focus on the authors' discontent with conventional medicine but rather seek to function as models for other patients by spreading the word about the power of “the inner resources of psyche and spirit” and “the nearly limitless capacities of the mind and the emotions to facilitate healing” (ibid). They suggest options like special diets and exercise, acupuncture and visualizations, or quartz crystals, lucid dreams, and naturopathic remedies. They emphasize *the importance of personal goals* and express the belief that “therapeutic success derives in part (some would say primarily) from the patient's attitude – the “will to live”” (ibid). Some examples of this category are the books: *Anatomy of an Illness: As Perceived by the Patient* (1979) by Norman Cousins, *Getting Well Again: A Step-By-Step Self-Help Guide to Overcoming Cancer for Patients and Their Families* (1978) by Carl Simonton, and *Love, Medicine and Miracles: Lessons Learned about Self-healing from a Surgeon's Experience with Exceptional Patients* (1998) by Bernie Siegel. Cousins advocates a happy attitude and laughter as a remedy. Simonton outlines the features of a cancer personality – a presumably wrong way of being that makes one more susceptible to cancer. And

Siegel contends that “[u]nconditional love is the most powerful stimulant of the immune system [...] Miracles happen to exceptional patients every day”, he asserts, “patients who have the courage to love, those who have the courage to work with their doctors to participate in and influence their own recovery” (the publisher’s description).

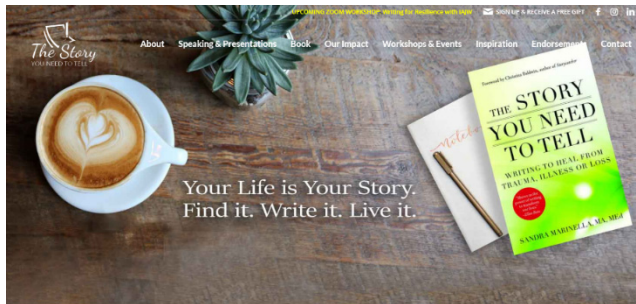
What the current reincarnation of this third type of illness narratives proposes on the practical level of action, and what now a large part of mainstream culture suggests is, among other spiritual practices, yoga, meditation, and mindfulness as essential supplementary practices to medical treatments for cancer. Books such as *Dancing with Cancer: Using Transformational Art, Meditation and a Joyous Mindset to Face the Challenge* (Erel, 2018), and *Strength Renewed: Meditations for Your Journey through Breast Cancer* (Corder, 2012), join forces with *Yoga and Breast Cancer: A Journey to Health and Healing* (Kollak and Utz-Billing, 2010) and many more similar titles that have established and operate within a very lucrative and flourishing market. What is implicit in all those types of stories, and what connects them to neoliberal ethics and a neoliberal conceptualization of personhood is the emphasis on individual responsibility and a consequent division between people: the winners and the losers. Those who deserve to live and who take the right action, and those who just don’t have what it takes. On the one side, the higher socio-economic status, educated middle/upper class, extraordinary, “exceptional patients” Siegel had been describing. Those whose stories get published and to whom “miracles happen”. Those who “have the courage to participate in their own recovery”. On the other side, the working class, the unemployed, no-health-insurance, higher-mortality-rate, underserved minorities, and women of color. The ordinary, unremarkable ill, from whom we never get to hear because they do not occupy the same story-world, or simply because they never thought they had a story worth telling. Perhaps, indeed, such stories never happened to them. As Jerome Bruner states in “Life as Narrative” citing Henry James: “stories happen to people who know how to tell them” (2004: 691).

## Story-Patterns and Coaxing

“Our scream, our seemingly private, seemingly incommunicable expression of anguish and pain has a trajectory, *even a career*, out in the world and over time, and its journey constitutes a story, a capacious human narrative that has largely gone unseen and unheard” (Weinstein, 2004: 6, my italics)

Against this background, a growing trend in self-help and writing manuals promotes “writing by prescription” (see: Van Goidsenhoven and Masschelein, “Writing by Prescription”: Creative Writing as Therapy and Personal Development”, 2021), and “coax” people to shape and share narratives of illness, trauma, and self alongside quite specific storylines confirming the master narratives of progress and triumph (ibid; see also: Van Goidsenhoven and Masschelein, 2016;

Smith and Watson, 2010). Publishers like Jessica Kingsley capitalize on therapeutic writing's popularity, emphasizing standardized formats and vocabulary to meet market demands. This repetition reinforces a commercialized approach to personal storytelling, prioritizing sales over diverse expression.



Picture 6. Image from the website storyyoutell.com.



Picture 7. Examples of books advocating and guiding journaling/memoir writing.

More of these tendencies and practices – but in a rather exacerbated form – have been identified, presented, and discussed by scholars working in the critical medical humanities, in the UK context. In the article, “The Recovery Narrative: Politics and Possibilities of a Genre” (2022), Angela Woods, Akiko Hart, and Helen Spandler examine the Recovery Narrative, “a highly circumscribed kind of storytelling”, an actual genre, long “recognized in practice and in policy as a key “technology of recovery””, in connection to the ways it is “constituted and mobilized, and with what consequences” (Woods, Hart, and Spandler, 2022: 221; see also: Smith-Merry, Freeman, and Sturdy, 2011). The scholars bring to our attention and put under the lens of their critical inquiry the Recovery Colleges, structures that offer short workshops, weekly trainings, and midweek retreats to people with mental health issues, and guide them as to how to “produce, refine and rehearse their own systematic recovery narrative” (Woods, Hart, and Spandler, 2022: 222). Recovery Colleges, the first of which “emerged in the US in the 1990s, informing a model that has been adapted and implemented across the world in the last decade” (Whitley, Shepherd, and Slade, 2019: 141), started emerging in the UK, as well, in 2009 (ibid), with currently operating there no less than 220. Hundreds more are spread “in 26 different countries across the globe” (<https://imroc.org/why-imroc/recovery-colleges/>), from Hong Kong to Sri Lanka, to Japan, to Uganda, materializing in a very concrete way what the Bildungsroman/quest/hero narrative is all about. Recovery Colleges “strive to be serious places of learning” (ibid), where “experts by experience” (students) team up with “experts by training” (clinicians). They offer precisely an *education* in an official, controlled, and quite specific educational structure where “[a]ttendees are *students* (not patients, clients or service users)” (Whitley, Shepherd and Slade, 2019: 141, my italics), and follow courses on illness management, self-care, life skills, and employment (ibid), with the goal of using health services less (or, even better, not at all) after their graduation, and of joining again the job market. But what about the Recovery Narrative, that fixed type of storytelling and technology of recovery? Recovery Colleges focus, as well, on directing people dealing with illness and trauma towards the construction of linear and clean recovery narratives, based on and beginning from a particular understanding of the events of their lives (Woods, Hart, and Spandler, 2022). Naturally, and as it happens with all genres there are principles one needs to follow:

“Some of these generic codes are laid bare in the “Sharing your Story” guides produced by major mental health charities in the UK, USA and Canada [...] Offering straightforward step-by-step advice for the production and dissemination of Recovery Narratives in writing, in person or through digital media, these publications give a consistent account of what individuals should be aiming for: stories which in formal terms are short (2–5 min, or 250–375 words), have an obvious beginning, middle and end, and use clear and accessible language [...] As well as being carefully crafted, often through the framework of a “journey”, they must be true and true to the individual (“Stories are powerful if they are honest and real... A thoughtful and organized story allows for a smooth delivery. It will also give your story a polished and truthful feel” p24);

told “from a strong foundation of recovery”; and contain “messages of hope or a ‘call to action’” (Woods, Hart, & Spandler, 2022: 228–229).

But that is not all:

“The Recovery Narrative cannot, in its tone, content or delivery, be too disturbing, too dark, too angry; nor can it be too light, frivolous, or happy. It has to offer enough shade for the light of hope to be foregrounded, but not too much as to shroud it. It is for the narrator *to manipulate her experiences but also her identity* in ways which meet these conventions” (ibid: 235, my italics).

Now, to be urged, impelled, goaded, or “coaxed” to share your story is one thing, and what is described right above is another. The Recovery Narrative is currently massively applied within clinically oriented contexts (Rudnick et al. 2011), within peer-support frameworks, and also by governmental and third sector organizations. It emerges, nevertheless, as a formulaic text that has very little to do with the telling of a deeply personal experience – which would “give(s) voice” to those who have been systematically disempowered” and promote social justice (Woods, Hart, and Spandler, 2022: 233), as the argument for its use goes – and resembles an entrepreneurial gesture, or something one would perform in the context of the professional world. Its description, “2–5 min, or 250–375 words” (ibid: 228), clear, coherent, and with an obvious structure (beginning, middle, end), made me think of an abstract prepared for submission to an academic journal, or a pitch for a project one wishes to present as competitive, solid, and relevant, and deserving funding. The project, of course, in this case is the self, now upgraded and again productive – packaged in the form of a story, written in the right type of genre and ready for consumption.

Unsurprisingly, the theorists underscore the importance of the genre/form in the actual shaping and delivery of any content (ibid: 235) citing the literary and cultural theorist John Frow, who argues that the “structuring effects (of genre) are productive of meaning” and “central to the organization of knowledge” (2005: 10 and 4), or, as Jerome Bruner maintains in his article “Life as Narrative” (2004), “it is form rather than content that matters” (ibid: 696). The Recovery Narrative, then, as a genre, “confers power to the reader/audience by soliciting a two-fold confirmation: first, that the narrator does indeed possess insight into her own mental distress, and second, that this insight has been hard-won through the shedding of false (erroneous, delusional, ideological or otherwise unhelpful) beliefs” (Woods, Hart, and Spandler, 2022: 230). This is reminiscent of the Bildungsroman genre, in which most of the current times storytelling is done, and, of course, as applied in mainstream breast cancer narratives: un-learning the bad ways and learning the good ones; education; improvement; self-development, always after a struggle. Connecting these to a “neoliberal framework” and to “certain ideals of neoliberal citizenship” (ibid: 236), as many theorists have already done, seeing “poverty and discrimination, an appalling lack of choice in services, and mistreatment [...] conveniently left out of the story” (Costa et al.

2012: 89), is no big leap at all. With “[f]avoured stories featur(ing) the uplifting message that with a little hard work and perseverance, you too can be cured” (Woods, Hart, and Spandler, 2022: 236), it makes perfect sense that many scholars today identify “an unholy alliance between the modern recovery movement” (as well as the broader therapy culture, I would add), and “the neoliberal restructuring of society” (ibid: 236; see also: Howell and Voronka, 2012). No wonder academics have come to seriously doubt that the broader social change promised as a result of therapeutic/recovery narratives can ever happen, as long as all social context and factors that fundamentally determine health remain largely ignored.

So far, I have given a brief and limited account on some strong contemporary tendencies finding expression in the Anglo-American world and beyond, and influencing greatly the ways we think of the self and what we believe to be necessary and important, or even possible, in how we deal with life. Through the examples I have gleaned and presented, there emerges a *network of connections* and a certain coinciding or overlapping of *neoliberalism* as an overall meaning-making, organizing, and disciplining system, *popular culture* discourses and manifestations (products, services, advice, and all types of implicit and explicit guidance), and trends in *academic research/knowledge*, such as in the fields of philosophy, psychology, medical sociology, and Narrative Medicine. What one gets both in the layman/popular culture and market/business side of things, both in government/health services and charity-funded initiatives, as well as in official/institutional sources of knowledge, is the conviction that people need improvement, development, recovery, or healing through writing down their personal experience, and that these are especially and crucially necessary for those dealing with illness and trauma, such as women with breast cancer.

Taking a peak at the constellation of agents acting together in creating and sustaining this big cultural phenomenon, we have touched upon a number of contemporary structures (of thought, economy, self-management, affect), cooperating in lending validity to writing the self as a natural practice of well-being, improvement, and healing. Philosophers asserting that self and self-narrative is one and the same, and that it is a natural and necessary thing to write your story. Websites that, based on narratology concepts, help you craft an epic memoir by which you will also acquire a new understanding of life. Publishers that warmly invite your manuscript and offer a wide variety of manuals on how to, preferably, construct your own journey. Recovery Colleges that take you by the hand and help you write your own Recovery Narrative, portraying a successful recovery. And journals, so many journals for you to choose from and buy and write your story.

The particular story-telling standards, summarized above – the quest/*Bildungsroman*, the journey of the hero, the transformational adventure – as well as thinking of life and life-narrative as one and the same thing, describe the conventional ways in which many breast cancer patients today interpret, along with the rest of us, their life experiences, and foreground the ways we all embody, circulate, and reproduce certain discourses. What has gradually emerged as the “master narratives that consciously or unconsciously serve as models for ours”

(Rimmon-Kenan, 2002:11) is the product of a historically specific conceptualization of the self as an entrepreneurial unit (Bröckling, 2016), shaped and promoted by broader social structures defining and supporting neoliberalism (Foucault, 2008; Rose, 1996 and 1999). But how did all that come to be?

## Neoliberalism, the Bildungsroman, and the picaresque

“A rhetoric formulating the self as *a project for change* has developed in our century. Within this rhetoric certain events and experiences are understood as occasions for changing the self; illness is a prime example” (Frank: 1993:39, my italics).

Neoliberalism, as a complex, multi-factor phenomenon that shapes contemporary reality, has been examined by academics from many different fields, such as education (Davies and Bansel, 2007), health-care (Baru and Mohan, 2018), neurodiversity (Runswick-Cole, 2014), disability studies (Goodley and Lawthom, 2019), feminism (Cruz and Brown, 2016), and biomedicine (Tseris, 2017), to name only a few. In the book *Neoliberalism and Contemporary Literary Culture* (2017), Mitchum Huehls and Greenwald Smith address the growing pervasion of neoliberalism as a critical concept in their own area of scholarship. In their introduction to the book, they trace the evolution of neoliberalism and identify four phases that describe its transformation from an issue of the financial sphere to the very nature of the human soul. They define the first phase as the *economic* one, starting in 1971 with decisions made by President Richard Nixon regarding the value of the dollar (ibid: 5). The second phase is *ideological*, taking place in the 1980s when “Reagan and Thatcher explicitly linked (the neoliberal) economic concepts to a political conservatism motivated by anticommunism, Christian morality, and a generalized fear of minorities and immigrants and pushed both neoliberal policy and ideology to dominance in their respective countries” (ibid: 7). The third phase, is defined as *sociocultural*, beginning in the 1990s, when different forms of art and culture “saturat(e) our daily lives with for-profit rationalities of commerce and consumerism, eventually shifting neoliberalism from political ideology to normative common sense” (ibid: 8). Finally, the fourth *ontological* phase, is speculated to have started in the 2000s and continues to our days, as “neoliberalism becomes what we are, a mode of existence defined by individual self-responsibility, entrepreneurial action, and the maximization of human capital” (ibid: 9).

Neoliberalism, then, as an ontological matter, that is, as a way of being in the world, heavily informs how we operate in both thinking about things and writing it all down, not only in the realm of illness narratives, but also in the literary field, more broadly, as booming recent scholarship substantiates (Greenwald Smith, 2015; La Berge and Slobodian, 2017; Deckard and Shapiro, 2019; see also: the special issue, Neoliberalism and the Novel, in *Textual Practice*, 2015; and the special issue, The Novel and Neoliberalism, in *Novel: a forum on fiction*, 2018),

and in a broad range of contemporary popular culture production (Chen, 2013; Baerg, 2014; Cherniavsky, 2017; McRobbie, 2020; see also the special issue: Neoliberalism and Popular Culture, in *The Journal of Popular Culture*, 2018). In this context, the Bildungsroman, a genre that emerged together with “the new and destabilizing forces of capitalism” (Moretti, 1987: 4; see also: Slaughter, 2011: 96), has evolved through the years and established itself in such a way that it currently serves as the dominant form of story-telling of our times (Moenandar, 2017: 1). Arguably, and just like neoliberalism, the Bildungsroman has become “[t]he “normal” way of understanding a situation or a set of assumptions, that has become so ingrained or widely accepted within a culture, that it appears to represent “reality”” (Winslade and Monk, 1999:123).

Bildungsroman stories feature a main character who faces various challenging situations, engages in a fruitful dialogue with them, and acquires valuable skills along the way, as well as a deeper understanding of life. Through these necessary steps, the hero finally becomes a better person having internalized important life-lessons without which she would have never achieved a higher version of herself. All traumas or wrongdoings inflicted on the character are effectively addressed, and the protagonist rises powerful and victorious. “Even the most damaging experiences can become life lessons, can be made valuable and retrospectively be turned into an investment” (Moenandar, 2017:4). A constructive dialogue with the world is essential for the character to find her rightful place in it, to abandon any circumstances that restrict her development, and to build herself a life that offers her possibilities for excellence. The Bildungsroman, “one of the cardinal documents of bourgeois literacy” (Swales, 1978: 148), shares these core values with the modern age, and that makes it the perfect model for neoliberal expressions and performances of selfhood (McGuigan, 2016). But where did the Bildungsroman come from? And how did it evolve?

The literary ancestor of the currently dominating novel of education (Bildungsroman), or coming of age story, is a story-type of very different traits, namely, the picaresque. This is a novel genre that flourished between the sixteenth and seventeenth century in Spain, influenced by older literary texts, such as medieval buffoon literature, the Arabic genre of maqāmah (entertaining anecdotes about rogues and beggars), Homer’s *Odyssey*, and also folklore trickster stories (Yadav, 2011: 617). The protagonist of the picaresque is the picaresque: coming from the lower social stratum, orphaned or thrown out of the family home, and burdened with shame for her family background. A first-person narrator, wandering alone in a world of violence and exploitation, passing from adventure to adventure in an episodic, open-ended narrative, constantly struggling to survive. In the seventeenth and eighteenth century, travelling to other European countries, such as England, France, and particularly Germany, the picaresque mutated and transformed. Translated and adapted to different contexts, it followed a process which radically changed the protagonist from practically every possible aspect, turning her “into an ‘anti picaresque’” (Sieber, 1977: 59). Miles, in his article, “The Picaresque’s Journey to the Confessional: The Changing Image of the Hero in the German Bildungsroman” (1974), examines precisely this evolution, as “the ‘picaresque’ (the

nondeveloping hero, the unselfconscious adventurer or man of action” turns into “the confessor” (the hero of personality growth, the introspective hero, the protagonist of consciousness, memory, and guilt)” (ibid: 680). So, “[i]n place of the picaresque’s blithe quest from adventure to adventure in a timeless eternity of unchange” and on the plane of surfaces, fragments, exteriority, and outwardness, we get a very different kind of “quest”, with the confessor/Bildungsroman-hero of interiority, depth, and continuity, and with “a painful awareness of change and growth – precisely the awareness that lies at the center of the Bildungsroman” (ibid: 981). It was, then, along these lines that the Spanish picaresque gave way to the German Bildungsroman, following the advent of modernity and “the reconceptualization of “selfishness” into the utilitarian social ethic of the bourgeois era”, so that, “[e]ighteenth-century European adaptations of the picaresque novel function as part of this transformation of materialism and egotism into a kind of social ethic” (Yadav, 2011: 620).

The socio-economic processes that brought about these evolutions in thinking and writing about the self are analyzed by Franco Moretti in his classic study, *The Way of the World: The Bildungsroman in European Culture* (1987). Moretti looks at *Wilhelm Meister’s Apprenticeship* (1796) by Goethe as an exemplary Bildungsroman and observes that the emergence of the genre coincides with the changing economic as well as cultural and ideological conditions caused by the rise of capitalism (see also: Dilthey, 1906; Lukács, 1916). He specifically locates this turn as “status society starts to collapse, the countryside is abandoned for the city, and the world of work changes at an incredible and incessant pace” (Moretti, 1987: 4). This is the period of “the plung(e) into modernity” (ibid: 5) when an accumulation of radical, multi-level transformations brought about a wave of social mobility. A mobility, nevertheless, which was not meant for all, but rather for the already well-off, white, male, and European. In this context, and amidst the “individualism of a culture whose sphere of interest was limited to private life” (Dilthey, 1906: 335), a new sense of interiority is being born, entangled with notions of “travel and adventure, wandering and getting lost” (ibid), an interiority, however, forever “dissatisfied and restless” (Moretti, 1987: 5).

This *interiority* and *individuality*, leading certain theorists to define the genre as the story of a hero “emerging as, if not a genius, then at least an exceptional individual” (Shaffner cited in Slaughter, 2007: 19; see also: Dilthey, 1906; Miles, 1974), along with the accompanying trajectory of *formation* and *reconciliation* with the demands of the social world (Lukács, 1916; Moretti, 1987), is what the bildungsroman stands for. A coming to terms then, a compromise between “the tendency towards *individuality*, which is the necessary fruit of a culture of self-determination [and] the opposing tendency to *normality*” (Moretti, 1987: 16). A balance which could be read as the hero having to be at the same time special (a unique, autonomous individual of will, responsibility, and action; special enough to have a story to tell) and normal (accepting dominant values and willing to conform). Extraordinary, but not too extraordinary to compromise/reconcile and fit in. Extraordinary and simultaneously typical. But how is this balance achieved, so that the Bildungsroman can carry out its political function of bringing together

these opposing tendencies and demonstrate that certain learning processes (*Bildung*) are “indispensable for becoming a well-rounded, productive member of society” (Slaughter, 2011: 94)?

Moretti explains that this should be the result of *consent*, in a way that the social order “must also appear *symbolically legitimate*” (1987: 16, underlining in the original). It is necessary, he points out, that “as a ‘free individual’, not as a fearful subject but as a convinced citizen, one perceives the social norms as *one’s own*. One must *internalize* them and fuse external compulsion and internal impulses into a new unity until the former is no longer distinguishable from the latter” (ibid, underlining in the original). This is reminiscent of the notion of “cultural hegemony”, developed by the Marxist intellectual Antonio Gramsci (1992), according to which the beliefs, ideas, and values of the ruling class become accepted by people as their own. It is linked to the analysis offered in the book *Manufacturing Consent* (1988) by the economist and social critic Edward Herman and by the linguist and activist scholar Noam Chomsky, who argue that the mass mediated messages “by powerful ideological institutions” in the U.S. “carry out a system-supportive propaganda function, by reliance on market forces, internalized assumptions, and self-censorship, and without significant overt coercion” (ibid: 306). It is also reminiscent of the concept “soft power”, introduced and popularized by Joseph Nye (1990; 2004), which refers to the ability to influence and shape the preferences and behaviors of people, not through coercion, but through attraction and appeal, in order to get the outcomes you want. Notably, Nye remarks that: “Seduction is always more effective than coercion, and many values like democracy, human rights, and individual opportunities are deeply seductive” (2004: x). This, in turn, brings to mind Joseph Slaughter’s absolutely crucial work, *Human Rights, Inc.* (2007), in which he shows international human rights law and the *Bildungsroman* to be linked insofar as they share “a particular conception of the human individual” and advocate for “the free and full development of the human personality” (from the description of the book). “Taking his point of departure in Goethe’s *Wilhelm Meister*, Slaughter focuses on recent postcolonial versions of the coming-of-age story to show how the promise of human rights becomes legible in narrative and how the novel and the law are complicit in contemporary projects of globalization: in colonialism, neo-imperialism, humanitarianism, and the spread of multinational consumer capitalism” (ibid).

Worth looking at here – in the context of adopting social norms as one’s own, as well as in the context of the contemporary storytelling boom, the therapeutic culture we discussed earlier on, and particularly breast cancer narratives – is what has been identified from the beginning of the *Bildungsroman* genre as its pedagogical potential. Morgenstern, who was the first to coin the term “*Bildungsroman*” in 1819, had underscored already then the pedagogical potential of the genre, claiming, in what Boes describes as “the most famous lines in (Morgenstern’s) lecture” (2009: 648), that the depiction of the development of the hero “promotes the development of the reader to a greater extent than any other kind of novel” (Morgenstern cited in Boes, 2009: 648). “For him, in other words”,

Boes remarks, “the Bildungsroman gazes not inward, at the development of its fictional protagonist, but outward, into the real world and *toward the development of its audience*” (2009: 648, my italics). This understanding is shared by Miles, who, embracing Morgenstern’s interpretation, refers to “the Bildungsroman, as a novel that “educates” by portraying an education” (1974: 981), the point being that “Bildung in the term “Bildungsroman” refers to the education of the reader as well as of the hero (betraying the genre’s origins in the pedagogical and optimistic age of the Enlightenment)” (ibid: 991). Slaughter takes the point further and more towards the, very relevant to this dissertation, direction of actual story-telling: not only getting educated/inspired by the hero’s development and going on to develop and reconcile yourself with the world in real life, but also *writing it down*. “One educational quality depicted within the bildungsroman and repeated for its readers entails learning to narrate one’s life as a novel – ideally, of course, as a bildungsroman. This also has a conventional manifestation in first-person Bildungsromane, which often end precisely where they began, with a scene of the protagonist sitting down to write the story we have just read; the story thus becomes the narrative of the Bildungsheld’s acquisition of the skills, habits, experiences, and attitudes necessary to write that story after the fact” (Slaughter, 2011: 96, see also: Slaughter, 2007: 137).

Taking into account the above and getting back to mainstream breast cancer narratives, we notice the following. These essentially neoliberal projects, promoting understandings of illness as an investment with serious benefits, and of the ill person as the mythical Phoenix (Frank, 1995: 98), reborn from her ashes by means of a tough but rewarding apprenticeship, came to exist and function in the powerful ways that they do today through long and complex evolutions. This happened on the planes of historical junctures, changing economic and social conditions, shifting ethics and values, and altered literary expressive modes. The picaresque novel, as a narrative mode communicating experience in different societies and times, yielded to processes of change and transformed into the Bildungsroman<sup>6</sup>, “educating” us in self-centeredness, self-improvement, and personal achievement, and diverting attention from the urgent need for a community-oriented mindset and for collective action, particularly important in the case of breast cancer. Similarly to the ways in which a certain literary genre transformed

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<sup>6</sup> I do not mean to announce here the birth of the *Bildungsroman* and the death of the picaresque, nor to imply that such mutations and transformations follow a linear logic or can be neatly categorized into distinct chronological phases. The picaresque kept evolving until today, as we see, for instance, in *The Picaresque Novel in Western Literature From the Sixteenth Century to the Neopicaresque* (2015) by Garrido Ardila, who traces the development of the genre up to the twenty-first century. As for the *Bildungsroman*, there existed pre-modern narratives of formation and quest stories, more akin to the *Bildungsroman*, as discussed in Sara Graham’s edited volume *A History of the Bildungsroman* (2019). What I give in my sentence above is a less detailed/nuanced (but yet, I think, sufficient for the purposes of my study) and research-backed description of a gradual move from picaro to *Bildungsroman held*, as presented by, among others, David H. Miles in “The Picaro’s Journey to the Confessional: The Changing Image of the Hero in the German Bildungsroman” (1974).

into its opposite to both reflect and create ideas about the world, more areas of activity followed the zeitgeist shaping our thought (philosophers seeing and advocating for self/life as a narrative, academics promoting self-narrative as healing, and so on). One more such area that actually turned into its opposite in order to serve neoliberal agendas is spiritual practices, such as yoga, meditation, and mindfulness. Originally rooted in communal and religious settings, these practices have been co-opted by a culture that emphasizes self-help and personal well-being at the expense of communal engagement and social justice. This commodified and depoliticized them, marketing them as tools for personal optimization and detaching them from their potential role in fostering collective consciousness and social change. I have already mentioned in passing spiritual practices and neoliberal spirituality in the context of my discussion of therapy culture. Given, however, that they play an important role in two of the narratives I study (*Cancer Made Me A Shallower Person*, and *The Gift of Disease*), as well as in the breast cancer landscape in the U.S. more broadly, I will dedicate a special section to them here.

## The Spiritual Neoliberal

“Void of a moral compass or ethical commitments, unmoored from a vision of the social good, the commodification of mindfulness keeps it anchored in the ethos of the market” (Purser, 2019: 7).

Spirituality, mindfulness, and yoga, as practices known to contribute greatly to people’s health and general well-being, have infiltrated nowadays various realms of life (Saari, 2018; Jennings and Siegel, 2015; Vidic, St. Martin and Oxhandler, 2017; Karjalainen, 2022). The promise of emotional control, of the development of coping skills, and of the eventual built-up of a sustainably autonomous, responsible individual – reliable, available, and present – have proven very attractive in the contemporary neoliberal economies of the self. Optimizing performance, focusing on the inside, and shielding that inside from external stimuli that might disturb one’s balance: these possibilities, opened up by imported-gone-mainstream spiritual practices, have led to massive promotion and following of techniques like meditation and yoga among widely varied social groups, including, very conspicuously, women with breast cancer.

Remarkably, however, even though mindfulness<sup>7</sup>, in its original, non-Westernized version, is very much concerned with the social, and “with promoting a freer and more equal society” (Arthington, 2016: 93), this fundamental aspect gets almost completely discarded in the neoliberal manifestations of mindfulness. Standard mindfulness programs promote it as a private experience “consist(ing) of classes, workshops, retreats, books, and audio materials that individuals buy”,

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<sup>7</sup> I use *mindfulness* as an umbrella term here that includes yoga and meditation, since mindfulness seems to be ubiquitous and rather very much a part of the other two practices (see: “mindfulness meditation”, and “mindful yoga”, or “yoga for mindfulness”).

while “[i]n class sessions, students spend very little time interacting with one another” (Hickey, 2010: 174). As mindfulness practices have been conveniently adjusted to neoliberal-friendly versions of spirituality they end up functioning in ways that do not disturb the status-quo but rather serve and accommodate it. They do so, furthermore, even in cases that could *and should* shake the existing oppressive, necropolitical conditions, such as breast cancer. The emphasis on individual responsibility conceals the role and impact – the very existence – of external conditions, prevents collaborative action, and keeps women with breast cancer on the level of solitary units, focusing, in a non-judgmental manner, on “the moment” and on “being instead of doing”, and trying to cope and thrive in a competitive world.

Organizing subjectivity as described above, and constituting a world-image that leaves space only for individual self-improvement, a search for inner peace, and better coping skills, the practices of yoga, meditation, and mindfulness seem to operate in disciplinary ways reminiscent of Foucault’s concepts of *governmentality* and *power/knowledge* (1980). Foucault’s understanding boils down to the dominance of authoritative, institutions-originating discourses subjugating counter-discourses and creating regimes of truth that are adopted by individuals, who are not anymore merely subjected to technologies of power, but actively try to constitute and express themselves according to the normative social arrangements.

Phil Arthington (2016) examines mindfulness, as practiced in the West, as one of the products of advanced capitalism, and considers it from a Foucauldian and critical psychology perspective. The close relationship of psychology, capitalism, and mindfulness becomes manifest at the focal point and organizing function of all three: the individual, as the basic or primary element of analysis and (reform-)repair, as an entrepreneurial, self-responsible unit perpetually moving towards optimization and maximization of its capital, and as the recipient-applier of spiritual techniques that facilitate the above. Mindfulness practices, then, stripped of their social justice character, have been folded into psychology discourses. In this context, mindfulness, made to work in conjunction with the master narratives of psychology and neoliberalism, “represents a form of psychological power/knowledge which obscures political and socioeconomic perspectives on the factors underlying unhappiness and distress in contemporary capitalist society” (ibid: 88). In a manner very similar to the functioning of neoliberalism and mainstream psychology, and with a strong Foucauldian ring, “[t]he mindfulness industry may be viewed as psychologising and individualising distress; yet it achieves this not through the exercise of power, but by presenting mindfulness as an attractive technique of self-improvement in such a way that individuals adopt it for themselves” (ibid: 95).

Ronald Purser in the book *McMindfulness: How Mindfulness Became the New Capitalist Spirituality* (2019), featuring the face of a Buddha statue on the cover, over which the features of a happy clown have been drawn with crayon, makes similar points. “As a management professor and a longstanding Buddhist practitioner”, states Purser, “I felt a moral duty to start speaking out when large

corporations with questionable ethics and dismal track records in corporate social responsibility began introducing mindfulness programs as a method of performance enhancement” (ibid: 5). Purser acknowledges the benefits and value of engaging with these practices. However, he keenly addresses mindfulness’s turning into a merchandise with reactionary functions, involving obsessive introspection and a Protestant logic of constant self-examination and self-monitoring by which, today, “instead of searching out sins, one hunts down negative thoughts” (ibid: 8). In keeping with Jeremy Carrette and Richard King, discussing the commodification of Asian religious practices and the subsequent production of a highly neoliberal and individualistic spirituality in *Selling Spirituality: The Silent Takeover of Religion* (2005), Purser argues that, naturally, “reductions in stress and increases in personal happiness and wellbeing are much easier to sell than seriously questioning causes of injustice, inequity and environmental devastation. The latter involves a challenge to the social order, while the former plays directly to its priorities” (2019: 9). Purser links mindfulness to “positive psychology and the broader happiness industry”, which have “depoliticized and privatized stress” (ibid: 3). In his chapter, “Mindfulness as Social Amnesia”, discerning further connections between mindfulness and the reformatory discourses of psychology, he remarks:

“[t]he promise of humanistic psychology has been reincarnated as the mindfulness movement. Instead of earlier quests for the authentic self in the farthest reaches of human nature, one just has to search inside oneself with “pure awareness.” [...] First, like humanistic psychology, mindfulness makes subjectivity sacrosanct. Second, both eschew any need to pay attention to social and historical contexts of distress, to power structures and monetary interests. The therapeutic-mindfulness industry may have created its own conformist psychology – complicit in maintaining the status quo of corporate capitalism and neoliberal government” (ibid: 66).

This complicity is discussed by Andrea Jain, as well, who, in *Peace Love Yoga: The Politics of Global Spirituality* (2020), examines these issues from a feminist-socialist perspective. Jain critiques the consumerist “self-care” practices of neoliberal subjects as

“[t]hey evoke and capitalize off discourses of purity alongside greenwashing and charitable activities, none of which are substitutes for political dissent since they do not entail efforts to actually transform the policies and systems (ideological, economic, behavioral, or political) that produce the environmental degradation, poverty, hunger, and other inequities they gesture against. Spiritual adherents, instead, resist the system and its consequences for living beings and the environment by consciously choosing certain commodities as an act of resistance. In this way, they make “good choices” without actually doing anything to prevent inequality, oppression, environmental devastation, or violence” (ibid: 9).

Jain's argument, involving specifically greenwashing and charity, is suggestive of prominent studies in the context of breast cancer, such as Samantha King's *Pink Ribbons, Inc. Breast Cancer and the Politics of Philanthropy* (2006), pointing to the highly questionable function of these activities meant to oppose or undo part of the harm but actually reinforcing systems of oppression, exploitation, and violence. Jain (see also: 2014) agrees with Arthington (2016) and Purser (2019) on the self-disciplinary and status-quo-serving character of the Westernized spiritual practices, as well as on the connection between them and "the long-established tradition of Protestant-capitalist self-improvement" (Jain, 2020: 2). Jain's conclusion, drawing from Mark Fisher's work on capitalist realism (2009), is that the spiritual practices of mindful individuals under neoliberalism are *gestural*, since "despite the countless ways spiritual entrepreneurs and consumers embrace values like environmental sustainability and world peace, there is a difference between gesturing toward such alternative values and collective dissent through concrete actions and platforms" (Jain, 2020: 8).

Nevertheless, and this is where Jain's inquiry can help us understand better our case studies, the author identifies in mindful practices "a tension between the values of the dominant neoliberal capitalist order and values antagonistic to it" (ibid: 8). She "does not consider spiritual consumers as merely passive victims of dominant cultural formations" (ibid: 5), but observes that the turn to spiritual practices "embodies forms of liberation and salvation, resistance and discontent" (ibid). Not wanting to reduce these strong contemporary tendencies to merely neoliberal functions, and drawing from the work of Stuart Hall (1981), she takes a position towards spirituality "as an area of global popular culture in the sense of that which consists of relations "in continuing tension" (Hall [1981] 2002, 189)" (Jain, 2020: 5). Hall, who has famously identified popular culture as "an arena of consent and resistance" and as a "struggle for and against the culture of the powerful", speaks of a "cultural dialectic" and of "a continuing tension (relationship, influence and antagonism) to the dominant culture" ([1981] 2002: 189). This description of a struggle taking place constantly in the everyday between "dominant and subordinate formations" (ibid) has to do with hegemony and with contesting for power and prominence. Such a perspective, in the context of breast cancer narratives, along with Jain's assertion that, when it comes to seemingly mainstream practices, there might be much more than meets the eye, allows for an understanding of master-and-counter dynamics as more complex and entangled than it can seem at first. It makes visible various exchanges of disparate elements in an ongoing process of selection and rejection, as well as the *coexistence* of heterogeneous and fluid units of meaning, which is sometimes surprising and not always clear, and which, even in cases of presumably status-quo aligned gestures, leaves open possibilities for subversive constellations that can trigger collective dissent. And... this is our cue to now turn to an examination of master and counter-narratives.

## Master and Counter-Narratives

“Most who write about storytelling focus on its community-building functions: Stories build consensus, a common culture of shared understandings, and a deeper, more vital ethics. But stories and counterstories can serve an equally important destructive function. They can show that what we believe is ridiculous, self-serving, or cruel. They can show us the way out of the trap of unjustified exclusion” (Delgado, 2000: 61).

We have already seen in the introduction and in the present chapter that there is, in the popular forms of sharing one’s personal experiences with breast cancer, a specific dominant cultural script that women follow, constructing and communicating an understanding of what happened to them. We have also considered the reasons why the scripts that have risen to prominence are harmful both for the people directly concerned – the women with breast cancer – and for the more extensive network of social and planetary life. To these majoritarian accounts, we have seen that there emerge counter-accounts by people who don’t quite fit in the dominant paradigms, who might feel oppressed and wronged, and who offer alternatives that challenge the truth and supremacy of mainstream discourses. Such are the stories by Kathy Acker and Miriam Engelberg that have been read and recognized as minoritarian accounts of resistance but also, because of their quality of being assemblages of heterogeneous elements, sometimes, initially misrecognized as complicit accounts that do not really oppose injustice. The reason then why a discussion of master and counter-narratives is necessary here is not only to understand better the cases in question, but also, crucially, to see what we imagine an oppositionist’s account can be, if we are in search of alternatives that can promote different models of being. Working first on our understanding of counter-accounts as bigger processes involving elements that can appear equivocal and ambiguous, we can then look more efficiently at the work of advocating for them, in ways that do not invalidate stories that could be viewed as failing to fulfill certain expectations of radical resistance.

So, counter-narratives are mainly understood as stories that emerge in opposition to master-narratives, or the accounts that have become dominant at a given historical time. In their introduction to the book *Considering Counter-Narratives* (2004), Michael Bamberg and Molly Andrews argue that “[o]ne of the key functions of master narratives is that they offer people a way of identifying what is assumed to be a normative experience. In this way, such storylines serve as a blueprint for all stories; they become the vehicle through which we comprehend not only the stories of others, but crucially of ourselves as well. For ultimately, the power of master narratives derives from their internalization” (ibid: 1). But what happens when some people’s experiences do not agree with the blueprint? “How can we make sense of ourselves, and our lives, if the shape of our life story looks deviant compared to the regular lines of the dominant stories? The challenge then becomes one of finding meaning outside of the emplotments which are ordinarily available. We become aware of new possibilities” (ibid). The

possibilities for new understandings and new stories pointing to directions outside the blueprint is what counter-narratives stand for, and it is no accident that the non-dominant, minoritarian, marginalized positions they express reflect mostly the realities of marginalized social groups, and gesture towards possibilities for resistance (Jiwani, 2011; Ender, 2019). Counter-narratives, then, at their best, “can be interpreted as creative, innovative forces fostering beneficial societal change”, particularly regarding “ethical issues such as justice and accessible resources” (Lueg, Starbæk Bager, and Wolff Lundholt, 2021: 4). In this context, the construction of counter-narratives holds particular appeal for the members of “outgroups” who want to see their own “counter-reality” acknowledged (Delgado, 2000: 64), and things changing towards a more fair world (Harter et al., 2006).

But there’s really much more that counter-narratives do. As Yiannis Gabriel argues, “master narratives do not exist as narratives until and unless they encounter counter-claims and counter-narratives in one form or another. Like Hegel’s master–slave dialectic, without a counter-narrative a narrative can hardly be recognized as a master narrative” (2017: 208). From this it follows that master and counter-narratives need each other in order to be recognized as such and, in this sense, they “co-create each other” (ibid).

A counter-narrative, therefore, does several things simultaneously: it articulates and posits a particular narrative as a master narrative, it demonstrates some of the flaws and contradictions of this narrative and it proposes an alternative narrative line with a new plot and metamorphosed characters that ostensibly redefine a particular phenomenon and offer a superior explanation for it. In so doing, and this is crucial, the counter-narrative unveils certain political interests and positions served by the master narrative and offers itself as a political intervention that undermines or subverts these interests and positions” (ibid: 209–210).

Interesting here is what Bamberg and Andrews remark regarding a sense of community emerging from the anti-disciplinary narratives of minoritarian groups. They argue that the underdogs who oppose the dominant order through their counter-stories “do so with a consciousness of being a member of an outside group”, therefore speaking out not only for themselves, but for a collective (2004: 1), and, “[w]hile they might position their stories as being on the margin, *they do not consider them to be unique*” (ibid, my italics). This somehow stands in an interesting contradistinction to what we saw earlier in this chapter when looking at the majoritarian narratives and the Bildungsroman, which, even though it presents the experience of the authors as typical – this being one of the core elements of dominant discourses – it simultaneously casts them as exceptional individuals who stand out from the crowd. At the same time, however, the outstanding authors do appear to belong to a community of like-minded women with breast cancer, whom they address and advise, setting for them an example on how to deal with their illness. The connections and interrelations here seem to be rather complicated, and certainly no less than what concerns the links and relations between master and counter-narratives, a fact that necessitates another good look.

Some of the most important questions in the scholarly discussions that have ensued around the topic of master and counter-narratives are the following: Are master and counter-narratives two pure and distinct entities of different origins, promoting entirely different agendas (Tore et al. 2001: 151; Squire, 2004: 235)? Do counter-narratives only arise in response to pre-existing master-narratives, and do they only make sense in relation to that which they counter (Bamberg and Andrews, 2004: x)? Can a counter-narrative be countered by another counter-narrative (Lueg, Starbæk Bager and Wolff Lundholt, 2021: 2)? To assume a fixed and strict dichotomy in people's accounts such as the one addressed by the two first questions would be "to exclude complex power struggles [...] which may exhibit more messy empirical configurations than the dichotomy allows for. For instance, power struggles between two master narratives" (Rasmussen, 2017: 171), but also one counter-narrative challenging another, to allude to an answer to the third question, too. Things are much less controlled and much wilder in the social world. It's not like there is a master-narrative, or more master-narratives and *then* one or more counter-narratives are produced to respond and to subvert, and to suggest a counter-reality. Nor are they, the master and counter-narratives, two, pure, distinct, entirely different entities with absolutely nothing to do with each other. There is a struggle for dominance going on between discourses, as is always the case in human culture – and as we saw earlier with Stuart Hall – but things are more complicated and more intermingled and fluid than a binary would let us understand. Corrine Squire (2004), for instance, suggests that a master-narrative can be easily transformed into a counter-narrative, depending very much on who is telling the story, a fact which exposes master-narratives as "always less stable and unified than they appear, more susceptible to fracture and subversion" (ibid: 235; see also: Stella Bolaki's *Unsettling the Bildungsroman*, 2011). An example of this is Kathy Acker's counter-narrative "The Gift of Disease", in which, after being let down by western medicine, she turns to spirituality and, under the guidance of spiritual healers, engages in introspection and in looking inside herself to heal from breast cancer. She follows what she calls a "school of the self" and "school of the body" at which she learns lessons, such as that "[d]isease comes from blockages of energy" (1997:6), that "[y]ou have to *want* to be well" (ibid: 5, my italics), and that "[y]ou will create your own healing" (ibid: 7). She acquires skills she did not have before, as it happens in a Bildungsroman/master-narrative, like the ability to forgive her self and take the blame off her parents. All these, however, even though strikingly reminiscent of a neoliberal spirituality discussed previously in this chapter, when told by an anti-authoritarian, anti-capitalist, punk writer such as Acker, and interweaved as they are with her scathing commentary on the unjust, alienating, and dehumanizing structures she experienced, take a completely different meaning: they are transformed into a poignant critique of conventional medicine and of how medical care is administered in the U.S., often objectifying and disempowering people.

However, and as the social fabric of stories "is constantly being created and re-created through elaboration, contestation and exchange of narratives" (Brown, 2006: 735), a counter-narrative not only questions the majoritarian discourses but

it can also challenge other counter-narratives (see: Humle and Frandsen, 2017; Jensen, Maagaard, and Rasmussen, 2017). The opposition, the interplay, and the conversation between narratives can manifest itself on the time continuum, as well, or as Boje (2001) argues, each text “opens different lines of interrelatedness to preceding and anticipated texts. And each line of utterance opens up dialogue with texts of other times and places” (ibid: 74). On this, again an example from the case studies of this dissertation: Acker’s counter-narrative, written in 1997 seems to challenge Engelberg’s counter-narrative of 2006 on the issue of spirituality. A practice – or constellation of practices – embraced and acknowledged by Acker as a valuable alternative that recognizes and builds on the agency and inner resources of the individual offering a collaborative means towards healing that does not objectify or offend, it is shunned and mocked by Engelberg who regarded it as one more technology supposed to make breast cancer patients cope better or even heal. These complex processes “highlight the performative aspects of, and relationships between, dominant narratives and counter-narratives” (Frandsen, Wolff Lundholt, and Kuhn, 2017: 3), defined by intertextuality (Koschmann, Kuhn, and Pfarrer, 2012) and ventriloquism (Cooren, 2010) as narrators draw on elements from both master and counter-narratives to build their stories (Hyvärinen et al. 2021). Stories always in dialogue, and “inextricably entangled in relations of power” (Meretoja, 2021: 30).

There is, however, more to be said regarding the stories I study – stories that I initially selected because they spoke to me the most and I gradually understood the reasons why. Because while for a considerable amount of time over the course of my research I have been reading them as counter-narratives of resistance linking them to clear notions of strong opposition, negativity, and dissent, I have come to understand that, specifically “The Gift” (1997) and *Cancer Made Me A Shallower Person* (2006)<sup>8</sup>, along with combining elements from master and counter-narratives and thus blurring strict lines of origin, intention, and utterance, they also occupy a position between refusal and resistance. These are two different but intertwined practices constituting the narratives as *both negative and positive*, and softening the possibly hard distinctions that might have, to an extent, guided my analysis so far. On the one hand, *resisting* in activist ways (publicly denouncing violences and injustices) and *refusing* to conform with the norms (in more nuanced, everyday, individual ways), and on the other, connecting to/building alternative-minded communities on affirmative models of thought and action. This is a function of counter-narratives which we have briefly discussed in this chapter as the creation of counter-publics, and into which we need to look a bit more in the following section in order to do justice to the positive, affirmative work performed by gestures of refusal and resistance.

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<sup>8</sup> I am not discussing “Eurydice in the Underworld” here because I see it as a deeply poetic/performative text, which, although it definitely refuses and resists, it requires a different treatment such as the one I attempt in the chapter dedicated to it.

## Counter-Narratives of Refusal and Resistance

“By recognizing that to refuse means to receive and to create – by giving primacy to the positive, salutary, generative pole – we can ask better research questions regarding our social and cultural lives. We can carve a new opening onto human experience: one through which to view and consider human becoming as well as human being, and human doing as well as being done to” (Sobo, 2016: 348).

Refusal and resistance, two modes of responding to structures of power, are interconnected but distinct. As Carole McGranahan explains in a 2016 issue of *Cultural Anthropology* devoting space to the notion of refusal, “[i]f resistance involves consciously defying or opposing superiors “in a context of differential power relationships” (Seymour 2006, 305), then refusal rejects this hierarchical relationship, repositing the relationship as one altogether differently” (ibid: 323). This, then, means not confronting or engaging directly with power in a struggle for a new order, but doing something completely different than what systemic structures expect you to and impose: not challenging and provoking, but turning your back and doing your own thing. Bhungalia, in her article “Laughing at power: Humor, transgression, and the politics of refusal in Palestine” (2020), writes that “[t]o laugh in the face of power is not to say: “I oppose you” – rather it is to assert: “your power has no authority over me.” It is to refuse that power authorizing force” (ibid: 389). And that is, as I have come to understand, the case with Acker and Engelberg. They invest themselves in things, directions, and practices that feel right to them, leaving behind stultifying and oppressive states of life. The two authors resist but they also refuse. They observe, scrutinize, critique, mock, and refuse. Acker refuses to stay in a medical care structure that objectifies and nullifies her, and dehumanizes her. Engelberg refuses to take up meditation and yoga and to become “deeper” as a result of her breast cancer experience.

Refusal as a decision to keep oneself “out” is linked to what Erica Weiss (2016) – whose fieldwork focuses on Israelis refusing to serve in the military for reasons of consciousness – describes as *abstention*. Weiss notes the difference between the publicly declared character of resistance, actively seeking the construction of another social world, and the inconspicuous qualities of refusal, remaining under the radar but making a difference in the long run. She states: “I argue for the radical potential of refusal as abstention. While public military refusal can be understood as resistance, refusal as abstention should be understood as *an affirmative investment in another possibility* [...] not showing up at the voting booth, the passport office, the doctor’s office, or the military enlistment center” (ibid: 351–352, my italics). This, translated in the breast cancer landscape, can mean not showing up for the Look Good, Feel Better beauty workshop for women with cancer, organized by the American Cancer Society, and giving away to cancer patients cosmetic products with toxic ingredients. Not showing up at the marathons for awareness, and at all events organized by pink groups and

sisterhoods. Not being there for the yoga class, not doing the journaling (Engelberg). Skipping the follow-up appointment with a paternalistic, emotionally abusive doctor, and the dreadful chemotherapy process that offers very little promise of recovery (Acker). Elisa Sobo (2016), whose work deals with vaccine refusal, writes in similar lines: “[r]efusal is more about avoidance than active opposition (the characteristic by which most scholars define resistance [...]): in refusal, the overt power contests, class antagonisms, or struggles for liberation or against domination that resistance entails are not necessarily directly implicated” (ibid: 342). In existing in the realm of the ordinary and the everyday, which, while politically dynamic, might not always announce itself as political, “practices of refusal are never a program of action, and such practices have occurred continuously in the history of political struggle without always being recognized as such” (Mengesha and Padmanabhan, 2019: no page). This brings refusal very close to the concept of the minor, and to what Erin Manning describes as minor gestures of resistance in her book *The Minor Gesture*, published in the same year as the above cited research on refusal (2016). Minor gestures are instances of objection and differentiation from the established order which take place in not directly noticeable or obvious ways. Minor gestures are instances of micro-politics. Refusal and the minor are not methodical and systematic, but rather spontaneous and unplanned. “It is a refusal to participate in forms of organized oppression or dissent, rule or revolt, repression or resistance” (Weiss, 2016: 357). And that is because the idea of the minor and of refusal is the negation of being representative of something while at the same time one/the refuser might want to act (in subtle, non-invasive ways, as refusal goes) for what one imagines as their own group and community. As Engelberg writes in the introduction of her book, in order to reach out to people who face difficulties similar to her own.

It seems to me, however, at this point that the discussion should include a note of explanation regarding what might appear as a contradiction to the reader. Because we have established that a gesture of refusal or a minor gesture is radical but subtle. As Marcelo Svirsky argues examining activism through the philosophy of Gilles Deleuze, it “occurs in a scrivener’s office, in a call for a love, or at home through the forces exerted by a change in posture of a woman’s body when a patriarchal tradition is challenged” (2010: 169). And as we have seen in the texts on refusal above, it can be no more than abstention or avoidance of practices one disapproves of. Acker’s and Engelberg’s refusal, however, consists in published texts, and, what is more, published in very accessible, popular forms: the first as an article in *The Guardian*, the second as a comic book. In both cases for sure one just cannot go any more public. The way I see it, though, this does not disqualify the creators’ work from expressing refusal, or more accurately, from standing *between refusal and resistance*. Because their texts (and images) do not forward or gesture towards an agenda for action and change, nor were they constructed for this reason, as anyone exposed to them can tell. What they *do* is communicate critique, disaffection, and discontent with specific oppressive structures and normative understandings defining our ways of dealing with breast cancer, and *gesture towards alternatives*. They are certainly not hard to find –

they are not lost or hidden in the nooks and crannies of the everyday – yet, at the same time they do not come forth as the polemical harbingers of a new order. Their creators are performing their own micro-activism from a position between center and margins (being neither marginal nor mainstream), belonging and not belonging, refusal and resistance, and each of them goes on a personal path of managing the situation: Acker abandoning conventional medicine and opting for spiritual healers caring for her as a person with agency, and Engelberg mocking spirituality and neoliberal attitudes as an excellent satirist that she is, while opting to keep herself away from “profound insights”.

Acknowledging that *Cancer Made Me A Shallower Person* and “The Gift” find themselves between refusal and resistance allows for a better understanding of their complexity, of the complexity of their creators, and of the socio-cultural forces that inform their construction. Similarly to what we saw in the previous section regarding the interplay between master and counter-narratives, a dialogic or supplementary relationship exists here, too, between gestures of refusal and resistance. This conjunction, however, has gone unnoticed at times. Anthropologist Sherry Ortner (1995) remarks that counter-cultural discourses and practices have been occasionally read as more uniform than they actually are for fear of harming their subversive power and the political goals of the people who perform them. Nevertheless, in master and counter-narratives informing each other, as well as in people’s practices fluctuating between refusal and resistance, “[t]he breaks and splits and incoherencies of consciousness, no less than the integrations and coherencies, are equally products of cultural historical formation. One could question, indeed, whether the splits and so forth should be viewed as incoherencies or simply as alternative forms of coherence” (ibid: 186).

Examining refusal and resistance from a different perspective, Mengesha and Padmanabhan detect dangers in the practice of resistance and favor that of refusal. Writing for the special issue of *Women and Performance*, “Performing Refusal/Refusing to Perform”, they argue that “[p]erforming refusal requires obstinance, bodily comportments that disassociate and emanate the desire *to not be included*” (2019: no page, my italics). “[A]im(ing) to highlight performative modes of non-productivity and non-reproductivity”, they engage with the ways in which “performing refusal details methods of wielding of opacity and obscurity, as a tactic to negate the call of minoritarian subjectification” (ibid). Crucially, the authors

“question(ing) the protestant work ethic that underpins even (and especially) the most resistant performances of minoritarian subjectivity [...] (They) take up a strand of Marxist feminist criticism to argue that an attachment to the liberatory potential of both performance and living labor can traffic in a productivist work ethic (Weeks 2011) manifested as the internalized faith and expressed call for minoritarian subjects to perform the labor of activism – by advocating for ourselves, diversifying the institutions we live and work within, and speaking out against our domination – and generally engaging in activities that reproduce us as protesting and protestant subjects” (ibid).

While I understand the authors' concern with neoliberal co-optation, not only of resistance itself and of the forms it might take, but also of the intention to resist (which already can position one as a laboring, minoritarian subject aiming to production through the work of activism), I find it hard to imagine how, in practical terms, social change can come about if refusal is not combined with resistance. Jack Halberstam, in their book *The Queer Art of Failure* (2011) draws from a "silly archive" (as he calls it borrowing the phrase of Lauren Berlant, "the counter-politics of the silly object), namely, popular and non-serious cultural objects such as children's animation films, to make a point about success and failure. Following Halberstam, I remember now in connection to refusal the Merlin film from 1998. Towards the end of the movie, the evil queen Mab is overpowered by the other (good) characters' and Merlin's sheer refusal to engage with her. Merlin tells her that she and the Old Ways are not relevant anymore; people will forget her and she will cease to exist. Everyone then turns their back on her and she fades away. This kind of refusal-magic seems possible and effective in the context of the Merlin story, but in the context of breast cancer mere refusal can only take us so far. It is not enough to refuse the damaging options that are made readily available to us (neoliberal attitudes, logics, and narratives, poisoned products, food, and water, and so on). We also need to create, through the work of resistance activism, healthy and sustainable alternatives.

Elliot Prasse-Freeman, in his article "Resistance/Refusal: Politics of manoeuvre under diffuse regimes of governmentality" (2022) in the *Anthropological Theory* journal, offers an analysis of evolutions in resistance studies tracing the beginnings of refusal as a theoretical concept, and the gradual shift in focus to "the micro-politics of encounters and the subjective experiences of resisters" (ibid: 104). Prasse-Freeman understands resistance and refusal "as *divergent but intertwined* tools for engaging different aspects of any given apparatus of power" (ibid: 102, my italics). He explains that

[w]here resistance describes opposition to direct domination (sovereign modes of power, following Foucault's schema), refusal describes the disavowals, rejections and manoeuvrings with and away from diffuse and mediated forms of power (governmentality). To the extent that contemporary apparatuses of power typically constitute a hybrid assemblage of sovereign and governmental forces, subjects of population groups draw upon both resistance and refusal tactics in their navigations of these apparatuses, navigations that refigure the collective resisting/refusing subject [...] Resistance and refusal not only constitute the conditions of each other's possibility, sharpening the particular interventions that each makes, but *demonstrate the necessity of a politics of manoeuvre* in which subjects – as individuals and part of collective groups – oscillate between direct confrontation and governmental navigation" (ibid, my italics).

The author remarks that he has seen this dialogic/supplementary relationship between refusal and resistance taking place in his own fieldwork. He writes: "in my long-term research with Burmese grassroots movements, I have observed how activists will often perform their bodies in ways that oscillate by the moment

between what refusal literature would call opposition to authority (hence resistance) and rejection of authority (hence refusal) registers” (ibid: 104). The same holds true for the textual/graphic performances of Acker and Engelberg.

In “The Gift”, Acker’s refusal to be part of a profit-oriented system that objectifies people is intertwined with the resistance she performed by looking for different options and by making her experience public. Her encounter with the breast cancer medical world and with realities she was probably not fully aware of before (health inequities, the environmental causes of cancer, cancer as big business), which she presents in the first part of the text, constitute at the same time resistance and refusal. She has decided to both refuse (abstain from engaging with further necropolitical processes) and resist (make all her critical observations widely available and look for alternatives).

Perhaps closer to what Prasse-Freeman describes, Engelberg oscillates, I think, and manoeuvres between refusal and resistance. At one moment, she shares with the reader, she reports and exposes social situations she found frustrating, oppressive, and unfair (resistance) and at the next, in the very same comic strip, she explicitly lets us know that she isn’t going to abide with the norms (refusal), but opt for alternatives that are meaningful to her, instead (resistance). But perhaps a very strict or clear distinction is not entirely possible or even necessary here. Resistance and refusal are different but overlapping (Sobo, 2016: 342) and “a politics of manoeuvre” (Prasse-Freeman, 2022: 102) is necessary for those who oppose punishing and exploitative systems of control.

What I would like to end this section with, however – which is also the point I wish to underscore the most in this entire discussion – is what Sobo calls “refusal’s productivity – not in terms of achieved regime changes or political gains, but of what refusal does for immediate social relations” (2016: 342). Contrary to understandings of refusal as a practice that separates individuals from the bigger social group and keeps them apart from the collective, this has to do with refusal’s *positive, affiliative function*, and its creation of bonds and connections to the community. In order to join the community of their choice, however, individuals have to refuse ideas and lifestyles that they might find dishonest or harmful, and thus, to perform “a deliberate move toward one thing, belief, practice, or community and away from another” (McGranahan, 2016: 319). As Sobo puts it, “[s]election precedes rejection” (ibid: 348). And so, refusal, despite its negative connotations, is not really (or mainly) about saying no to mainstream practices and notions that the refuser finds undesirable and oppressive, but more (or primarily) about saying yes to alternative pathways and to differently thinking groups of people. In this sense, it doesn’t have so much to do with what is rejected or avoided (patterns of behavior, models of life and so on) but with what is chosen and with the communities one can identify with. This, in turn, is linked to the anthropology of becoming (Biehl and Locke, 2010; Biehl and Locke, 2017), which draws on the work of Deleuze and Guattari on potentiality and desire (1983), and “emphasizes the primacy of desire over power” (Biehl and Locke, 2010: 317), thus, acknowledging people’s agency under oppressive circumstances, and its ability to “break open alternative pathways” (ibid: 318).

All this, in the context of the breast cancer counter-narratives I study, means that Acker and Engelberg follow their respective desires to belong to specific communities representative of the things they value, rather than a will to disavow, reject, and oppose. The latter necessarily follows but it does not precede their actions and trajectories, which are “more about who one is and with whom one identifies than who one isn’t or whom one opposes” (Sobo, 2016: 346). In this sense, their refusal/resistance is not anti-social and marginalizing, but “a highly social act – an act that, each time it is undertaken, reinforces social belonging by vitalizing community ties” (ibid). What is more, an activist gesture engaging with multiple frameworks in complex ways, which might require flexible and open understandings acknowledging people’s agency. As Biehl and Locke argue:

“In learning to know people, with care and an “empirical lantern,” we have a responsibility to think of life in terms of both limits and crossroads – where new intersections of technology, interpersonal relations, desire, and imagination can sometimes, against all odds, result in surprising swerves and futures, even when our liberal projects of the good life writ large have turned into “cruel optimism.” This is not to recommend giving up on attempts to discern relationships of causality and affinity in social and medical phenomena, or to deny the often deadly force of social realities and inequalities. Rather, it is to urge increased focus on our receptivity to others, the kinds of evidence we assemble and use – the voices we listen to, the silences we notice, and the experiences and turns we account for – and how we craft our explanations. Our analytics must remain attuned to the intricacy, uncertainty, and unfinishedness of individual and collective lives” (2017: 43–44).

## Conclusion

In this chapter, we took a look at the workings of an expanded network consisting of socio-economic processes, narrative genres, books as objects of signification exercising persuasion and appeal, popular and scholarly notions about the self as identical to a story, and a market making profit out of the promotion and general acceptance of certain neoliberal ideas. All of these, we have noted, form the background for the current hyper-production of majoritarian breast cancer narratives (mostly written by white, middle/upper class women), imbued with the ideals of neoliberal individualism and foreclosing possibilities for critical thinking, solidarity, and communal action with the goal of social change.

We saw that in contemporary times in the Western world, and in the U.S. in particular, therapeutic culture positions individuals as fundamentally vulnerable, necessitating perpetual emotional healing and self-care: a cultural paradigm that promotes self-improvement and coping through techniques saturated with a consumerist ethos, and fostering neoliberal affect, while they take away our agency to create different meanings and realities in the social world. Similarly, neoliberalism has co-opted spiritual practices such as yoga, meditation, and mindfulness – originally communal and spiritual endeavors – repurposing them as

tools for personal optimization. This shift has detached these practices from their community-based roots and from their potential as agents of social change, reframing them as yet another means of self-improvement within an individualist society. These “techniques of the self” are intensely promoted to people dealing with illness and trauma, and even more so to women with breast cancer; techniques now forming part of a standard healing package sold to them as soon as they get diagnosed. Part of the same package is journaling and writing for healing – writing as a transformative, therapeutic practice, guided by manuals teaching people how to use specific generic forms towards the production of their own story and inviting them to send their manuscripts. In the same spirit, Recovery Colleges offer their services to people dealing with mental health issues (which could be also anyone with a physical condition, like breast cancer), in the context of which, the users of the services are regarded as students receiving an education, instead of as ill people. This “education” culminates in the final writing of a paragraph giving a brief and clear account of the students’ former struggle and their final victory, and in the reciting of it at different events. Linked to this broader arrangements is Narrative Medicine, a prominent field in the medical humanities which makes use of literary narratives communicating the experience of illness as a means to improve the doctor-patient relationship and generate empathic care. Narrative Medicine educated practitioners understand the consultations with their patients as stories that need to be shared and listened to in order to lead to better human connections and medical diagnoses. Infiltrating and determining all these processes is the Bildungsroman narrative genre, which has gradually seeped into our consciousness and in the ways we make sense of the world. Evolving through socio-economic changes marked by the advent of modernity and capitalism, the narrative of the hero who learns lessons, corrects her mistakes, and turns out a better version of her self at the end of the story, the Bildungsroman story-telling genre has become the normal way we understand reality through the manufacture of consent, that is, the acceptance of social (neoliberal) norms as our own.

While the above describe, I believe, fairly accurately the current state of affairs, there is yet another significant player in these complex interactions. These are the counter-narratives told by people who challenge what is socially taken for granted and who alert us to violence, cruelty, and greed. Without being purged of elements that make part of the master narratives, counter-narratives move between refusal and resistance in positive, affirming, affiliative ways, and manage to tell truths from a place between center and margins gesturing towards much-needed alternatives for all of us. Three of them we will examine in the next two chapters: “The Gift of Disease” (1997) and “Eurydice in the Underworld” (1997) by Kathy Acker, and *Cancer Made Me A Shallower Person: A Memoir in Comics* (2006) by Miriam Engelberg.

## CHAPTER 2. THE GIFT OF DISEASE AND EURYDICE IN THE UNDERWORLD

### Introduction

In this chapter, I look at two dissident illness narratives, “The Gift of Disease” (1997) and “Eurydice in the Underworld” (1998), by the American experimental writer Kathy Acker (1947–1997) who died of breast cancer. Acker (1947–1997) was a radical punk poet, multimedia artist, and avant-garde writer who blended inextricably in her text-creation practices “literature, radical theory, politics, and the social order of the West in the late twentieth century” (Henderson, 2021:1) offering what has been considered as “the most devastating narrative critique of Western culture to appear in American literature” (Siegle, 1989: 48). She was famous both in her native United States and in England, not only through her writings and public readings-performances, but also for her overall presence and ‘bad girl’ attitude, which allowed her to emerge as a cult figure, and a literary rock star with a well-deserved place in the counter-canon<sup>9</sup>. Acker wrote experimental, post-modern fiction mixing the high and the low, as well as essays, reviews, and librettos influenced, among many other things, by classic literature, pornography, philosophy, French theory, and the work of William Burroughs. A staple in and distinctive feature of her practice was appropriating parts of other authors’ writings, which she mutated and mixed with her own texts, constructing irreverent collages interspersed with hand-drawn maps of her dreams and visions, or of the imaginary places she described in her prose.

Acker’s work was scathingly critical of neoliberal, necropolitical values, rationalism, and patriarchy, as well as gendered symbolic and material violence, and all structures of oppression and exclusion. In her books, the main characters are always the abjected, the misfits, and the marginalized: outlaws, rebellious streetwise girls and women, prostitutes, picaros, and pilgrims. It is such guises that she takes herself, too, and such identities she tries on to speak in her texts in voices different than her own – in the voices of those left outside the official histories; the oppressed and the dispossessed; the precarious and the vulnerable others; those reduced to less-than-human. This multivocal enmeshment of textual fragments, drawings, and all that has been disparaged and abused, allowed her, on a first, more personal level, to challenge and force her own persona to a crushing point: break the self open, “crack up the old identity god” (Acker cited in Kraus, 2017: 84), thus imagining, flirting, and experimenting with different possibilities of being. It also enabled her to challenge sovereignty, which “operates by determining the limits of life and the categorical borders of humanness, by recomposing and policing the boundaries between the self and others, by demarcating a thinkable and livable human propriety that is inevitably white,

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<sup>9</sup> I am referring to what Acker herself has described as the “other tradition”, explaining that “‘marginal,’ ‘experimental,’ and ‘avant-garde’ are often words used to describe texts in this other tradition” (1997: 7).

Christian, masculine, heterosexual, healthy, fit, and, above all, property-owning and law-abiding” (Athanasίου, 2006: 43–44).

Female sexuality is an important theme in Acker’s explicit and provocative prose mixing her own memories (mostly of working as a sex show performer, but also of her childhood and school years, passionate love affairs, and sadomasochistic sexual relationships) with popular culture and experimental literature forms. Her body was an important part of her work in many ways – as a site of seduction, pleasure, and pain experienced, remembered and wished for, as a site of oppression and punishment but also of resistance, and as a tool to explore what language can look like if written during masturbation.

The punk element is essential in Acker’s writing, the spirit of her overall work being typically understood as inherently linked to punk<sup>10</sup> aesthetics and concerns, and as influenced by the picaresque<sup>11</sup> narrative genre. Just like the punks, Acker made her own experiences – of alienation, isolation, oppression, abandonment, and of physical and emotional needs in a robot world – part of her work, as she weaved autobiographical sections into her cut-pasted landscapes. The DIY (do-it-yourself) aesthetics, the cut-and-paste technique, the destruction of conventions, emblems, and symbols, explicit politics of resistance to oppressive structures and institutions featuring prominently in what Acker has created, situate her in a punk lineage<sup>12</sup>. As Henderson observes in her book *Kathy Acker Punk Writer* (2021) “[s]imilar to punk music’s attempt to express discordantly what the dominant culture ignored or suppressed, Acker’s writing is desublimatory. With its aesthetics of shock, transgression, parody, Debordian détournement, caricature, and montage, her oeuvre reimagines the fin-de-siècle United States as a schlock horror film for her punk girl protagonist: Acker’s cipher for herself and other rebellious and nonconformist women” (2021:3).

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<sup>10</sup> See Henderson’s book, *Kathy Acker: Punk Writer* (2021); McCaffery’s chapter “The Artists of Hell: Kathy Acker and “Punk” Aesthetics” in Friedman and Fuchs (eds.) *Breaking the Sequence: Women’s Experimental Fiction* (1989: 217–230); and the chapter “Punks’ Positive Dystopia” (on Acker and Burroughs), in Konstantinou’s *Cool Characters: Irony and American Fiction* (2016).

<sup>11</sup> For instances of identification of strong picaresque elements in Acker’s writing see: Henderson (2021:144); Friedman & Fuchs, (1989: 39); Dillard, <https://www.nytimes.com/1988/10/16/books/lesson-no-1-eat-your-mind.html>; Kraus (2017: 84).

<sup>12</sup> For an examination of an iconic punk group, see Jon Savage’s *England’s Dreaming: Anarchy, Sex Pistols, Punk Rock, and Beyond* (1992). For a broader and comprehensive study of punk, see Dick Hebdige’s book, *Subculture: The Meaning of Style* (1979). Hebdige presents the ways in which punk protested against established values but is critical of the punk movement. “In punk, alienation assumed an almost tangible quality. It could almost be grasped. It gave itself up to the cameras in ‘blankness’, the removal of expression (see any photograph of any punk group), the refusal to speak and be positioned” (1979: 28). Lee Konstantinou, *Cool Characters: Irony and American Fiction* (2016) is also critical of the revolutionary, anti-capitalist values of punk. He argues that “punk is in practice anything but antinormative” (ibid: 114) and that “its critique of administered life [...] effectively won the day, helping reorganize or reinvent the spirit of capitalism” (ibid: 115).

The strong picaresque element in Acker's stories manifests itself in similar ways as the punk influences. Snatching fragments, the picaro – an outsider like the punks – struggles to survive, and the episodic structure, a main feature of the picaresque, always present in the author's work, shows the main character passing from one situation to the next, thus exposing an exploitative world. Role-playing and changing identities, which Acker did in all her writing, is an essential characteristic of the picaresque, since “[m]etamorphoses and changing roles are part of the picaro's survival kit – as the world is in flux, so he can change roles to face it. Picaresque life is a constant change of masks on the world-as-stage” (Wicks, 1974: 247). What is more, in Acker's stories the world and the central character never become integrated. The chaotic assemblage of scraps and fractions, and the thrownness of the picaro will never change, while (Acker's punk-) picaresque “satisfies our darker yearnings for demonic disharmony, disintegration, ugliness, disorder, evil, and the gaping abyss” (ibid: 242).

Acker was diagnosed with breast cancer in 1996 and opted for a double mastectomy. At a post-surgical consultation with her doctor, she was informed that, despite his pre-mastectomy reassurances of there being little chance of the cancer having spread to the lymph, the findings now pointed to the opposite. The doctor, in what Acker describes both in “The Gift of Disease” and in “Eurydice in the Underworld” as a patronizing and insulting manner, instructs her that “all of us are going to die”, and that she will have to do chemotherapy, which would raise her survival chances only by 10 per cent. Acker, who had experienced her surgery as a horrifying event, dreaded chemotherapy. Having felt utterly infantilized in the context of western medicine, reduced “to a body that was only material, to a body without hope and so, without will, to a puppet who, separated by fear by her imagination and vision, would do whatever she was told” (Acker, 1997: 3), she left the doctor's office and conventional medicine never to return. She turned to nutritionists, herbalists, acupuncturists and spiritual healers instead, in an effort to get well in her own terms, just like she had always tried to live her life. However, her cancer quickly metastasized, too advanced by the time she found out about it for her to take any action, and Acker died in 1997, at the age of 50.

In what follows, I examine the author's two testimonies, two texts very different in style and in function from each other: “The Gift of Disease”, a matter-of-fact account critiquing violences and injustices in the breast cancer landscape and describing Acker's encounters with alternative healers (written when she thought she was healing), and “Eurydice in the Underworld”, a semi-fictional, genre-bending, activist textual performance (written when Acker knew she was dying). I discuss these texts' intentions, their hybrid natures, their activist powers, and their poetic elements, understanding them as powerful counter-narratives and employing in my thinking processes the genres of Bildungsroman and picaresque, the concepts of the punk and the pagan, the patient's agency and a critique of medical practices and of the breast cancer industry, as well as the age-long oral poetry tradition of the Greek laments.

## The Gift of Disease

“The Gift of Disease” was published in 1997 in *The Guardian*. It is a dense seven-page narrative that presents Acker’s breast cancer and Western medicine experience in a realist way, giving the facts of her health adventure from the beginning until what she thought was the end of it. It recounts her rejection of mainstream medicine and her turning to alternative healers, guiding her to recover from breast cancer in non-conventional ways. In this chapter, I read “The Gift” as a counter-narrative of refusal and resistance to oppressive norms, particularly as they operated in Acker’s time (and still do today), mainly in the context of the doctor-patient relationship. In my analysis of the text, I identify three interconnected points of critique prompted by Acker’s own experience: *health inequities* in breast cancer treatment in the US context; *environmental causes* of cancer and cancer as lucrative business; and *dehumanization in medical care*.

Despite the clearly articulated critique, however, of normative, necropolitical structures, and despite the distinct voicing of different needs and desires on the level of the political within the everyday, in the context of Acker’s interactions with the healers we come across positions and statements that sound neoliberal. These assertions essentially communicate and disseminate the myth of individual responsibility: you caused it and you have to fix it; you are responsible, it’s up to you. With the healers, Acker had to look inside her self and heal her emotional traumas that presumably had made her sick. She had to be educated in self-healing. This is phrased by the healers as follows: “We learn from diseases: they are gifts” (ibid: 5). “Disease comes from blockages of energy” (ibid: 6). “You have to want to be well. You have to learn what well is” (ibid). “To focus attention. That’s how you get rid of symptoms” (ibid). “You will create your own healing” (ibid: 7). “It all comes down to faith” (ibid). Acker’s own understanding of this process, on the other hand, is formulated like so: “My meeting with Greg Schelkun signaled my entry into a school” (ibid: 5). “I saw the network of causation so clearly [...] I had to forgive myself” (ibid: 6).

All these are reminiscent of the self-help/therapy culture we have discussed in previous chapters, as well as of versions of mindfulness and spirituality that have become very popular in the last twenty years. The co-existence of these elements with Acker’s critique and, at the same time, these very elements *as a form of* critique, configure “The Gift” as a hybrid counter-narrative between genres. *Bildungsroman* and a “school of the body” and “school of the will” that Acker found with the spiritual healers; lessons learned and a transformation. *Picaresque* and an outsider main character who still doesn’t fit in at the end of the story. Someone who tried things in order to survive without knowing what exactly to believe, but gave a chance to anything that could possibly keep her alive.



**Picture 8.** Photographs of Kathy Acker found on the internet.

## Health Inequities/Cancer as Business

From the very first page of “The Gift”, Acker confronts the reader with the *financial side* of breast cancer and with the, mostly overlooked in breast cancer narratives, fact that not all patients can manage it equally uncomplicatedly, depending on their economic status and availability of health insurance or lack thereof. A side which, at least in the US context, is not to be taken for granted for many uninsured/unemployed/underemployed women, who have to make important health related decisions according to their low or non-existent budget<sup>13</sup>. Such systemic functions and practices boil down to what several theorists have described as deathmaking (Wolfensberger, 2002), necropolitics (Mbembe, 2003), biopolitics (Foucault, 2008), slow death (Berlant, 2011), and economies of abandonment (Povinelli, 2011), or what Nikolas Rose, examining biomedicine,

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<sup>13</sup> Social class, and therefore economic status, together with race, have been explored for decades as a cause for higher mortality rates among disadvantaged women as well as for the poorer quality health care offered to them. In the 1986 statistical methodology research article, “Social Class and Black-White Differences in Breast Cancer Survival” (Bassett and Krieger), the authors had to actually make a case for the inclusion of social class “as an important determinant of cancer mortality” (ibid: 1402) and suggest its crucial value as a factor in future research, since up till then scientists focused almost exclusively “on *biological differences* between Black and White breast cancer patients” (ibid: 1400, my emphasis). For contemporary research, it is obvious that social class must be present in an examination of disparities. See, for example, the chapter “Barriers and Burdens: Poor Women Face Breast Cancer” (2000: 183–210) by Anne Kasper, in the book *Breast Cancer: Society Shapes an Epidemic*. Also, the qualitative research article, “Effects of Social Injustice on Breast Health-Seeking Behaviors of Low-Income Women” (Bowen et al., 2013), or the research piece, “Disparities in Breast Cancer: Through the Breast Cancer-Care Continuum” (2013), by the radical activist organization Breast Cancer Action (<https://www.bcaction.org/site-content/uploads/2018/04/Disparities-and-Breast-Cancer-w-updated-address.pdf>), with percentages and factsheets. The problem definitely remains.

power, and subjectivity in the twenty-first century, and following Foucault, has called *The Politics of Life Itself* (2007). Within this system, it is always the individual body where disease is located, an attitude stemming from an acute “medicalization of social problems” and an “aggressive medical imperialism” (Rose, 2007: 10) totally obscuring – in the case of breast cancer – the “political neglect of carcinogenic effects of conditions of poverty in postcolonial capitalism and chemical modernity” (Lykke, 2019: 108).

Acker got a taste of this, which connects her to a broader story: inequity. “[W]orking as a visiting professor at an art college” (1997: 1) at the time, and “not qualify(ing) for medical benefits” (ibid), she “didn’t have medical insurance” (ibid) and had to “pay for everything out of (her own) pocket” (ibid). This seemed to be clearly an issue for Acker. Her choice of a double mastectomy, the most affordable of the solutions offered to her, together with an actual price list she gives us concerning different surgical operations and treatments one might need in connection to breast cancer (1997: 1), spell out the inexorable fact that this was then, as is now, a matter of selling and buying.

Acker, of course, came from a white, upper class background and, even though she had cut ties with her family very early in her life and faced financial difficulties herself, she cannot be said to belong in the same category as many disadvantaged women of low socio-economic status with an internalized history of structural and systemic inequity and injustice. A history that interferes with and hinders their health-seeking behavior as much as their limited means do. However, when the conjunctures of events bring Acker to the hospital for her breast cancer, the author, facing similar constraints to those of the underprivileged women, makes the same choice as they do and for the same reasons. A mastectomy with no radiation costs less than a lumpectomy with radiation and, hopefully, it will spare her further expensive and torturing dealings with the cancer world. Right after that mastectomy – and in a quite bad post-surgical state – just like all the uninsured, Acker has to go. She writes, “I wasn’t staying the night, and couldn’t even if I wanted to, because only people with medical insurance were allowed to. But I couldn’t stand up [...] An orderly wheeled me to the vehicle while I fought against my nausea” (ibid: 2). Moreover, like the low status women, Acker, too, felt mistrust and frustration at the way she was treated by the health care providers<sup>14</sup> being, in her own ways (punky style, short-cropped hair, tattoos, piercings, leather jacket) different than the normative, white middle/upper class patient, and therefore unacceptable and not-belonging.

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<sup>14</sup> One very strong instance of that is Acker’s meeting with her surgeon after her surgery (dealt with further in this inquiry), which has been a traumatic experience of abuse for the author. Another example comes from the semi-fictionalized account of her breast cancer treatment in “Eurydice in the Underworld” (1998). There, Acker writes that at the operation theater “[t]he GREEN MOVING FIGURES confer among themselves about YOU’s strangeness and her piercings” (1998: 14). YOU is another name for Eurydice, and for Acker herself.

## Environmental Causes/Cancer as Business

The second critical point Acker makes in the first part of the text, concerns the links between cancer and *environmental factors*. Acker brings to our attention statistics of the time showing that in the Bay area of California, where she lived back then, “one out of seven women was being diagnosed with breast cancer” (ibid: 1). She shares information she got from a friend, “a noted nutritionist”, according to whom “experts are predicting unofficially that these figures will rise to one in three and that The Center For Disease Control in Atlanta, Georgia, has been called in to investigate” (ibid). A piece of information that, following Acker, had been kept from the public. Nevertheless, “[e]ven according to officially-approved statements, the rates for breast cancer in northern California are the highest in the world” (ibid).

Acker’s reference to the breast cancer cluster in this specific area, which points to one of the instances of geographical difference in breast cancer incidents in the US, expresses the confirmed by scientific research concern for the implication of environmental causes. It also, insofar as it gestures to a source of causation outside the patient, moderates, if not negates, the dominant epistemological paradigm, which places individual choices (Brown, 2007: 20), as well as genetics at the center of the breast cancer problem. This line of thinking led to an activist-scientist alliance in the San Francisco Bay area in the early 90’s<sup>15</sup> that challenged linking breast cancer to reasons stemming almost exclusively from individual responsibility. Lifestyle factors cannot fully explain a particularly high occurrence in a specific area, and genetic reasons account for less than 10 percent of all cases<sup>16</sup>. Genetics “may account for some individual susceptibility, but it cannot explain why breast cancer rates have increased in a period that is too short for genetic changes to occur in the population” (Brown, 2007: 65)<sup>17</sup>.

Acker’s inclusion of this concern in the context of her personal story takes her individual experience to the level of the collective. In the next couple of lines, she remarks that breast cancer is a huge profit-maker in western medicine, an actual “big business” (ibid), and that “[t]he two largest industries in the US are weapons and medicine (ibid). In connection to Acker’s first statement, I think of the research of Nikolas Rose, who argues that in contemporary times “health and illness (are seen) as merely another field for calculations of corporate profitability [...] medicine has been reshaped by its intense capitalization [...] (and) illness and health have become major fields for corporate activity and the generation of shareholder value” (Rose, 2007: 11). Regarding Acker’s second claim, Beatriz Preciado makes a thoroughly illuminating argument in her impressive work,

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<sup>15</sup> See Brown’s *Toxic Exposures: Contested Illnesses and the Environmental Health Movement* (2007: 81–86).

<sup>16</sup> See Brody and Rudel, “Environmental Pollutants and Breast Cancer” (2003: 1008), and Brown, *Toxic Exposures: Contested Illnesses and the Environmental Health Movement* (2007: 65).

<sup>17</sup> See also, Brody and Rudel, “Environmental Pollutants and Breast Cancer” (2003: 1007).

*Testo Junkie: Sex, Drugs, and Biopolitics in the Pharmacopornographic Era*<sup>18</sup> (2013). Preciado, among other things, elaborates precisely on the connections between techno-scientific developments made in the context of wars and mass killings (drugs/surgical processes/psychological manipulation) and the introduction/promotion/application of this new knowledge as products to the public with the goals of consumption, control, and accumulation of capital.

The two main points we have looked at so far, namely, health inequities and environmental causes (both of them with the same bottom-line of cancer-as-business), constitute a clear challenging of the neoliberal, necropolitical system that accumulates economic profit and lets vulnerable people die. Such critique is not to be found in breast cancer stories of the conventional type, let alone on the very first page, and it already sets the mood for a personal narrative that is simultaneously a protest. This finds a rightful continuation – and, indeed, escalation – with Acker’s third point of opposition, which becomes her most urgent dissent because she felt it right on her own body.

## Dehumanization in Medical Care

Three weeks after her diagnosis, Acker is there for her double mastectomy “at the same hospital where the biopsy had taken place, one of the finest in San Francisco” (1997: 1). Being at such a nice hospital seems to have made a positive difference for Acker – warm spaces, lovely colors, beautiful decorations, kind and friendly nurses – but only up to a certain point. That is the point when the procedure begins, with specific, standardized steps that follow a particular medical protocol. Being taken to an unheated room where they would prepare her for the surgery, but in a wheel chair, which constitutes her as a weak, dependent, invalid subject, despite the fact that she can walk and that she feels, for the moment at least, quite alright. Suddenly being surrounded by “green-capped and green-clothed figures” (ibid), which she has difficulty recognizing as humans. Being administered a preanaesthetic that makes her brains nauseous. Having a green cap put on her head and cover her eyes preventing her from seeing. Having scotch tape wound around jewelry that could not be removed and on the skin around it, thus “being reduced to something (she) couldn’t recognize” (ibid: 2). Acker’s description reads like the process of a torture and what she seems to be

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<sup>18</sup> “We are being confronted with a new kind of hot, psychotropic, punk capitalism. Such recent transformations are imposing an ensemble of new microprosthetic mechanisms of control of subjectivity by means of biomolecular and multimedia technical protocols. Our world economy is dependent on the production and circulation of hundreds of tons of synthetic steroids and technically transformed organs, fluids, cells (techno-blood, techno-sperm, techno ovum, etc.), on the global diffusion of a flood of pornographic images, on the elaboration and distribution of new varieties of legal and illegal synthetic psychotropic drugs (e.g., bromazepam, Special K, Viagra, speed, crystal, Prozac, ecstasy, poppers, heroin) [...]” (Preciado, 2013: 33). For a better understanding of the author’s argument, see pages 30–36 (2013).

talking about is the traumatic experience of her dehumanization in the western medical context<sup>19</sup>.

They took her to a room, huge and even colder than the previous one, where the terror unfolds even more wildly than before and with additional nightmarish, surrealist elements. More green figures wander around the huge cold space in the middle of which stands an object that is “partly a table and partly a bed” (ibid). They instruct her to climb on it and she notices the machines connected to it, which “looked like Dr. Seuss animals” (ibid), a comment that foregrounds the unreality of the situation and Acker’s alienation from it. Next thing, “[t]hick straps were placed around (her) arms and legs, then buckled tightly [...] red suction cups connected to steel cords were placed on (her) torso” (ibid). “Why are you doing this?” (ibid), she asks. “Because we don’t want you to harm yourself” (ibid), they answer, incomprehensibly. Acker is weakened, disoriented, and nauseous, alone in the midst of a terrifying experience, trapped in an appalling room she would rather escape, with people who feel like aliens to her, and whose behavior causes her even more fear. She writes: “I want to describe as exactly as possible what it is like to experience conventional cancer medicine. However, I am omitting the more horrific details” (ibid).

Two days after the mastectomy, and still unable to move her left arm, despite the doctor’s assertions that she “could begin exercising the day after (the operation)” (ibid), she goes together with her lover to meet her surgeon and get her pathology report. The meeting turns out to be a terrible experience, so bad that she has trouble registering it as real (“What next happened I remember as if it were in a play”, ibid). In the dialogue Acker transcribes, the surgeon emerges as a paternalistic, insensitive, and oppressive figure: less a real human being and more a patronizing representative of the medical establishment and of the status quo<sup>20</sup>. In six out of eight lymph nodes they found signs of cancer. He had said that there was little chance for that but “[t]hat was before the operation. Now things are different” (ibid). He tries to put it simply to her so that she can

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<sup>19</sup> In their article, “Dehumanization in Medicine: Causes, Solutions, and Functions” (2012), Haque and Waytz argue that “[d]ehumanization is endemic in medical practice” (ibid: 176). They “identify six major causes of dehumanization in medical settings (deindividuating practices, impaired patient agency, dissimilarity, mechanization, empathy reduction, and moral disengagement)” (ibid), almost all of which we encounter in Acker’s “The Gift of Disease”. Dehumanization in medicine has been the focus of research from various methodological and theoretical perspectives. For example, Pdmanabhan’s (2020) “Halting Dehumanization in Medicine” where he advocates that the dehumanization processes “need to be understood from a deeper mind-body-spirit perspective” (ibid: 43). Todres, Galvin, and Holloway (2009), “The Humanization of Healthcare: A Value Framework for Qualitative Research”, which draws on existential-phenomenological and sociological perspectives, and foregrounds the potential of qualitative research in re-humanizing practices. For a good review regarding dehumanization in medical contexts, see Diniz, Bernardes, and Castro (2019), “Self- and Other-Dehumanization Processes in Health-Related Contexts: A Critical Review of the Literature”, which draws on socio-psychological perspectives.

<sup>20</sup> Acker illustrates the oppressive character of this meeting even more vividly in her story “Eurydice in the Underworld” (1998).

understand: “All of us are going to die. Some of us are going to die in 20 years; some in five...” (ibid). He explains he isn’t telling her she is about to die. He simply wants her “to understand this situation” (ibid). She might survive, but she must do chemotherapy, which raises her chances by 10 per cent. Regarding diet and environmental pollution, these are certainly not connected to cancer. Studies have proven that, and Acker’s doctor has “read the best” (ibid).

Acker gets out of that office determined to never return. Conventional medicine, its people, and its procedures – what she had already seen and what was still coming: the dreadful chemotherapy, the poisoning that was to her worse than cancer – meant more death than life, more elimination than salvation. She writes, “I realized that if I remained in the hands of conventional medicine, I would soon be dead, rather than diseased, meat. For conventional medicine was reducing me, quickly, to a body that was only material, to a body without hope and so, without will, to a puppet who, separated by fear from her imagination and vision, would do whatever she was told [...] When I walked out of that surgeon’s office, I thought that I might be about to die, to die without any idea of why. My death, and so my life, would be meaningless” (ibid: 3).

From this short but telling passage, I understand that what Acker couldn’t stand in the medical context was the taking away of her agency and her complete and utter reduction to materiality. Becoming nothing more than a body with breast cancer, a body that couldn’t take initiative, have opinions or desires, a docile body that would follow orders, which is, she remarks, “a necessary part of the practice of conventional western medicine” (ibid). To her, that equaled death because “[t]o live was to stay alive and to not be reduced to materiality” (ibid). Acker never contacted that doctor again “except to pay his bill” (ibid). From that point onwards, she was on her own, searching for help. This impelled her to turn to alternative ways of dealing with breast cancer.

### **“First, one must want to be well”**

Acker had now abandoned western medicine for good. Desperately “looking for someone (she) could turn to” (ibid), and afraid that the time she had might not be enough, she sought the help of spiritual healers who directed her the one to the next, and who could, she hoped, relieve her of cancer. Conscious of the improbable of this decision, and more gambling than really believing in what she was doing, she writes: “At this point I walked completely away from the society I had known. I took a leap of faith” (ibid: 4). She describes this as her “entry into a school” (ibid: 5), and embarks on a breast cancer apprenticeship, during which she would have to learn specific lessons, take different steps, and follow an order of stages – like every apprentice.

For instance, some of the lessons Kathy Acker had to learn, according to her spiritual healers, are the following: “It’s about learning” (ibid). “We learn from diseases: they are gifts”. For a breast cancer patient to think in terms of “‘good’ health and ‘bad’ health [...] (this is a) value judgment(s)”. [Y]ou get rid of

symptoms” by “focus(ing) attention”. “You have to want to be well. You have to learn what well is”. More lessons in stock for Acker were: “Disease comes from blockages of energy”. She was sick because her “body (wasn’t) in harmony”. She has to stop obsessing about traumas, “take the blame off mummy and daddy”, and learn “to examine (her) major energy centers”. Finally, “[a]ll healing has to do with forgiveness” (ibid: 5–6).

The gist of the healers’ teachings is clear: it was all up to her. Will moves mountains, and if only she could “situate” those “scars” of memories her body had held and overcome them (ibid: 6), she would be free of cancer. In her desperate struggle to survive, Acker moved in the manner of a pilgrim from one holy shrine to the next, following the guidance of spiritual masters who referred her the one to the other. From the psychic Frank Molinaro, to the trauma-healer Georgina Richie, to the trained in the mountains of the Philippines Greg Schelkun, to the visualization specialist Ellie Wood, and then in London, to the Chinese herbalist Ken Lloyd, the cranial therapist Beverly Katz, and finally to Stephen Russell, the Barefoot Doctor. A succession of mentors, advisors, instructors whose resources, focusing on the power within, weren’t tools good enough to keep Acker alive.

What is hard to miss is that the metaphorical images/understandings of cancer as a “gift” or “school” and as a precious opportunity for learning and for deepening of the self, are identical to those one comes across in mainstream memoirs. One is rather surprised to see that, quite suddenly, cancer didn’t have to do with the toxic environment, after all, nor with Acker’s exposure to poisoned food and all sorts of products that are full of carcinogens. Not a word anymore about the bay area, alarming statistics, and governmental/medical establishment responsibility. It was the “blockages of energy” all along, and the story Acker relates resembles a pilgrimage towards what she believed and hoped was health. In a similar way as the hero of a fictional narrative, she goes out to the world to meet different helpers/healers/teachers who bring to her their skills in order to show her how to restore her health. They offer her the teachings, the knowledge, the weapons, but she is the one who has to use them and save her life. They, as well as everyone else in the world (mega-corporations, major industrial polluters, the American Cancer Society) are free of responsibility concerning the breast cancer patient Kathy Acker and why she got sick. The responsibility – as in mainstream notions and illness stories – lies entirely with her.

The similarity between the neoliberal, business-like, self-help approach and that of the spiritual healers is striking: putting the responsibility on the individual, ignoring the necropolitical violence of inequitable policies, corporate complicity, and constant, involuntary carcinogenic exposures, and turning the whole thing into an apolitical matter of personal will. Jackie Stacey, in her book *Teratologies: A Cultural Study of Cancer* (1997) identifies and comments on this essential sameness in her aptly titled first chapter, “Heroes”. Stacey, writing from a British context, notes that owing to “government cuts in public health provision” and to “placing health firmly within a world of competition and consumerism”, “the scope for appealing to individuals to take charge of their health is ever-widening”

(ibid: 2–3). She concludes that “[t]his is perhaps the most glaring overlap between some alternative approaches to health and the Thatcherite legacy of the cult of the individual. In the marketization of public sector areas such as health, there has been a shift in responsibility, and thus funding, that encourages us to heal ourselves” (ibid: 3).

Stacey’s commentary, made in 1997, definitely speaks for a very similar contemporary U.S. context, as well. Notably, her book was published the very same year as “The Gift of Disease” shortly before Acker’s death. Stacey herself had ovarian cancer and she, too, had turned to alternative healers and wrote extensively in her *Teratologies* about it, combining however what the healers offered with conventional treatment. Rosi Braidotti, in her text “Enduring Self-Health” (1998), which is primarily a review of *Teratologies*, intertwines Stacey’s book and Acker’s case, because of the proximity of these events, and also precisely because of the similarity of the subject matter. Braidotti agrees that “mainstream bio-medicine” and “alternative self-health philosophies” are “co-extensive and even complicitous with each other” (ibid: 426). She writes: “New Age therapies link negative emotions to the production of disease: emotional disorder leads to cellular mismanagement. Both official and alternative medicine enforce the same kind of hyper-individualism” (ibid: 428). Regarding the choice Acker made, Braidotti states: “She was no victim, not the Kathy Acker I knew: not once in her adventurous life was she ever victim to circumstances. She just could not afford proper medical care in the liberal, 'personalized' 1990s. Only afterwards did she turn to alternative self-health practices” (ibid: 427). That is, indeed, one part of the truth. The other part, and perhaps the most powerful one, resides in what Braidotti mentions a bit further in her text about “the male medical profession, whose depersonalized, business like style is the object of 'a view from below' by the patients. The objectifying medical gaze is alienating and it alone justifies trying alternative medicine” (ibid: 428).

Acker’s story, from a certain point onwards (that is, right after her critique, which is intertwined with her experience), follows the logic of a master-narrative with a hero who focuses on the inner self, evolves, acquires new skills, and is able to manage better in the world. However, the existence of these elements in “The Gift” and Acker’s following alternative practices does not signify a negation of her previous self or of the values she stood for. It rather underscores her categorical refusal to comply with the medical norms – with any norms – that would turn her into a docile subject without will. Her walking away from conventional medicine constitutes a very strong, a very powerful transgression. The Bildungsroman character of her time and dealings with the spiritual healers (the apprenticeship, the school of life, the lessons, the self-healing) is unsettled and undermined precisely by who Kathy Acker was.

My understanding is that, being emotionally injured by her experience of mastectomy and by her surgeon’s attitude, this was the only thing Acker was willing to try in her search for some kind of healing. She took this option for the very basic reason that it didn’t reduce her to materiality, but acknowledged her as a person with agency and will of her own. Her treatment or healing, in this

context, would be a collaborative effort between herself and each of her healers. Not things done *to* her without any contribution from her person any more than just showing up and conceding to having chemical substances administered to her, but things done *with* her, things in which her *active participation* would be of crucial importance. Repeatedly, whenever Acker makes a mention to professionals whose services she sought before and after her breast cancer diagnosis, she refers to the meetings or sessions she had with them as collaborative efforts, as a teaming up of sides with cooperation towards a common goal in mind. For example, referring to her acupuncturist and to her nutritionist, she writes: “I had been working with both men for about six years” (ibid: 1). We come across the same wording multiple times, elsewhere: “Frank Molinaro, a psychic with whom I had worked for about a year” (ibid: 4). “When I first started working with Greg and Georgina” (ibid: 6). And also, towards the end of the text: “I’m trying to understand what Greg has been doing to me – or is it with me? – all these months” (ibid). “[T]he healing work that I did, am doing, and that was done to me” (ibid: 7). This is not how most people would talk about having sessions with health care professionals. One doesn’t think of it as “*working with* them”. It’s usually an appointment where you get the expert’s opinion, after which you just make sure you take and do whatever was prescribed for you and follow their orders. Indeed, in our culture we refer to what the health care professional has recommended as *orders*: “doctor’s orders”. Nevertheless, in all the instances right above, Acker doesn’t seem to conceive of this very common idea in quite the same way. She will not do this but only in a manner that makes sense to her; and her terms are different. At some point, Acker remarks that her attitude towards doctors is not very different than that of most other people: “I took it for granted, as I think many of us do, that doctors are people who know how to get rid of disease, that one turns to a doctor in order to be cured of physical affliction” (ibid: 7). However, most of us would not get to the point of expressing much discomfort in response to that particular surgeon’s approach, for example, and, even less so, make the decision to leave both him and all things medical behind. But Acker does take issue both with the surgeon and with the whole situation she has experienced. So much so that – a cancer afflicted woman, with no other relatively safe alternative ready, no other concrete plan – she walks away. But, once more, why did Acker turn to them? Why did she stick with them, too? I think it was because of three interconnected reasons, which, taken together, allow “The Gift” to emerge as a counter-narrative of its time, testifying to a woman’s refusal to submit to what “normal society” expected her to do, to her overall ethics and politics of resistance, and to her nonnegotiable freedom.

## Agency

The first reason was being able to take an active role in what was a matter of life and death without being crippled by western medicine that treated her as a sick body to be handled by experts making her redundant in every single stage. A drowning person will clutch at a straw, as the saying goes, and if that drowning person could find empowerment with the spiritual healers' kind of straw, she would clutch it for sure. "I could heal without having to trust someone else with my life, as I had done with the surgeon [...] I could be responsible for myself" (ibid: 7), Acker writes. "Responsible" here, though, I believe, does not have the same meaning as in the self-responsible, neoliberal individual. "Responsible for myself" means I am not a puppet – I have agency. She did have to trust the healers, though, that was the risk she took, a risk that was, however, somewhat soothed by the fact that, with them, she could retain her agency. The healers' paradigm suited her much better than that of the surgeon, and, correspondingly, of the whole of conventional breast cancer medicine. In her last page, she explains: "A doctor, for me now, is not someone who cures for, as Greg (one of her healers) says, no one cures life. Rather a doctor is a *facilitator and teacher* and the doctor-patient relationship a *spiritual, as well as medical, one*" (ibid: 7, my emphasis).

## Connection

A second reason is that – apart from actually asking Acker to be active in her healing – the healers were present for her as a person, and not as the host of a disease. They listened to her closely, asked questions, tried to get to know and understand her. This went both ways, as well, because they, too, communicated with Acker as real people, and not as therapists or experts of a neutral and indifferent variety. They told her their own stories, and how things came to be for them, in each particular case: where they started from and how they ended up where they were when she met them. They shared emotions, expectations, disappointments, and peculiar or unexpected events that proved to be landmarks for their personal and professional trajectory. They spoke about moments when they didn't know what to do, about strange twists of fortune, and feelings of recognition when faced with what they inwardly acknowledged as the right path for them. Even though Acker doesn't go into great depth about her healers in "The Gift of Disease", in the sketches she draws of them<sup>21</sup>, we see each of them emerging as a distinct person, human, in opposition to the green-clothed, green-capped figures at the hospital about whom she felt uncertain whether they were humans or not. Absolutely, also in opposition to her surgeon, who resembles a kind of automaton bearing the mask of a human; a robot programmed to execute specific, technical

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<sup>21</sup> For example, Georgina Richie, Greg Schelkun, and Stephen Russell (see, correspondingly, pages 4–5, 5–6, and 6–7 in "The Gift of Disease").

functions that, at least in the Acker-surgeon meeting description (ibid: 2–3), verge on abuse.

## A World of Wonder

These reasons alone would already work for many patients starving for connection with and real support from the person who takes them under their professional care precisely at a moment when they get to hear that their life is under the threat of cancer. But I think that what the spiritual healers offered appealed specifically to Acker even more for a third reason. A reason that reflects who she was in life: a girl-child who wanted to be a pirate, spit on conventions of all sorts, invent her own language, not have a self to imprison her, try out different identities, be and live wild. In her essay “Seeing Gender” (1995), she writes:

“When I was a child, the only thing I wanted was to be a pirate. Because I wasn’t a stupid child, I knew that I couldn’t [...] I could never be a pirate because I was a girl [...] Barely born, I was dead. The world of my parents, my bossy mother and my weak father, the world in which I had to wear white gloves and panty girdles even though I was skinny, was a dead world. Whereas pirates lived in the *living* world because pirates had fun [...] I’m no longer a child and I still want to be, to live with the pirates. Because I want to live forever in wonder” (1995: 78–79, italics in the original).

So, the healers’ world appealed to her, I believe, for the same reason for which in the beginning she distrusted it: because it was, in a sense, “away from normal society” (Acker, 1997: 3): a world of strangeness where unforeseen and unthinkable things were actually possible. In “The Gift” we read, for example, that one of Acker’s healers, Greg Schelkun, travels to the Philippines to make a film on indigenous healers, follows one of them in the mountains for five days, and ends up staying with him for two years and becoming himself a healer (ibid: 5). That Georgina Ritchie “saw a kidney transplant done with a rusty knife” after which “the patient just walked away” and, on another occasion, “watched a healer [...] perform psychic brain surgery [...] (and) close the wounds with his own hands” (ibid). That Stephen Russell, afraid that a nuclear disaster would end the world, leaves England, his studies, and business behind, and travels to the U.S. to ask “Thomas Benyaka, the Keeper of the Prophecy for the Hopi Indians [...] if the world was going to end” (ibid: 6). To which, “Thomas Benyaka said, ‘No, our prayers have taken away that disaster’”, adding that Russell had “to go away and heal (him)self before (he) can heal other people” (ibid). “This man told me who I was going to be and then he told me that I had to go away” (ibid), Russell concludes. The stories told by Acker’s healers, their experiences describe and create a world of magic, irrationality, transgressions, the fantastic. A world where normalities are overruled. Indeed, a world of overpowering, of turning upside down what is commonly thought to be the natural order of things. Going against the rules, then. Cheating, in a nonsensical, incomprehensible, supernatural way,

and finally making it work for you. Forgive yourself, and heal through your own forgiveness. I understand that these things, for all of Acker's (or any modern person's) anti-rationalism and attraction to wonder, might still sound a bit strange, but are they?

## **Bricoleurs and Brewers of Time**

Thinking in binaries is what actually causes the trouble. Us and Them. Nature and Culture. Scientific and Non-scientific. Rational and Irrational. This type of dualistic thinking, these dichotomies, obstruct us from seeing the complex inter-connections between different things, and the hybrid nature of the world. Acker's decision, as well as her narrative (which is a counter-narrative bearing some features of mainstream discourses) makes perfect sense in the context of linkages and relations. The anthropologist Bruno Latour (to whose work I turned also in the introduction), in his book *We Have Never Been Modern* (1991) understands the co-existence of seemingly disparate or incongruous elements that make up a human being not as a contradiction or even as something exceptional, but just as the way things are. Latour suggests that "'we are exchangers and brewers of time' (Serres and Latour, 1992)", and that "[i]t is this exchange that defines us, not the calendar flow that the moderns have constructed for us" (ibid: 75). According to him, "[w]e have never moved either forward or backward. We have always actively sorted out elements belonging to different times. We can still sort. *It is the sorting that makes the times, not the times that make the sorting*" (ibid: 76, italics in the original).

This is reminiscent of another French anthropologist, Claude Levi-Strauss, and his concept of bricolage, which he defined in *The Savage Mind* (1962) as the skill to combine whatever is at hand in order to create something new. Levi-Strauss, however, makes a comparison between the bricoleur (the savage mind, who uses pre-existing things combining them in new ways without caring much about coherence) and the engineer (the scientific mind, who starts from scratch to create an entire solid system originating in himself, and making, out of the available resources, brand-new tools). Levi-Strauss identifies the bricoleur with the ways mythology works, and the engineer with the functions of modern western science. This problematic distinction drew the attention of Derrida in his text "Structure Sign and Play in the Discourse of the Human Sciences" (1970) where he criticizes such a binary as well as the possibility of anyone being "the absolute origin of his own discourse" (ibid: 6), and argues that "the engineer is a myth produced by the bricoleur" (ibid). In the final analysis, there can be only bricolage and we are all bricoleurs, always making patchwork sense out of things in ways that are not necessarily coherent. What is more, as Latour would have it, in ways that, despite our ideas of progression and different modes of existence and thinking in a linear time, are not very different than what people have been always doing.

Anne Boyer, in *The Undying* (2020) makes a similar point. Boyer begins the book by introducing Aelius Aristides, a Greek orator, who, getting sick at the age of twenty-six, followed a practice common in ancient Greece and went as a pilgrim to the temple of god Asclepius to sleep and wait there until he received the god's prescriptions, delivered to him in his dreams. Boyer refers to Aristides and his own memoirs (*Hieroi Logoi*, meaning, Sacred Tales) throughout her book to indicate how healing practices have changed in the centuries, but also remained the same. Boyer draws parallels between the faith of ancient Greeks who followed the divine prescriptions delivered in their dreams and our contemporary faith in what images on a screen tell about us, authoritatively confirmed by a doctor. "Illness that never bothered to announce itself to the senses radiates in screen life, as light is sound and is information encrypted, unencrypted, circulated, analyzed, rated, studied, and sold. In the servers, our health degrades or improves. Once we were sick in our bodies. Now we are sick in a body of light" (ibid: 15). She compares ancient Greeks searching their dreams for healing paths and prescriptions to contemporary people searching the Internet for information and statistics, in what she understands as "an ulterior mysticism" (ibid: 21). "A newly diagnosed person with access to the Internet is information's incubant. Data visits like a minor god. Awake, we pass the day staring into the screen's abyss, feeling the constriction of the quantitative, trying to learn to breathe through the bar graphs, head full of sample sizes and survival curves, eyes dimming, body reverent to math" (ibid: 22). To Boyer, the modern day hospital or cancer treatment center is not so different from that ancient *asclepeion*, the temple of the Greek healer god.

Acker believed that she was healing, the healers having assured her that she was "on her way to health" (Acker, 1997: 7). The account that she offers us in "The Gift" begins with horror and ends with an affirmation of life, imagination, and will – the reaffirmation of her own power. Acker closes her narrative by sharing the most important for her outcomes of her experience. She summarizes these as three shifts of paradigm. One of them is learning that her body is connected to the world around her and that it is a physical *and* emotional entity that needed to be treated as such. Another, concerns the experience of going to the doctor, and perhaps the most important one, pertains to the doctor-patient relationship:

"I took it for granted, as I think many of us do, that doctors are people who know how to get rid of disease, that one turns to a doctor in order to be cured of physical affliction [...] A doctor, for me now, is not someone who cures for, as Greg (one of her healers) says, no one cures life. Rather a doctor is a facilitator and teacher and the doctor-patient relationship a spiritual, as well as medical, one" (1997: 7).

Acker engages in spiritual healing processes which give her comfort and talks in meaningful to her ways with the healers as an equal. Very much unlike her doctor, the healers emerge as real and colorful people with rich lives who share with her their own journeys, and she experiences this as a nurturing and learning thing.

What I think Acker describes in the gift is her passage from the alienation, horror, despair, and anger she experienced with conventional medicine, to human connection and communication, and non-objectification, which she had with the healers, and also wonder and magic in the ways they operated and in the stories they told her, and in defying rationality trying to beat breast cancer by a sheer act of will and by healing emotional traumas. Acker began to explore possibilities beyond the medical that could possibly work for her in these most urgent circumstances of her life, not as a serious *Bildungsroman* hero who looks to fix mistakes, broaden her skillset, and adjust to the world, but as a desperate picaro who makes do with what is at hand, with whatever hurts her less, and might do the job. Somewhere in the middle of her narrative, she remarks: “As I did this – as I sought out the help of Frank, then Georgina – I saw myself, a person faced with her own death, turning to psychics, and I laughed” (ibid: 4).

### Conclusion of “The Gift”

In “The Gift”, Acker gives us a bricolage of dread of death and hospital horror, spirituality and alternative healers, wonder and magic, and “walking away from normal society”, as she wrote. She finds new understandings (her three shifts of paradigm), like a *Bildungsroman* hero, but these understandings far from being lessons that will help her function better in the world as it is, they constitute a powerful critique of how things operate and help her articulate her opposition to this world. Hegel, in his *Aesthetics* (1975), wrote:

“The conclusion of [a sensitive hero’s] apprenticeship usually amounts to the hero getting the corners knocked off him ... in the last analysis he usually gets his girl and some kind of job, marries and becomes a philistine just like the others” (ibid: 593).

In Acker’s case, not only the corners do not get knocked off her, they become even sharper. Moreover, she concludes her story not by any uplifting and victorious final statement, or a distillation of wisdom earned, but by saying that she does not quite understand what happened: “I have written down some of what happened to me in the past nine months, though I as yet understand little” (1997: 7). Acker does learn things from the lessons prescribed by her mentors and passes through different stages at the “school of the body”, as one of the healers defines their sessions for her. Yet, this “hero”, at the same time as being affected by what happens, is also reluctant, unbelieving, and rather maintaining the distance of an observer that reports back to us from a bewildering world, rather than fully immersing herself in her apprenticeship, as is the norm. She goes on a quest to save her life, which follows an episodic, picaresque structure. She engages in deliberate action that focuses exclusively on her as an individual. Nevertheless, she ultimately opens up her own case of individual healing to a community. Her shifts address broader political-economic-social structures that pervade and

define the realm of the medical today. They repeat and distill her initial poignant critique to the materialist, coercive, abusive forces of death that have brought her, and millions of other women, to the point of trying to survive breast cancer without knowing what their body-self-life-in-them actually is, neither what they could/should expect from a patient-doctor relationship and from the experience of receiving medical care. To wrap up my analysis, as I see it, these facts configure Acker's "The Gift of Disease" as a hybrid counter-narrative of minor resistance to normative narrative models of responding to breast cancer.

## Eurydice in the Underworld

"Eurydice in the Underworld" (1997), a text very different than "The Gift of Disease", is Acker's last radical story written only a few months before her death and while the author knew she was dying. A work of post-modern fiction that blends genres (from theater play, to diary writing, to auto-thanatographic travelogue, mixed with surrealist elements, poetry and drawings) and defies categorization, "Eurydice" conveys the author's experience with breast cancer, her traumatic contact with western medicine, and, ultimately, dying, and functions as a space where Acker struggles with, re-claims, and queers her own death. Acker re-imagines the Greek myth of Orpheus from Eurydice's point of view and undermines the central (Orpheus) in favour of the marginal (Eurydice) already by assigning to Orpheus a very different role than the one he holds in the hetero-normative Euro-modern imaginary of a multiple ancient myth (Lykke, 2022). Referred to as OR, which conveys his ambiguous character, he – the white, male, heterosexual, alive, and dominant subject – the poet, the creator, the maker about whom the myth has been composed, is not in the centre of Acker's "Eurydice". From being the hero of the narrative, he has now turned into a secondary character, while the previously passive, ghostly, and repressed Eurydice (referred to as YOU, a decision which involves directly the reader) is the protagonist, the subaltern who finally gets to speak.

Acker in "Eurydice" performs a very powerful activist gesture of mourning, something which, along with death and dying, is almost always excluded in mainstream breast cancer narratives. Mourning can be experienced as "*ethically and politically positioned affect*" (Athanasίου, 2006: 41, my italics) versus the emotional capitalism<sup>22</sup> (Illouz, 2007) of individualist narratives of self-transformation and triumph. Mourning can be expressed as *militancy* (Crimp, 1989) and as an activist gesture towards "public and collective formations by which trauma is addressed in all its affective, social, and political or biopolitical implications, intimacies, and limits" (Athanasίου, 2006: 42; see also: *The Cancer Journals* by

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<sup>22</sup> "Emotional capitalism is a culture in which emotional and economic discourses and practices mutually shape each other, thus producing what I view as a broad, sweeping movement in which affect is made an essential aspect of economic behavior and in which emotional life – especially that of the middle classes – follows the logic of economic relations and exchange" (Illuz, 2007: 5).

Audre Lorde, 1980). In both of these forms, though, mourning in the standardized breast cancer stories is lost. But it is not completely lost. Some renegade voices such as Acker's do exist, and suggest different possibilities.

Acker in "Eurydice" distinctly employs *mourning as activism* bringing together a community of women, in the sense that the voice that speaks to us and the story we read is not that of one person, but a polyphonic blending of multiple stories and people. Under this light, I think of "Eurydice" as connecting to an age-long Greek oral poetry tradition: the polyphonic laments, or *moirologia*; songs of mourning and social protest sung until rather recently in rural Greece by women at funerals, whenever a death occurred in their villages. In their pagan, mournful performances, Greek rural women have for centuries collectively challenged oppressive societal norms that have controlled and restricted their lives, when, in protest and unity at the moment of death, they have manifested political power and desires for social change. I interpret these performances as queer and transgressive inspired by Acker who queers the Greek myth of Orpheus and any kind of hetero/chrononormative readings of it to retell it from Eurydice's point of view – from the vantage point of the marginalized and the oppressed. Through her own mournful, textual performance, Acker unites with all the shadowy Eurydices who are poisoned, like her, and relegated to the Underworld.

Acker's "Eurydice", written against individualist expectations of a neoliberal, unified subject speaking from a dominant centre and from the position of the seamless and the whole, enacts a minoritarian, queerfeminist, artistic-activist performance from the margins, and from the position of the fragment, queering dying and mourning, as well as binaries of self-other, fictitious-real, and even life-death. While the majoritarian, neoliberal breast cancer narratives preach composure, poise, and self-control, "Eurydice" calls poisoning and dying by their proper names, and tells an alternative story of resistance and dissidence to heteronormative-patriarchal rationalities of oppression. While the memoirs aligned with the normative center present the adventure of one, brave, solitary "hero", Eurydice/Acker, referred to in the story as "YOU", opens herself up to the collective by forging bonds with other, precarious women. Performing as "YOU", she includes all women who read her story – not as mere observers, but as protagonists, dying together with her, in the present tense of the narrative. People who, as discussed by Povinelli in *Economies of Abandonment: Social Belonging and Endurance in Late Liberalism* (2011), suffer oppression and injustices in a necropolitical world in which they are nameless and where their death does not matter.

I examine "Eurydice" as a queerfeminist account in a dual sense. I propose that Acker's text can be interpreted as an alternative, queer, critical, and creative piece of writing and mourning, and as a way of rearticulating the subject in terms of merging and collective resistance in (the face of) death. Firstly, with "Eurydice" Acker radically challenges neoliberal breast cancer narratives. Secondly, her text can be understood as connecting to another type of activist performances of female mourning, the *moirologia* performed for centuries by women in rural Greece. I discuss these performative gestures that articulate

meanings of dead or dying multi-vocal, inter-connected subjects and seek potentially meaningful links between anti-conformist, punk-pagan mourning(s) of death. I regard these two types of mourning as *different but interrelated modes of resistance* against institutions and normative narrative structures that define what is thinkable in terms of action in the contemporary world.

## Margins and Fragments

Reading Acker's story with an eye to its queer-minoritarian, counter-narrative mode of writing, and considering again her choice to turn to Greek myth in order to speak in the name of all women through the archetypal figure of Eurydice, an association occurred to me. "Eurydice's" way of making mourning public and exercising it as an ethico-political gesture of protest that forges bonds with a community of women made me connect it to an age-old Greek oral poetry tradition: the laments or *moirologia*, polyphonic-dialogic songs of mourning and social protest performed until rather recently in rural Greece by women at funerals in order to grieve the deceased collectively and to protest against social injustices afflicting particularly women. *Moirologia* (laments), studied by – among others – Margaret Alexiou (literature, folklore, and history), Anna Caraveli (folklore, gender, and lamentation), and Nadia Seremetakis (cultural anthropology), represent a unique and historically continuous practice dating back to ancient times (Alexiou, 1974). They are hybrid compositions, in terms of genre, positioned between structure and improvisation; between established conventions and the poetic agency of the performer. These ritual-activist performances, bearing strong pagan elements and positing themselves against institutional religion and political order (Caraveli, 1986: 171), were suppressed by the state in ancient times (B.C.) and later on by Christianity and the official church (Alexiou, 1974: 14–35). Functioning as instruments of female cultural power emerging from the margins, the Greek laments exercised social critique, interwoven with embodied processes, but also dreams, imagination, and the non-human world. Interestingly, regarding the comparison I attempt here between "Eurydice" and the Greek laments, Seremetakis notes:

"The institutions and instruments of internal and external colonization may have changed from one epoch to another, but the experiences of colonization and ongoing resistance by women constitute long-term structures [...] A group exposed to external and internal dominations (by men, church, the state, medical rationalities) experiences cultural fragmentation as the very condition of its existence. There can be no holistic experience in the margins, only the creation of refuge areas that provisionally assemble the holistic from fragments in order to intervene in the public structure of domination. The experience of discontinuity and break prevails in the margins. The myth of holism and continuity is the ideological creation of "centers" and of dominating groups" (1991: 2).

Thus, thinking with concepts such as the “whole” and the “fragment”, as well as the “centre” and the “margin”, which occupy a central place both in Acker’s work and in what she stood for, and in *moirologia*, I intend to bring “Eurydice” and the genre of the Greek laments in conversation. In doing so, I argue that Acker/“Eurydice”, both in opposing mainstream narratives, and in perhaps consciously performing modern re-enactments of genre-traits from the female (counter)-cultural practice of the Greek laments, is an alternative, queerfeminist way to speak about breast cancer.

Speaking is difficult, though, when language is a tool “reserved for patriarchal significance” (Chisholm, 2005: 49), shutting women outside a full-fledged existence. In “Seeing Gender” (1995), Acker writes:

“as a girl, I was outside the world. I wasn’t. I had no name. For me, language was being. There was no entry for me into language [...] Is it possible that the girl can find her actual body, and so what gender might be, in language? [...] I am Alice who ran into a book to find herself. I have found only reiterations, the mimesis of patriarchy, or my inability to be” (ibid: 80–84).

Against this background, she tried to see how this language/power predicament could be overcome for those in the margins, those who, being at the lower end of hierarchies, are more exposed to the violence of identities. Nicola Pitchford, writes:

“The question that runs throughout Kathy Acker’s work is how people outside the mainstream of power – primarily women, but also men of color, gay men, and the poor – can claim agency when in fact they are very much “insiders,” their identities defined within existing systems of language and power. In Acker’s novels, society is a series of texts written by the powerful; its unfortunate characters must exploit the subtle differences among the multiple discourses of dominant culture if they are to rewrite themselves” (2002: 59).

Acker believed that the “self” of self-expression is packed with the culture’s language and prescriptions, so that in “self-expression” it is the culture that is given voice” (Friedman and Fuchs, 1989: 40). To this effect, Acker used textual fragments reshuffling others’ words and passages to open a passage to “what lies on the cultural periphery [...] construct(ing) a poetics of the margins” (Rock, 2004: 192) that queers the dominant story (Bradway, 2017). Staying faithful to her queer-feminist, text-making process until the end, Acker composes, in “Eurydice”, an account that abolishes linear time, employs fragments, and speaks for more than her individual circumstances. By adopting as her persona “one of the most intense figures in Greek mythology [...] connect(ing) the worlds of the living and the dead” (MacDonald, 1999: 107), she goes beyond the “self” and her specific identity, queers individualistic tropes, and blurs the boundaries between her own (semi)fictionalized experience and the larger picture.

In several aspects, there are similarities between Acker’s “Eurydice” and *moirologia* in their capacity of mournful poetry performances of a ritual

character, executed by women at funerals in rural Greece, and traced to the choirs of the Greek tragedies. The practice of resisting and constructing power in the margins by protesting against oppression and injustices afflicting women in particular, are central in *moirologia* (Alexiou, 1974; Caraveli, 1986; Seremetakis, 1991), as they are in Acker's "Eurydice". In *moirologia*, "[t]ime shifts back and forth from past to present from actual to mythic" (Caraveli-Chaves, 1980: 141), which can be seen as a queering of ideas of linearity and realist accounts. The *moirologia* incorporate social critique, the relationship of the deceased to those present at the funeral, fragments from the village history, dreams, mythological and religious references, as well as elements from the natural surroundings: stones, trees, animals, birds, which are ascribed agency. In employing all these different sources, "[t]he mourning ritual is embedded in polyphonic media: poetry acoustic effects, techniques of the body, vocal music, and the arrangement of physical artefacts as material narratives" (Seremetakis, 1991: 3).

Correspondingly, Acker's non-linear story blends a poignant critique of Western medicine and the thanatopolitics of Western culture, particularly afflicting (non-normative) women, Eurydice's relationship with Orpheus, citations of Plato<sup>23</sup> and Maurice Blanchot<sup>24</sup>, the mythological figure of Eurydice, other women dying marginal deaths, and Acker's own experiences, mixed with fantasies and dreams. She uses polyphonic media, too. Material narratives, namely, her drawings of the Underworld positioned in between her text (1998: 17, 21), as well as poetry/songs meant to be performed by Orpheus (*ibid*: 4, 9–10). She weaves in descriptions of landscapes of the Underworld and references to animals, as well. A wolf in the very beginning of the story who is "faithful to her" and "won't leave her" (1998: 2). Her stuffed animals, which Acker carried along in her many travels, now acting as a silent but emotionally engaged audience, witnessing what happens between YOU and OR, perhaps protecting Eurydice – "[t]he animals watch them" (*ibid*: 3); "[t]he animals are now still" (*ibid*: 2); "all the stuffed animals who, now like her, live in another world" (*ibid*: 4). Acker makes also symbolic references to death, such as winter and bare branches, symbolic imagery being a common practice in *moirologia* (Seremetakis, 1991: 47–61), and, at some point – which we shall discuss in more detail later in this chapter – she presents herself as a bear in a hole under the earth (1998: 16).

What stands out, nevertheless, as a major similarity between the two cases and as "Eurydice's" major difference to mainstream illness narratives, is the performative-political effort of the oppressed to queer the official discourse,

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<sup>23</sup> Acker states citing Plato that Orpheus may have ventured to the kingdom of shadows and death not to save Eurydice, but to be the only one among the living humans who has this experience and use it to elevate his art.

<sup>24</sup> Acker refers to Blanchot's essay "Orpheus' Gaze" (1982). Acker writes: "Maurice Blanchot says that Eurydice is the extreme to which art, Orpheus's art, can attain. What Orpheus wanted wasn't Eurydice, but that moment when he disobeyed the gods, all that he had been told, when he turned around and looked at Eurydice full in the face [...] For Blanchot, art comes out of such a moment. Everything must be sacrificed to that moment: seeing that which is hidden. Otherwise people don't exist" (1998: 23).

construct a language of resistance from the margins speaking back to the dominant centre, and make, out of their narratives, an instrument of counter-cultural power. This is a core function of counter-narratives (Bamberg and Andrews, 2004), a function which the *moirologia*, too, fulfil, through the lamenters' strategic handling and manipulating of tradition/given culture. The lamenters of the *moirologia* act, as does Acker, as "*bricoleurs*", who critically "alter the received story" (Pitchford, 2002: 61, italics in the original).

## I and YOU

As we have seen, Acker regarded the self as a product of culture that perpetuates structures which oppress and exploit those in condition of precarity and she challenged it in her writing. This challenge came about through a blending of her life experience with fiction, and also by mixing her voice with the voices of other marginalised women. Exploring role-playing, collage, and appropriation throughout her work, Acker was constantly "trying to become other people" (Acker quoted in Kraus, 2017: 145) giving birth to perpetually new images of self, new personas to perform, try on, reject, kill, and then copy-paste/parrot/assemble/collage some more. Identity is neither stable nor fixed for Acker and her characters frequently transform from one scene to the next, changing bodies, names, and genders. Acknowledging the connections of multiple elements constituting all that surrounds us, in *Bodies of Work* (1997b), she writes: "if there is a self, it isn't Hegel's subject of the centralized phallic I/eye. If there is a self, it's probably the world" (ibid: 10). In keeping with these dialogical modes and intertextual literary practice reflecting "the radical interrelatedness or intersubjectivity of the self and the other" (Rock, 2004: 191), Acker composes "Eurydice". In "Eurydice", she creates a powerful ritual of passage and an ethico-political experience of mourning forging bonds with other precarious women. With Eurydice being referred to as YOU throughout the text, Acker's story does not grant the reader the illusory luxury of imagining herself outside poisoning, Cancerland, death, dying, the grave. It is, at the same time, Eurydice, Acker, and the reader who, poisoned, descend in the Underworld.

Discussing "Eurydice", Claire MacDonald argues that "[t]he use of myth here is significant" because "it moves the narrative of a living figure into a place outside time, to that shared invisible world which in Western culture is still haunted by those ancient, pre-Christian dreams, the Greek myths" (1999: 107). This movement, together with Acker's multi-voice practice, is crucial in making her text speak on more than just the individual, one-perspective, one-life-story level, and address massive, systemic violence and injustices suffered by a multitude of Others who have faded away without speaking back. It somehow makes her the first (koryfaia) of an immense, dark chorus of dying and dead women speaking to us from a place of loss and dispossession but also empowerment, with their amplified, reverberating, thunderous voices of Greek tragedy: the Others and the repressed of the world, those whose existence has

been poisoned, like Eurydice, who was bitten by a snake, to finally be heard speaking from their own Underworlds.

This becomes most clear in the part of the story titled “Diary written by Eurydice when she’s Dead”, which blends Acker’s voice with the voices of fictional and factual others, killed by men: unnamed non-normative, non-grievable women of the Underworld (the murdered girls lying in dirt; Acker, 1998: 15) in the company of whom YOU traverses dark, surrealist spaces (1998: 15–18). She does so also in the company of the Russian poet Marina Tsvetaeva, whose rebellious and tortured biography is intertwined with YOU’s story (ibid: 19–20). As Dianne Chisholm remarks, and in what I regard as a collective, agonistic spirit of minoritarian activist resistance, “[b]eing dead, Eurydice breaks out of the ‘deathhouse’ that ‘rules had placed [her] in’ in life” and, from that vantage point, she examines “the mortifying girlkilling institutions of ‘real living’” (ibid: 50). “Mad”, “insane”, nurtured by childhood, feelings, her senses and dreams, and all that opposes normative ways of being, she passes through several deathhouses, such as “the courtroom of the dead” and “the school of the dead”: surrealist, memory-fantasy reflections of deathhouses of the Overworld.

The fact that she is not alone neither in the deathhouses nor in the grave, the fact that YOU and the murdered girls are an extricable part of her, is instrumental in making Acker’s critical, anti-authoritarian, textual passage from reality’s murderous structures to illness and from illness to death collective, and therefore transform it into a powerful political gesture performed by many more than only one. “Though intimate, her diary is not personal” (ibid), just like the myths of the classic antiquity, or the great Greek tragedies are not personal, but speak bigger truths recognized by the communities that have created them, or speak truth to power. That makes Acker’s “Eurydice” outgrow the category of autobiographical illness (and death) narrative, emerging as a performative-political expression of outcry and dissent, and as an agonistic protest of the revolting dying and the dead. This fact is instrumental in making her anti-authoritarian passage from reality’s murderous structures to death into a collective passage, and in transforming it into an activist, polyphonic gesture of mourning.

Polyphony, but also antiphony, manifest themselves in the Greek laments: the women’s mourning performances are never the product of one single voice. With polyphony, the lament comes to stand as co-constructed by many, while antiphony characterises its focus on dialogic interaction. One of the women acts as the leader of the group or *korifea*. In singing and in verses, she asks the other women questions, or makes statements they might confirm or deny, challenging the patriarchal order of the community and even influencing a certain state of affairs by giving guidance/orders to those present at the mourning ritual. Seremetakis compares this practice to the chorus and the *corypheus* (its leader) in Greek tragedy. She states that:

“Antiphonic reciprocity between women in the mourning ritual entails *the intensive interpenetration of collective and individual* poetic creation. In this framework, the lament performance, given the scope of its affective dynamics, cannot

be treated only as an individuated psychological or literary artifact. The construction of self and sentiment in the lament performance is *an ongoing social process*" (ibid: 3, my italics).

Granted, in "Eurydice" there is no actual presence of others. However, Acker's intertextual practice, her effort to step outside her identity into a shared space of resistance blending with other women – the fact that Acker, too, unites with the chorus, establishes a connection between "Eurydice" and the Greek laments. As in the *moirologia*, also in "Eurydice", the self is not fixed or finalized or independent from the selves of others; "the self is never complete, never consistent, and never a platform from which to comment on the world. It is an identity that emerges through the act of *writing*" (MacDonald, 1999: 109, my italics), which, to Acker, meant *dialogue* after her own fashion: through appropriation, collage, and the mixing of her writings with the writings of real and imaginary others<sup>25</sup> (see: Acker, 1997b: 10) to attack and denounce a tyrannical order that gives women no voice. In the section titled "Diary written by Eurydice when she's dead", Acker writes:

"Inside, two girls have just been murdered. I know this is true because when I look at them, they look like store-window dummies. Therefore, the same could happen to me or to any of the girls who are with me. The following's all that is known about this murderer: male [...]"

I guess we continued to travel farther, south, because now we're in the house of which the first was an image. I intuit, that is I know, that the murderer's here. My girlfriend is tall, solid physique,

straight brown hair in page-boy to shoulder. I watch the murderer kill her while she's lying beside me on a white-sheeted bed. "Now I know she was as good as dead before the murder began" (1998: 15–16).

In the Greek laments, the female protest against oppressive, misogynistic social structures in the androcentric village "recognizes a "sisterhood in pain" among women", and communicates "a sense of communal victimization", which takes a more open, direct and militant form than the subtler but equally poignant criticism we encounter in "Eurydice". In the case of the *moirologia*, it is clearly expressed

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<sup>25</sup> Regarding avant-garde, polyphonic practices, such as Acker's, Larry McCaffery in his article, "The Artists of Hell: Kathy Acker and 'Punk' Aesthetics" (1989), asserts that experimental strategies are necessary for women authors in order to express their lived experience (ibid: 217). He argues that traditional novelistic features (a character that makes sense, a coherent plot, an eventual resolution) "not only perhaps fail to provide a means to examine the nature of the female self but they imply that women's desires and the sources of their victimization can be "contained" and made sense of by the same procedures (logic, rational analysis) and by the same public discourse that have served our male dominated, exploitative systems so effectively" (ibid). Breaking the rules is, thus, crucial also because not doing so means siding with the dominant discourses (literary and otherwise) that have historically oppressed women. In this context, McCaffery points to the need for female writers to become literary criminals (ibid: 218) and identifies Kathy Acker as precisely one such notorious criminal in her employment of punk aesthetics in her radical work.

as “an invitation to communal grieving” making a gesture of activist public mourning (Caraveli, 1986: 182):

“Come women! Let you who are still untried, and us, who’ve  
known sorrows,  
Join together our tears, shape them into a river;  
And let the river turn to lake, to seashore, water fountain

Performer: Alexandra Tsoumani

Recorded by Anna Caraveli, Tsepelovo, Epiros, August 15, 1978” (ibid: 182).

The social protest dynamic of such public ritual performances has been researched, among others, by the folklorist Ilhan Basgöz (1982), who argues that this type of performative traditions do not resolve but exacerbate tensions, which can lead to social change. “Like other art forms such as literature, painting, music and the graphic arts, folklore functions to dramatize conflict, to encourage dissent, to cause disunity, and to rouse people to activism and even to press for revolutionary changes in the social system” (Basgöz, 1982: 6, cited in Caraveli, 1986). The Greek women lamenters in a circle, beginning from the event of an individual death, weave together with the plight of the deceased their own protests and grievances. The first lamenter sings while the others weep, wail, and moan, thus taking turns until the end of the ritual, which is steeped in intensity and deep emotional engrossment. The pagan elements of this arresting performative act are hard to miss, and that brings us right to the next section.

## The Punk and The Pagan

While mainstream breast cancer narratives often foreground the uncomplaining attitude of a winner who won’t engage in social critique (Nielsen, 2014), Acker adopts the punk movement’s aesthetics and forms, which, rejecting and subverting familiar discourses, were “perfectly suited to undermine the complacency of the dominant power groups that had marginalized its members’ lives” (McCaffery, 1989: 219). Acker turns her own experiences – of alienation, oppression, and abandonment – into a literary-terrorist attack (Milletti, 2004), just like the punks. She operates, as well, in her own lament, in a similar way to the *moirologia*, complaining, mourning, and bemoaning all the offenses and wrongdoings she had to endure.

The entire first half of “Eurydice” functions in precisely such a manner giving us (in-between the actual and the fictional) a “History of the Deceased”, which constitutes a full-blown protest against all that happened to her during her dealings with breast cancer medical care. A history of the deceased is also one of the first thematic units in the Greek laments that include a section describing actions that took place before death occurred, or the events that led to the death of the deceased (Caraveli-Chaves, 1980: 137). Significantly, this is a section which frequently takes the form of “protest against doctors and practices of

modern medicine” as shown in laments recorded by Caraveli in 1978 in Crete, communicating the lamenter’s “sense of impotence in the face of medical technology, as well as her disapproval of questionable medical practices” (1986: 183). Here are two brief examples:

“Ah, deeply pained child, I have loved you so much!  
They tore your belly open with their knives twice,  
Looking for the sickness in your guts, my white dove.  
But the medicines were drained, the healing herbs were lost;  
So they left your pain uncured, my small child.

Performer: Alexandra Pateraki  
Recorded by Anna Caraveli,  
Dzermiades, Crete, July 15, 1978” (ibid: 183–184).

“Ah, my beloved child, my only son!  
They were practicing their craft on you, my darling!  
They were practicing on you and learned their craft, my child.  
They learned about medicine my golden, my glad boy.  
Oh, they thrust their machinery inside your belly, child,  
And more machinery in your hand, my glad son, my king.  
They put tubes of oxygen through your nose, my darling,  
And fed you blood through the other hand, my king, my good son.  
Ah, how can I bear all these now, my child?

Performer: Tomais Veringou  
Recorded by Anna Caraveli,  
Dzermiades, Crete, July 15, 1978” (ibid: 183).

Acker in “Eurydice” follows a similar pattern letting us know what happened with Eurydice-Acker-YOU, while she was still alive, diagnosed with breast cancer, operated, and hoping to survive. In this part, the very beginning of the narrative, we see Eurydice at home, only five hours after her mastectomy, lying in bed, scared, in pain, and suffering a terrible nausea. We witness her meeting with her surgeon two days later, which turned out to be a very unfortunate encounter with Acker feeling insulted and infantilized and deciding to have nothing to do anymore with doctors. We are, then, taken along with her to the hospital on the day of the surgery that has, of course, preceded all we have read so far, a choice that disturbs linear time, something common also in Greek laments (Alexiou, 1974). We follow the entire torturous medical procedure, the stages of which Acker divides in three distinct sections: “the first station”, “the second station”, and “the third station (death)”, which is reminiscent of Dante’s *Inferno* and his own passage through different areas of hell. Waiting for the doctor at his office together with Orpheus two days after the surgery to hear the results, Eurydice is naked, which shows her emotional state, exposed and vulnerable in a terrifying situation, while Orpheus isn’t (1998: 5). Eurydice gets a chance to see

the doctor's face before he realizes he is already in the room, and she knows it's not good news.

"He composes his face. Now it's stunningly obvious that he looks like a movie star. He dresses conservatively. Since this conservatism doesn't hide, but rather enhances his good looks, he seems to be perverse. As this scene continues, he becomes more charming [...]

EURYDICE sinks down to the ground, the office floor. Into a child's pose [...]  
DOC: I must explain the situation to you. This is not a death sentence. You won't be able to comprehend everything I'm saying to you at this time, but let me explain... (He takes one of EURYDICE's hands and pats it in a fatherly way.)"  
(ibid: 5-6).

The power asymmetry here becomes immediately obvious. The doctor seems to be perceived by Acker as a grotesque figure, distant and submerged in his own superiority (he looks like a movie star... he becomes more charming), which, in the current situation, makes him look wicked, or as Acker writes, perverse. Acker, horrified, naked, sinking into a child's pose in front of the doctor, in a state of powerlessness. The paternal doctor, patiently trying to make her understand things that are most likely too complicated for her. Acker writes that at the doctor's office, Eurydice and Orpheus are in a cell "[b]arely large enough for ORPHEUS and EURYDICE's bodies" (ibid: 5). She must have been suffocating. Further on, in "the second station", as Eurydice is waiting in a wheelchair for the surgery, we read:

"A far wider hallway devoid of warmth. Of anything that makes life human. Everything, the color of lizards. Moving figures in pale, that is puke-green, who may or may not be human glide by YOU and OR and ignore them. Above, glaring lights dominate reality.

YOU (so cold that she snuggles under the blanket into the depths of the wheelchair and begins to accept the chair): I don't want to be here [...]

Another NURSE comes up to the wheelchair. All the nurses and doctors now seem to be the same cause they're all in pale or puke-green. YOU is on an IV which she hasn't noticed before simply because she hates it worse than the wheelchair.

NURSE2: We just have to... (Not too carefully, she winds scotch tape around YOU's earrings and the skin to which they're attached, around the motorcycle bracelet on YOU's wrist and adjacent skin, over the piercing on YOU's bellybutton.) We don't want anything that an electrical wire could touch. Is there anywhere else?" (ibid: 11).

In "the third station (death)", in which she has been moved into the operating theater, she reports more experiences of alienation and escalating horror:

"GREEN MOVING FIGURE (to EURYDICE as she's being rolled in): Take off your top gown and climb onto the table.

YOU does as she's told.

A GREEN MOVING FIGURE places thick straps around YOU's arms and legs, then fastens the buckles on the ends of the straps.

YOU: Why are you doing this?

GREEN MOVING FIGURE: We don't want you to hurt yourself during the operation.

YOU tries to understand.

A GREEN MOVING FIGURE places the suction pads at the end of electrical cables on her body.

YOU: What are these?

GREEN MOVING FIGURE: Electrical cables.

YOU tries to understand" (ibid: 13–14).

It seems to me that what Acker is telling us here is this: they told me I must have surgery and I was taken into a terrible place that had nothing to do with life as I know it. People didn't look like real people, and I was reduced into a thing on a wheelchair that I could hardly recognize<sup>26</sup>. I couldn't deal with any of them as an equal, and my only option was to be passive and docile. At the end, they even told me, in an awful way, that I might die. And before all that I was fine<sup>27</sup>. Acker expresses her opposition, her dissent, her discontent, in a performative way<sup>28</sup>, which is deeply intertwined with the political.

Her critique of necropolitical institutions and their oppressions continues in the section "Diary written by Eurydice when she's dead" where the "courtroom of the dead" and the "school of the dead", function as surrealist, Underworld representations of disciplinary structures that, in the world of the living, control and punish mostly non-normative people and women. Nurtured by childhood, feelings, her senses and dreams, and all that opposes normative ways of being, Eurydice passes through these deathhouses just like, while still alive, she passed through the deathhouses of the Overworld. In "Eurydice" – as Kathryn Hume points out in *Aggressive Fictions* (2012) in connection to all of Acker's writing – Acker gives us a story defined by frustration and intensity: a "*relentless articulation of discontent* [...] characterized by *strong emotive elements*" (Hume, 2012: 44, italics in the original). These emotive elements can be perceived as "whining", and might be hard to accept for those who value "positive attitudes" (ibid).

In this sense, and because of its protesting, emotional character – never aligning with normative illness accounts' patience, resilience, and self-control – "Eurydice" is reminiscent of the Greek laments associated with pagan-like

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<sup>26</sup> "NURSE: Stick out your tongue.

The thing under the cap sticks out its tongue" (Acker, 1998: 12).

<sup>27</sup> "YOU (interrupting him): Are you telling me I'm about to die? I was healthy as hell until you, or your gynecological colleague, felt that lump" (Acker, 1998: 6).

<sup>28</sup> The performative character of Acker's writing has been noted by many scholars and commentators of her work, such as Claire MacDonald (1999: 105), attesting that Acker "acknowledge(d) her debt to conceptual art, performance, film-making, and poetry" (ibid: 108), and Peter Wollen, stating that "writing as a performance form [...] stayed with her through every twist and turn of her career" (1997: 3).

practices of mourning such as wailing and screaming, pulling one's hair and scratching one's face. These mourning processes are so intense that "they were dealt with, in antiquity, by the institution of a separate set of laws "forbidding everything disorderly and excessive in women's festivals, processions and funeral rites"" (Alexiou, 1974: 15, citing Plutarch). What is more, docile Christian attitudes towards death conjecturing "a rewarding afterlife for the pious" (Caraveli, 1986: 184) and "preach(ing) patience, acceptance, and perseverance" are undermined and negated (ibid). This brief historical note indicates how different modes of oppression were overcome both by lamenters and by Acker in "Eurydice". In the first case, the prohibition of female protest by law, which did not manage to alter the character of the laments, and in the second, the prevention of unruly female emotions before these even occur, by the cultural enforcing of neoliberal subjectivities, "survivors" and "winners, which have no place whatsoever in "Eurydice".

## Queering Death, Dying, and Mourning

As already noted, in "Eurydice" we observe the same structure that Alexiou (1974) attributes to the genre of the lament: typically built on a pattern of oppositions and binary relationships regarding before and after, here and there, the world of the living and the underworld. But both in "Eurydice" and in the Greek laments these binaries – including the binary/boundary between the living and the dead – dissolve. In "Eurydice", we find the most important instance in the beginning of the section "Diary":

"It is Christmas Day when all the world goes under the earth. I live here. I'm a bear. I'm in a hole. There's a window that looks outside.

I'm a seedling. It's winter and all the plants are stripped. Whatever of them is able to rise above the earth waves branches in the air.

I am starting from nothing. So slowly" (Acker, 1998: 16).

In the excerpt above, Acker experiences life and power in her death; potential, and energy. She is still evolving, becoming, like the seedling, still capable of changing things. Her death is vibrant (Lykke, 2022: 247–249) and she preserves her ghostly agency, the in-betweenness of a spirit that cannot quite die, but haunts the living of the deathworlds above with her mourning song. She queers and decolonises death, dying, and mourning by moving away from binaries of "the same" (life) and "the other" (death), and "from monotopic imperial to pluritopic decolonial hermeneutics" (Tlostanova and Mignolo, 2009: 15), as she has always done in her work by rejecting the rational principles of the dominant centre, and by trying on marginal, "other" identities and voices, which positions her undoubtedly in the pluritopic. By planting this seedling of life right in the middle of her death story, she performs her own "epistemic and aesthetic (aesthesis,

sensing) disobedience: the disobedience of the other toward imperial designs of the same” (ibid: 20). Queering death here signifies “critically-affirmatively shifting the meanings of death [...] substituting conceptualizations and imaginaries of death as a final endpoint within a chrononormative linear temporality, and instead opting for understandings situated in geo- and corpo-political frameworks outside of Western modernity” (queerdeathstudies.net).

In the same vein and to similar effect, *moirologia* reject the notion of death as inescapable rupture or separation. According to the ancient cosmologies from which both *moirologia* and the myth of Orpheus and Eurydice emerged, not only the relationship between the dead and the living continues after death, but one fundamental function of the laments is that of facilitating this ongoing connection:

“laments bridge and mediate between vital realms of existence: life and death, the physical and the metaphysical, present and past, temporal and mythic time. The lamenter becomes the medium through whom the dead speaks to the living, the shaman who leads the living to the underworld and back, thus effecting a communal confrontation with death and, through it, a catharsis. In her capacity as a mediator between realms, the lamenter affects the entire community” (Caraveli-Chaves, 1980: 144).

In connection to this, one of the Greek laments I have come across in my research comes strongly to mind. A lament performed in the village Dzermiathes in Crete and recorded by Anna Caraveli-Chaves in “Bridge Between Worlds: The Greek Women’s Lament as Communicative Event” (1980). The lament was sung by Alexandra Pateraki on the occasion of the death of the midwife of the village:

“Ah women of Dzermiathes, weep! sing laments for her!  
She too gave you her words to comfort and to soothe you.  
Where are you women of Dzermiathes, decked out in your best clothes?

The midwife is going, who used to hold your children.  
Give her your forgiveness now, and give her your last word  
because she's travelling away and won't return again...” (ibid: 148–149).

What Caraveli-Chaves remarks in her analysis of this excerpt is interesting in the context of the dissolving of the death/life binary. She explains that “[j]ust as the midwife delivered their children to life, so should the community deliver her to death now, and become, in essence, midwives in their turn” (ibid: 149). Already the very phrasing of this sentence, and of course also the actions and processes it illuminates, blur the boundaries and meanings of life and death. If the women of the community need to “deliver” as midwives another woman to death, then maybe, as Acker, too, makes manifest in Eurydice, death is much closer to life than we are used to think<sup>29</sup>.

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<sup>29</sup> Nina Lykke in *Vibrant Death: A Posthuman Phenomenology of Mourning* (2022) looks at the myth of Orpheus and Eurydice regarding the life/death binary. She reports that “the wider

## Conclusion of “Eurydice”

Queering neoliberal agendas of story-telling and sense-making, and pointing to alternative, queerfeminist modes of writing, “Eurydice” materializes mourning in the context of breast cancer as an eloquent, ethico-political praxis against necropolitical institutions and their injustices. Following her punk, dialogic process, she questions individualist-neoliberal articulations of suffering, and establishes “subjectivity as a continuous process of production, transformation, and interconnection” (Rock, 2004: 191), forging bonds with other non-normative women. Choosing to use an ancient myth, and specifically the myth of Orpheus and Eurydice, she “moves the narrative of a living figure into a place outside time” (MacDonald, 1999: 107) which, together with Acker’s multi-voice practice, makes her story speak on more than the individual level, and address massive, systemic violence suffered by a multitude of others who have faded away without speaking back.

Functioning in ways similar to the counter-cultural, ritual practice of the Greek laments – from which she might have consciously or unconsciously drawn – and very different from the formulaic, individualist breast cancer narratives’ “triumph over tragedy” plot, Acker revives a paradigm of death, dying, and mourning made public and seeking social change. She moves close to pagan conceptualizations of death as agentic, communicative, and vibrant – as experienced in *moirologia* – and far from Western notions of it (death) as a static endpoint. She disturbs and queers binaries creating a powerful ritual of passage and protest from the margins that does not grant the reader the illusory luxury of imagining herself outside poisoning, death, dying, the grave.

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field of a-modern cosm-ontologies to which the Orpheus/Eurydice story belongs thrived as so-called fertility cults in early agrarian societies in the areas which today are defined as the South-Eastern parts of Europe and the Middle East. In these cultures, which have been studied as matriarchal [...] death figured in markedly different ways from those in which Christianity constructed it. Death was not a point of no return in the sense of a linear teleological trajectory, launching the human subject from an earthly life to a final endpoint in heaven or hell, as depicted in Christianity” (ibid: 243).

## CHAPTER 3. CANCER MADE ME A SHALLOWER PERSON

### Introduction

*Cancer Made me a Shallower Person: A Memoir in Comics* (2006), by Miriam Engelberg, is a work of graphic medicine<sup>30</sup>, an emergent interdisciplinary field that explores the potential of comics as a medium for communicating the experience of illness (Donovan, 2014; El Refaie, 2019; Squier, 2008), founded by Ian Williams, physician, artist, and writer. Its goal is to promote the expression of medical experiences in graphic form, to employ such graphic expressions as a tool for the education of health professionals, and to bolster the transformative power of graphic pathographies and their capacity to create communities (Czerwiec et al., 2015). In this context, the medium of comics is seen as quite pertinent for the purpose of sharing health experiences. As Susan Squier notes, comics “can show us things *that can't be said*, just as they can narrate experiences without relying on words, and in their juxtaposition of words and pictures, they can also convey a far richer sense of the different magnitudes at which we experience any *performance* of illness, disability, medical treatment, or healing” (2008: 131, emphasis in the original). By now, there is a considerable body of remarkable work in graphic medicine on the gendered embodiment of illness from a feminist perspective (DeShazer, 2005; Chute, 2010; Stoddard Holmes, 2013; Waples, 2013 & 2014; Sundaram, 2017), and as Hillary Chute remarks in *Graphic Women* (2010): “some of the most riveting feminist cultural production is in the form of accessible yet edgy graphic narratives” (2010: 2). In his chapter, “Comics and the Iconography of Illness”, in the *Graphic Medicine Manifesto* (2015), Ian Williams emphasizes the transformative, world-making power of comics, and how beginning from individual stories we can trace and influence broader structures and connections that pertain to the social and political organization of our societies. He understands graphic pathographies as offering an unofficial iconography of medicine, and underscores the power of change that is contained in the hybrid medium of comics, stating that “[i]mages do not just mirror the world; they help build it” (2015: 118). It is precisely on this world-building prospect of graphic memoirs that I will focus here examining Miriam Engelberg’s *Cancer Made Me a Shallower Person: A Memoir in Comics*.

Engelberg was an American computer trainer and programmer who worked in the non-profit sector and had always loved comics, known today for her best-selling graphic novel narrating her experience with breast cancer. Engelberg was diagnosed in the fall of 2001, when she was 43 years old, and started making her comics as she was waiting for the biopsy results. On the very first page of her book, we see that this is not a survivor’s story. In a brief five-liner underneath her picture, and right after the information on her other works in the genre of comics, we read: “She is survived by her husband and son” (2006, the page is not

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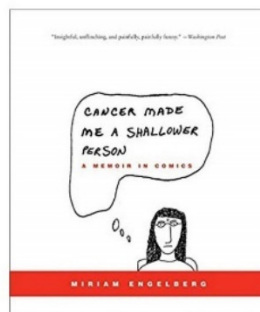
<sup>30</sup> A work in the field of graphic medicine can be both a graphic pathography and a scholarly text analyzing and promoting graphic pathographies.

numbered). Engelberg got metastases in her brain and bones and died five years later, a few months after her book was published. She had no formal training as cartoonist but she loved comics and had made more published comic strips in the past, relating her experiences of motherhood, as well as her office-job reality in the non-profit sector (<https://planet501c3.tumblr.com/>). Her graphic-narrative account radically differs from the conventional, hopeful, optimistic, and insightful breast cancer memoirs, as it is steeped in negativity, disobedience, irony, critique, and refusal to comply with the norms (Stoddard Holmes, 2013; Waples, 2014). It is a counter-narrative (Andrews, 2004: 1–2) full of humor and intelligence (DeShazer, 2013: 92–118), and a critically mordant investigation of the breast cancer social and medical landscape in the U.S., as Engelberg experienced it.

Creating comics about this experience was Engelberg’s lifeline and her way to cope with it. She used to go every day to a café for thirty minutes to work on her comic strips before she went to her regular office job, documenting in a personal and quite distinctive style (amateurish-looking black-and-white drawings, something that possibly the reader could also have done), the entire story of her illness. Her book, around 100 pages in total, is structured in a manner that follows the progression of the character’s illness and treatment, but is, nevertheless, fragmented: consisting of comic strips – independent stories, varying from one to four pages – not numbered, and each with their own title, presenting one aspect or event of the story (“Breast Cancer as a Hobby”, “Judgment”, “Hypochondria or Intuition?”). Many times, these short accounts in comic form function as proofs or testimonies of injuries inflicted upon her, as an ironic but serious indictment, which makes this memoir a minoritarian and activist work. Other times they function as reflections on and depictions of the artist’s engagement with people and things that gave her comfort or stimulated her in ways she could appreciate. Each of these short assemblages of pages, give the memoir a serial feel and Engelberg the opportunity to take an inquiring, satiric, and denunciatory stance towards each and every one of the situations she experiences, such as toxic positivity and compulsory spirituality, the cultural emphasis on individual responsibility, the expectation people have of breast cancer patients to be strong and brave warriors and learn important things about life, as well as the general tendency to look away from environmental-economic factors. This episodic structure, along with Engelberg’s overall persona (a character that does not evolve, and that remains, in important ways, a critical outsider) gesture towards the picaresque (Sieber, 2018; Garrido Ardila, 2015). A first-person narrative, typically structured in a chain of episodes each of which features adversity or confrontation for the main hero, the *picaro*, a trickster and outsider, who passes from situation to situation exposing hypocrisies and injustices, and trying to escape dangers and threats in an unsafe and hostile world (ibid). Engelberg, in her picaresque adventures, is, in a sense, compiling a file: documenting, investigating (Svirsky, 2010), perhaps partly with the activist goal of bringing evidence together to make an irrefutable point against the oppressive, dominant understandings of breast cancer in the U.S. today. However, the intertwining of these features with other elements, foreign to this genre, such as Engelberg’s keenly

introspective side and her need for belonging, gestures to an understanding of this work as a hybrid, bearing many picaresque features, as well as some Bildungsroman traits in connection to the main character, but not regarding her education/development, or the unfolding of the story.

This blending of generic elements is of frequent occurrence in narrative, and, as I shall discuss in this chapter, it does not interfere with the minoritarian character of Engelberg's work, which disrupts familiar stories, "codified by the cultural archetype of the survivor" (Waples, 2014: 180), and operates on a satiric and rebellious mode (Stoddard Holmes, 2013: 158). In *Cancer Made Me a Shallower Person*, Engelberg declares that she does not want to be transformed by her breast cancer, and certainly not in any popular culture way. She adamantly refuses to be a positive thinker, to be hopeful and optimistic, or to be a fighter and put on a brave face. In the same spirit as "the failures and losers, the grouchy, irritable whiners who do not want to "have a nice day" and who do not believe that getting cancer has made them better people" (Halberstam, 2011: 4), she emerges as an utterly non-heroic figure, negative, discouraged, and depressed, who will not "gain a deeper insight" from this experience, or have an epiphany of sorts, and come up with something profound about human existence. All these qualities, along with the artist's critique of the oppressions of Cancerland, constitute her work as a political gesture of activism. The fact, however, that Engelberg's comic book does not announce itself as such, the fact that it operates on a subtler and more nuanced register, abounding with humor, and bearing mixed traits, make it function in a minor key. And this is, as Erin Manning argues (2016), the weakness and the strength of every minor gesture. For the minor can be easily overlooked and for this reason is precarious, since, conventionally, we recognize much more readily the major gestures, those that are commonly classified as revolutionary and activist, and we tend to miss the minor ones, failing to perceive how through their coming into being they function to open experience to new forms and variations.



**Picture 9.** Miriam Engelberg and her graphic novel, *Cancer Made Me a Shallower Person: A Memoir in Comics* (2006).

In this chapter, then, along with the examination of *Cancer Made Me a Shallower Person* as a minor gesture of activism and as a counter-narrative, I make a case for the minor, or the micro-political: the small-scale that is generated out of a very specific, concrete situation in which people find themselves, as Engelberg found herself in a life with breast cancer. A case for the minor choices and performances; the local resistances; the various, dispersed micro-powers produced out of the encounter of bodies, ideas, and things. Micro-powers that concretely and intimately operate against the grain of the grand narratives. Under this light, I also look at Engelberg's memoir as a work of minor literature (La Cour, 2016), as defined by Deleuze and Guattari (1986), and I argue that it bears the features of such a literature, which I consider alongside specific examples from the comic book. Writers/creators speaking for a minority, like Engelberg, are, according to Deleuze and Guattari, most suited to produce minor literature (ibid: 16) and, by making use of "the same terms as a major (literature) but in a different way" they manage to stir up movement/difference/change "from within the major" (O'Sullivan, 2005: 105). What is more, Engelberg, working in the field of comics, takes advantage of the affordances of her medium to make language minor, and to convey minor political meanings, just like she does on the level of the content or the story – which, of course, in the case of comics, cannot be separated from the images. This way, Engelberg's comic strips emerge as a series of activist gestures, each one of them a site of dissonance, problematizing, critiquing, and denouncing what she sees as wrong-doing on the part of a society's established structures and norms, which is what Foucault has described as our "real political task": "to criticize the workings of institutions which appear to be both neutral and independent; to criticize them in such a manner that the political violence which has always exercised itself obscurely through them will be unmasked, so that one can fight them" (Foucault & Chomsky, 2006: 41).

Engelberg, does this by asking questions, such as: Why are there so many everyday involuntary exposures to chemicals that cause cancer (in water, food, pesticides, and so on)? Why people keep implying that it was my own wrong choices that brought this on? Why am I expected to be positive and cheerful, and urged to engage in spiritual practices (yoga, meditation, etc.) in order to feel better? By showing us around in Cancerland, she proves that, as Lochlann Jain remarks, "[t]he common sense notion that cancer is a name for cells that divide too quickly does not even come close to recognizing the world of cancer" (2015: 5). By failing to comply with the norms, she turns failure into what Jack Halberstam identifies as a powerful option of resistance to majoritarian behaviors that inhibit imagining "other goals for life, for love, for art, and for being" (2011: 88), and she takes us along to "all the in-between spaces that save us from being snared by the hooks of hegemony", even if these "alternatives dwell in the murky waters of a counterintuitive, often impossibly dark and negative realm of critique and refusal" (ibid, 2011: 2).

## In-between

One gets a rather accurate idea, regarding both Engelberg's character and the opposing tendencies at play, already from the introduction of her book. On the one hand, she strikes us as an introspective person; a thinker, really – sensitive and perhaps even a bit tormented. Pondering about the self that she is and experiencing discomfort or uneasiness being that self. Looking to feel more at home in the world and wishing to reach out and help by sharing her breast cancer story. Engelberg tells us about the creative projects she had been involved in, her attraction to comics, and starting to make her own. Then, her decision to have a baby and the way she experienced caring for her little boy. Finally, her breast cancer diagnosis when her son was only four. Towards the end of her introduction, she writes: “We all have issues that follow us through life, no matter how much therapy we've had. The big one for me is about feeling different and alone – isolated in a state of Miriam-ness that no one else experiences” (Engelberg, 2006: xiii). That is what pushed her, she explains, to read and write autobiographical comics, which will hopefully “be of comfort to other readers who might be struggling with issues similar to (hers)” (ibid).

On the other hand, and in the same confessional, self-reflective tone, she emerges as a creature of the surface who resolutely refuses to “go inward” resisting what she felt as a “pressure to become someone different – someone nobler and more courageous than (she) was” (ibid). Faced with a choice between depth and shallowness, she opts for the latter (ibid), stating that “maybe nobility and courage aren't the only approaches to life with an illness; maybe the path of shallowness deserves more attention!” (ibid). While having “always had a pre-occupation with figuring out the point of life” (ibid: xii), when the critical moment comes, she very consciously positions herself against doing that figuring out. The woman who in her youth had “pictured intellectual achievement as (her) reason for being” (ibid), now, with a breast cancer diagnosis, immerses herself in endless hours of cheap television programs. She writes: “They say hardship reveals one's true character, and it was clear right away that I wouldn't be the heroic type of cancer patient portrayed in so many television shows and movies. My immediate response was to spend a lot of time in front of the television. I didn't go inward, I looked for pop culture distraction” (ibid). Engelberg performs her refusal to look inward with an attitude that is simultaneously humoristic and very ironic towards the presumably acquired “depth” of feeling and thinking and finding the answers to all the big questions – ubiquitous in breast cancer culture. Satire is certainly her most powerful weapon in exposing and castigating all types of violence and wrongdoings. The last two sentences of her introduction read: “death, enjoyment, and suffering... as I get older I feel more uncertain than ever about the point of it all. Maybe someday I'll have something profound to say about these important issues, but right now I have to go – it's time to watch *Celebrity Poker*” (ibid).

We notice that in the first set of features summarized above, Engelberg seems to exhibit several of the Bildungsroman hero traits, and particularly those related

to individuality. A rich interiority, a soul-searching attitude, thinking seriously and deeply about her life, and mindfully positioning herself towards what happens to her, as well as acknowledging her existence in a broader world in which she belongs and to which she is eager to make a difference. Moreover, an ongoing inner struggle, an effort to delimit her personal boundaries and to create a space of her own from and through which she can communicate, belong, and make a meaningful contribution. However, the most important Bildungsroman trait – self-development, adjustment, and reconciliation with the world – is conspicuously missing. Engelberg will never learn precious lessons or evolve as a person in her “breast cancer journey”.

Then, in the next, and quite different, set of traits, we cannot fail to see Engelberg’s prominent picaresque side. In similar ways to the picaro, and contrary to the Bildungsroman hero, Engelberg is not concerned about reaching any sort of culturally defined so-called “balance”, or striving towards it (Moenandar, 2017: 5). The picaro – and, largely, Engelberg, too – will not set goals and work hard to achieve them nor will she do self-assessment, or self-management aiming to self-improvement. For the picaro is essentially a creature of the moment and of the surface, of what is at hand and of immediate survival. Engelberg, too, like the picaro, is in a sense a “trespasser”, a “trickster” and “shapeshifter” (ibid), who occupies a marginal position outside the social order, and finds herself in hostile environments leading “a hunted existence” (ibid. 6). Defined by her con-formity and marginality, her challenging the norms, exposing them, and destabilizing them with her acutely political satire, Engelberg is really close to the picaresque hero. In opposition to the Bildungsroman where we see integration, order, and harmony gradually establishing themselves as the story unfolds, in the picaresque – and in Engelberg’s memoir – the disharmony will remain and the picaro will learn nothing at the end of the story nor will she change her life.

As it becomes evident, despite Engelberg’s negative, uncompromising stance and her episodic narrative with no quest, no epiphany, and with a witty, ironic narrator, very similar to the picaro, her story is not a pure picaresque. For it abounds with antithetical tendencies, desires, and tensions between order and chaos, shallowness and depth, marking it as a hybrid that upsets the neoliberal logic of the majority. Considering Engelberg as a character through the genres of Bildungsroman and picaresque, the best description for her would be: a picaro with elements of the main character of a Bildungsroman. In multiple comic strips, we see her existing in-between opposite tendencies that constitute her precisely as such, with a marked propensity towards the picaresque.

Such hybridity is not uncommon. On the one hand, marginalized and oppressed groups (such as women, postcolonial people, and people of color) have offered alternative configurations of the world-view presented in the *Bildungsroman*, often critiquing and twisting the dominant mode of sense-making implied by this kind of narrative (Felski, 1989; Kaplan, 1992; LeSeur, 1995; Karafilis, 1998; Bolaki, 2011). On the other hand, as research in counter-narratives has shown (Tore et al., 2001; Bamberg, 2004; Frandsen, Kuhn, and Lundholt, 2017), tensions between antithetical elements exist frequently in people’s accounts, and

“critical stories are always (and at once) in tension with dominant stories, neither fully oppositional nor untouched” (Tore et al., 2001: 151). In this light, the hybridity of Engelberg’s memoir does not compromise the minoritarian, micro-activist character of the work, but rather reinforces it. For it makes manifest, in an honest way, the blending of different discourses and outlooks we all are, while at the same time offering alternatives for resistance “in real-life cases of narrative oppression, where dominant stories are imposed on us” (Moenandar, 2017: 2–3).

While Engelberg retains her Bildungsroman qualities, as noted above, she never follows the Bildungsroman plot neither does she evolve in a Bildungsroman fashion. She is vulnerable to the treatment that makes her sick and to the social and cultural attitudes that oppress, hurt, and offend her, but also detached, since she will not fully participate in what is happening, but will always take a few steps back and be a critical observer. She is at the same time in and out. Indifferent and mocking all the self-help platitudes, the mentality of overcoming, and the idea of changing one’s self. Yet, eager to connect and belong. In a narrative landscape infested by entrepreneurial understandings of personhood that, even in the face of death, discourage people from looking at the causes of cancer and keep them striving towards some imagined notion of self-improvement, she disturbs entrenched ideas and offers interesting alternatives.

## Examples

In what follows, I will present and discuss five sets of examples from *Cancer Made Me a Shallower Person* (2006): three that are more clearly of a minoritarian, micro-political nature, explicitly opposing the dominant models of being, and two that can be potentially received as siding with more conformist or majoritarian attitudes. By making this distinction, I do not want to imply that there can be a clear-cut categorization in Engelberg’s memoir that might allow us to distinguish between instances of minoritarian resistance at specific parts and of majoritarian complicity at others. The differentiation I make is more of a functional character. It serves as a starting point which will allow for a closer and more careful look, and it only conveys what seems to be a more dominant tendency in each of the chosen examples. This tendency might be blurred or undermined in the discussion that will ensue, or it might be confirmed and established as the primary function of the gag strip examined. In any case, Engelberg’s book surely honors hybridity in circumstances under which a seriously ill woman decided not to accept the norms of what currently constitutes a “sensible” state of affairs, and went on to carve her own path of resistance.

The examples I am about to examine address each a different aspect of life in Cancerland. They either explicitly target offenses and injustices, or begin as of a more mixed nature to then undermine any majoritarian traces and evolve into satire, or even stay, perhaps ambiguously, somewhere in the middle, leaving it to the reader to decide, always within the context of the entire work. Thus, in the

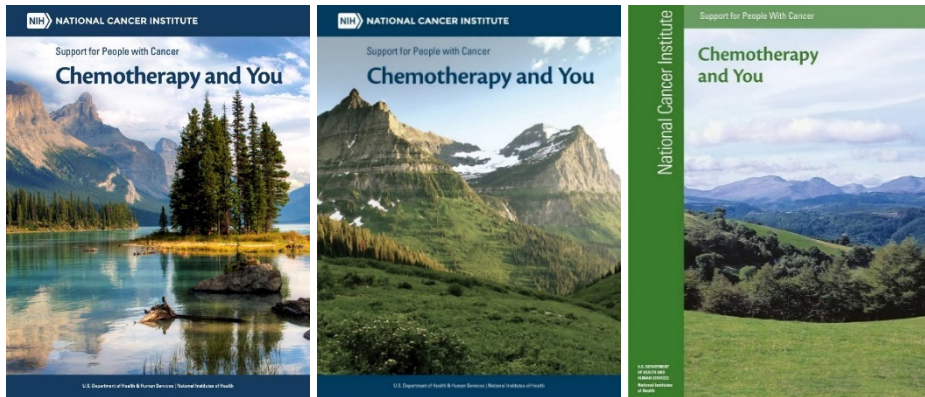
comic strips that I have selected, Engelberg attacks the toxic positivity of our culture (overcoming, gratitude for lessons learned, undefeated winner's spirit), present even in spaces where one would least expect it, such as a breast cancer support group. She makes into a target of her critique the hypocrisy of that culture which offers breast cancer patients supposedly easy-to-follow guidance towards healing while saying and doing nothing about prevention and the environmental causes of cancer. And then, on a different tone, intrigued by the possibility of trying out new looks, engages in wig-hunting, and cannot resist to make some hilarious jokes that only her, as a breast cancer patient, could have thought of. But let's get into it.

### **Toxic positivity**

In the gag-strip "Keeping Up with the Joneses", Engelberg starts in a quite positive tone: "My support group really helped keep my spirits up". She takes it immediately down, though, by adding: "until..." over the drawing of a bald woman sharing her experience with the group: "I threw up 30 times! At the hospital they couldn't find a vein for the IV". "But now", adds the woman in the next frame with a big smile on her face, "they've adjusted my medication and I'm fine!" To which Engelberg contemplates: "I felt I wasn't keeping up with the Joneses". Amazed, she ponders: "Wow – how can she stay so cheerful after all that? I was more depressed even before I had cancer!", and jestingly, but also bitterly, concludes: "I realized I needed a support group for my support group..." Looking out of the frame straight at the reader, she states in astonishment: "She throws up 30 times and she's still cheerful! I'm depressed just by being nauseous!" (underlining in the original). In the last frame of the gag-strip, another woman looking at Engelberg, thinks: "Wow – how can she stay so cheerful after doing chemo? I feel so inadequate", which makes the reader think that anyone should feel inadequate in these toxic and emotionally oppressive surroundings, unless they would hear other people speak their minds and share their objections out loud.

Another example is the gag-strip "Something Unpleasant and you", where Engelberg attacks the hypocrisy of our society and of the medical world in their choice to produce and disseminate among cancer patients educational booklets that present cancer treatment as something manageable, perhaps even almost rewarding. Regarding these booklets, Engelberg notes that "[t]he cover often features an illustration of a nature scene", and draws underneath this remark a booklet cover showing a dolphin jumping in the sea near a palm beach. To this, she wryly comments: "I was dreading chemo, but now that I can associate it with this lovely beach scene I'm looking forward to it!" Searching on the internet for "Chemotherapy and You" booklets, I came across the following three, made available by the National Cancer Institute, with nature scenes featuring in particular mountains, and giving one rather the impression of a travel brochure than of a document providing medical information about a serious health condition. Imparting, moreover, the understanding that one will be replenished and revitalized (which is not the case with chemotherapy), as well as – through

the symbolism of the mountain, I suppose – that these high peaks might not be for the faint at heart.



**Picture 10.** National Cancer Institute information booklets on chemotherapy, found on the internet.

But there is more to discuss when it comes to the Cancerland booklet world. In the next frame, Engelberg gives us a booklet cover with “insanely cheerful patients”: three women sitting around a table with their drinks – one bald, another with a headscarf on, the third one wearing a wig – and having, apparently, a blast of a time. “I always wonder what the patients are discussing so animatedly...”, she ponders, and she continues her exposition of the educational booklets’ manipulative absurdity by making further points through drawings, in a juxtaposition of their content and her own reality. Happy breast cancer patients around a cozy table with drinks versus Miriam, bald, alone, and crying. Breast cancer patient lying on a beach under a palm tree versus Miriam, bald, alone, at home, watching TV. Booklet info point stating, “With just a few simple tips you’ll feel good as new” versus Miriam’s booklet points stating, “I feel lousy. What’s the point of life and death? Woe is me”. In another frame of the same strip, she suggests that at least an exclamation mark should be added to the “cool and calm” booklet statement, “You may experience some nausea during chemo”. She would phrase it differently, too: “You may experience horrible, debilitating nausea during chemo!” This two-page gag-strip, in only twelve frames exposes and castigates expectations and claims made of breast cancer patients to believe what they are told – that this situation is endurable, and full of precious moments of bonding and togetherness. People are turned into zombies this way, Engelberg comments in her final frame of this gag-strip, where she depicts herself addressing the reader with a very bright smile: “Exercise can help radiation fatigue. Ginger tea cures nausea”, while her husband with a puzzled expression on his

face, eyebrows raised, asks her: “Why are you talking like some kind of Stepford<sup>31</sup> cancer patient?”

In both these examples, Engelberg poignantly critiques the neoliberal, breast cancer culture of heroic resilience and positive spirit, in the face of all suffering, where people are supposed to be ready to manage challenges of whatever caliber, to successfully overcome difficulties, and be prepared and eager to accept the next dare. Protesting, complaining, and feeling angry or depressed is hardly tolerated in the context of the breast cancer cult. As Barbara Ehrenreich (2001) asserts, “[i]n the mainstream of breast-cancer culture, one finds very little anger, no mention of possible environmental causes, few complaints about the fact that, in all but the more advanced, metastasized cases, it is the “treatments,” not the disease, that cause illness and pain” (Ehrenreich, 2001: 48). Against what one would expect, the attitude of the women is “more commonly grateful; the overall tone, almost universally upbeat” (ibid), while they often perceive cancer as a gift and an opportunity to improve themselves and change their lives. This is a local manifestation of a much broader phenomenon. For “[i]n contemporary Western culture, we are encouraged to think of our lives as coherent stories of success, progress and movement. Loss and failure have their place but only as part of a broader picture of ascendance. The steady upward curve is the favoured contour” (Stacey, 1997: 9). Engelberg, evidently, shares these concerns, and makes a point out of raising her dissident voice, with echoes and variations of the thoughts and feelings described in these particular comic strips abounding throughout the entire book (see for instance, “Waiting” and “The Cheerful Tech”).

### **Environmental causes and individual responsibility**

In the gag-strip “5 Ez Steps”, Engelberg takes on the persona of a TV hostess reminding us of certain activists who draw people’s attention to injustices by “satirically impersonating their enemies” (Day, 2011: 1). She is sitting next to a stack of books titled: “The No-Food Diet”, “Toxins and You”, “Be Afraid!”, and “Be Very Afraid”, confidently smiles and asks her audience: “Want to avoid a recurrence of your cancer? It’s simple!” And goes on to give five pieces of advice that, in the contemporary carcinogenic world, are almost impossible to implement. By doing this, she mocks the entire a-few-simple-steps, quick-fix culture which treats highly complex, multi-factor issues with infuriating hypocrisy, giving outrageously provocative advice to people at risk of dying. She also addresses the all-pervasive “you-can-do-it!” spirit, and the neoliberal, corporate, and even scientific readiness to put the responsibility on the individual and to negate all claims that environmental causes need to be seriously examined and acted upon. Her satire targets the promotion and diffusion of precisely such culturally mediated responses to breast cancer patients, adding insult to injury.

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<sup>31</sup> Reference to the film “The Stepford Wives” (1975, 2004), based on the 1972 novel by Ira Levin, in which smart, independently-thinking women, once in the town of Stepford, turn into meek, smiling housewives, at the service of men. “A novel so frightening in its final implications that the title itself has earned a place in the American lexicon” (www.goodreads.com).

First step is: “Eat right”, followed by the remark that “Studies have definitively shown that diet may possibly decrease cancer risk... maybe”. Despite the apparent uncertainty of the results of those studies, the artist does try, but it is more of an ironic scenario, a role-playing demonstration, to actually show the impossibility of this “easy step”. For this purpose, we see in the same frame Engelberg-TV hostess or Engelberg-convinced subject at her kitchen table with a plate of food, pot, and open book in front of her. The book is titled *The Dread of Cooking*, and Engelberg informs us that the food is called “omega fatty acid and flaxseed delight”. Her point is that in the contemporary context of (highly) unsafe products/recipe ingredients sold at the super-markets, it seems that one, if willing to follow this “scientific” advice”, must engage in a lab-like process of creating dishes resembling less real food and more a coming-together of nutrients that might, maybe, protect us from cancer. She makes a similar point in the gag-strip “Diagnosis”, where, pushing her supermarket trolley, looks around and ponders: “Vegetables are healthy, but these aren’t organic. Fish contains toxins from pollution. Meat has hormones. Dairy is supposed to be dangerous. Fat is bad. Sugar is harmful. White flour lacks...”, concluding that “The only safe solution is to stop eating!” She gets to the cashier with just a small bottle of water in her hand, only to remember that “Uh oh, did I read that bottled water can have high levels of arsenic?”

Back to our “easy steps” now, and the second step is, “Be cheerful”, accompanied by the, again, scientific-sounding statement that “Depressed women have been shown to be at higher risk for breast cancer”, which is one more opportunity for Engelberg to protest against “the tyranny of cheerfulness”, as Samantha King calls it in *Pink Ribbons, Inc.* (2006), published in the same year as Engelberg’s graphic novel. Lying in bed, Engelberg’s avatar thinks, “Maybe I caused my cancer by being depressed... That’s so depressing”, which shows that someone could very well find themselves trapped in a destructive loop, should they believe that being depressed could be a real cause for their cancer. It functions, moreover, once again, as commentary on neoliberalism’s faulty assertions that one’s well-being/happiness/prosperity is up to their own free will, finding expression in mottos, like: “Good things happen to good people”, or in suspicious questioning, like: “Maybe you didn’t try hard enough?” Respectively, in the gag-strip “Judgement” we see Engelberg held accountable for the amount of sugar she consumes and interrogated on whether she exercises – queries always introduced by the clarifying remark that there is no judgment or blame intended by her inquisitors. Engelberg’s irony is employed once again, as she goes on to confirm that: “After all, women with breast cancer are known for their risky lifestyles [...] (and) “reckless choices” – buying non-organic food because it’s twice the size for less than half the price of organic, having “a glass of wine with dinner every night”, and deciding to skip the symphony (despite the scientific research that has revealed that attending cultural events decreases the risk of getting breast cancer!), and “stay at home and eat conventionally grown strawberries”. Women who get breast cancer, Engelberg concludes, will just not listen to the good advice of all the well-meaning friends and acquaintances, and, “bent on self-destruction”

as they are, will not follow a set of simple commandments – which turns out not to be simple at all. Susan Sontag in *Illness as Metaphor*, among many other understandings of illness, deals with the notion of illness as deserved (1983:43). In connection to will power, and having caused one’s own disease all by one’s self, along with a plethora of other sources, Sontag cites Schopenhauer: “The will exhibits itself as organized body, and the presence of disease signifies that the will itself is sick” (ibid).

Then, step three, instructs: “Avoid places with those cancer warning signs”, underneath which there is a hospital area with the warning sign: “This area contains chemicals known to cause cancer”. A very baffled Engelberg staring at that sign, wonders: “Uh Oh... Do they make home visits for surgery?”, thus, pointing out that involuntary exposures are inevitable. How can you avoid it if you have to be there? If such are the spaces and options your society offers for medical treatment? It does not stand to sense to pretend that people’s safety is under their control and advise them to avoid toxic, carcinogenic chemicals and places as though it were something they could easily do.

Asking people to preserve themselves from cancer in a world where toxic substances are practically everywhere (where there are signs indicating this and where there are not) is already bizarre, to say the least. But if beginning to wonder whether things can get any more absurd, readers should just wait for step four: “Don’t drink water”. In the frame, we see Engelberg with a cactus plant in front of her, sharing with us some modern-day facts and the desperate-crazy solution she has come up with, in the face of these facts: “Tap water is full of chemicals, well water has pesticide run-off and bottled water contains toxins from plastic. That’s why I only drink liquid squeezed from cactus plants”. The outrageousness of such a solution aptly reflects the outrageousness of our neoliberal consumer culture that asks people to be responsible for their health while next to nothing is done to control the vastly spread damage this culture has caused on the environment and on all natural resources basic for life.

In the very last frame – carrying a backpack, cactus plants in the background – Engelberg has ironically decided to follow the fifth step, too: “Move away”. She looks at us again and says: “Obviously there was something carcinogenic in my environment, that’s why I’m moving to the desert!” However, right next to her and hard to miss, is a sign post stating: “Nevada Nuclear Test Site 3 Miles”. No escape available, therefore, and not a single spot left uncontaminated. Such a critique we never get to see in the majority of mainstream cancer narratives where cancer seems to be one’s own lot (as pointed at, as well, in the comic strips “Judgment” and “Family History”), one’s own personal battle to win or lose, and often-times even something that the sick person herself might have caused.

### **Compulsory Spirituality**

Spirituality gets a lot of Engelberg’s attention at several points in the book, but the artist gives it a special response, as well, in the homonymous gag-strip. There, as always, tongue in cheek, she assures us that for her it was a matter of bad

timing. She had, unfortunately, already used up all her spiritual awakenings at a young age and now it is not possible anymore for her to get back to it. At her support group, there has been talk about spirituality, and several women said they got a lot out of meditation and visualizations. That, however, did not seem very likely for Engelberg who had “been trying to develop some sort of spiritual practice” even before she got breast cancer, but without success. After having considered and rejected several options (from praying to meditation to journaling), she ends up asking herself: “Hmm, I wonder if I could develop a spirituality of TV watching?” What a terrible situation, she remarks. To go now, that she finds herself in urgent need of inner strength, right to the opposite direction! It is really quite strange, particularly given her background: “I have a master’s degree in Theology! I used to do centering prayer twice a day, for God’s sake!” What went wrong? It was then that it dawned on her: “I’d done it all backward; I’d had my spiritual adventures in my youth, and now I was jaded”. In the hilarious frames that follow, Engelberg depicts herself giving advice to a young man who is meditating on a mat, urging him to think of his future and of the day when he will really need a spiritual awakening. He shouldn’t use it up too soon. “When I was young I recklessly pursued enlightenment as if there were no tomorrow... [...] Don’t do things in the wrong order! Save your awakenings for later in life when you’ll really need them”. Had she done things in the right order, she would be now in position to say: “This is horrible! How will I cope? Hold on – this is my chance to turn my life around – to look inward and find out what’s really important!” (underlining in the original). Engelberg’s irony towards the supposedly enlightened state of the breast cancer patients who have been deepened by their experience dominates every frame. She did have a revelation, though, she admits. Clutching tight against her chest *Entertainment Weekly* and *TV Guide*, she glances determinedly at the reader, a resolute frown in her eyes, and declares: “I’m sick of always trying so hard to do the right thing. I don’t feel like sitting quietly and praying or meditating, so I’m not gonna!” She decides to make cartooning her spiritual practice instead, and goes every day to a café to draw for half an hour. Similarly, in the gag-strip “Stress”, she addresses the reader from her bed – TV on, remote control in hand, winter hat on her bald head –

“Yeah – I know, I should be meditating and journaling and reflecting... but I don’t feel like it. I’m still waiting for some kind of epiphany so that I can use illness to turn my life around. But in the meantime I’m just going to watch “Judge Judy” and read a magazine”.

These are just a couple of the many moments of *Cancer Made me a Shallower Person* when Engelberg refuses to conform to what seems to her as fake spirituality, to believe that the majority knows better, and to buy what they’re selling her – and that is something we very rarely get in breast cancer narratives.

## Looking Good

Although Engelberg's overall attitude is definitely uncompromising, and with a distinctive micro-activist tone, there are points in her narrative where one might surmise that this is not the case all the way. Interestingly, and despite or along with her critical approach, Engelberg has moments when she acts in what could be considered as a more majoritarian fashion, and in ways that might resemble mainstream approaches to breast cancer, as these are encountered in conventional memoirs. We come across such instances in the gag-strip "Hair", where Engelberg enjoys trying out different types of wigs and experimenting with her looks, and in the gag-strip "Hilarious Never Before Heard Jokes", where she seizes several opportunities in the context of her cancer treatment to make funny jokes.

The gag-strip "Hair" begins with Engelberg going, a week after surgery, to Supercuts, her hairdresser's salon. Her hair had been "looking bad for awhile", but when she tries the products the hair professional recommends she finds he was right: her hair now looks amazing. After that, she had to meet her oncologist, though, who informs her that she will start chemotherapy and her hair will fall out. Engelberg is very disappointed. "Oh no!!", she exclaims, "I just found the right shampoo-conditioner combo!". Still, she is rather comfortable with the idea of losing her hair. Over a cup of coffee with a friend, she says: "It'll be OK. I'm going to buy some fun wigs", to which her friend replies, "Just think – it's your chance to go blonde!"

A short haircut before her hair starts falling, and off we go trying to find the right wig. The first failed attempt (wrong store, wrong salesman) is succeeded by a more fortunate one: "After my hair started falling out, my friend Sherri shaved it down to a buzz cut and took me to a wild store on Haight Street". There, Engelberg finds a bright, blue wig, which looks great on her and which everyone loves – she gets lots of compliments from her friends and even attention from random people on the street. She makes more purchases, later on: two wigs from the hospital store in which she "never felt right", and a red and very pretty one, again from the store on Haight Street. Engelberg loves that wig which "didn't stand out like the blue one" but was definitely a big success. Again, people at restaurants and bus stops comment on her lovely hair: "And everyone told me I looked like a natural redhead..." When out for drinks with a friend, she gets: "With your light skin and freckles, that color totally suits you!" She is extremely content. At which point, her irony strikes again, and she starts mocking and undermining whatever trace of complacent femininity or smugness had been generated by her "Hair" adventure. Most importantly, she dispels any notion that she is now re-inventing herself; that she is seizing this opportunity, granted by cancer, to transform and give her life its truest, most suitable shape. "Obviously I'd been living with the wrong hair color my whole life. Now I could become the person I was always meant to be", she sneers. Under this, she draws herself with the beautiful red wig on, sitting at a bar, smoking, drinking, and casually addressing the bar tender: "Another Manhattan, George. Just add it to my tab". In the next frame, she is skydiving (red wig still on) with a cigarette in one hand and

a cocktail in the other, shouting, “Yee-ha! I should have done this years ago!” In yet another frame (red wig always on), she stands at a podium addressing her audience: “I’ll start by reading from my bestselling memoir. In this chapter, I’ve just entered rehab in Malibu”. In the last frame of the strip, we see Engelberg back at home. Looking at us, she affirms, “Yep, things are going to be great!” However, she does so as she takes her lovely red wig off to place it on her drawers chest, letting us see her head, completely bald, and reminding us once more exactly what things look like right now, pretty and fun props aside. She is very well aware of it and knows that nothing is finished or secured yet.

### **And She Cracks Another One!**

Another instance when Engelberg assumes an easy-going and rather open towards the situation attitude is the gag-strip “Hilarious Never Before Heard Jokes”. In the first frame, she is sitting with a couple of other women, having drinks: “...So then I said, “My haircut? Oh that’s courtesy of chemo!”” The women laugh and one of them responds: “I never would have thought of that!” (underlining in the original). In the second frame, Engelberg is with a medical professional who is just about to prepare her for her treatment and she cracks another one: “Tattoos for radiation, huh? Could you make mine a rose?” (underlining in the original). Bursting into laughter, the man blurts, “No patient has ever said that before” (underlining in the original). Then, we see her at the oncology pharmacy getting her medication. As the pharmacist is handing her a small bottle, Engelberg exclaims: “Oooh... Ativan. Cancer has its perks!” and the giggling pharmacist says she needs to “get a notebook to write that one down”.

This joking attitude, which finds expression in more of Engelberg’s comic strips – although definitely not always in a light-hearted way but mostly rather in a satiric, mordant way – could be viewed as ambivalent. One could possibly suppose that she is actually enduring what is happening to her with a smile, or that she tries to be brave and “think positive” and look at the funny side of things even in the bleakest of life scenarios, such as getting breast cancer. Of course, that would make *Cancer Made Me a Shallower Person* a generic illness narrative. One more of the standard, feel-good, life-affirming memoirs that are widely circulated applauded for their successful take of the neoliberal rhetoric of the self. Could such a case be made for Engelberg?

Judy Segal, in her article “Cancer Experience and its Narration: an Accidental study” (2007), asserts that indeed this is the case and that despite being “funny”, “irreverent”, and “self-deprecating”, “Engelberg’s book reveals many of the features of the standard breast cancer story” (Segal 2007:15). It is, moreover, “self-congratulatory” insofar as “it cannot help but praise itself for its own sense of humor, for humor is claimed in personal narrative as a moral choice” (ibid). Segal concludes that Engelberg “writes a ‘be like me’ story too” (ibid. 16), which could not be considered as minoritarian or as offering a real alternative to the survivors’ formulaic narratives. In yet another article, Segal maintains that Engelberg embodies a persona that re-inscribes what mainstream narratives do but “sideways”

and that “in promoting the figure of the cancer-patient-with-a-sense-of-humor the book shares some of the coercive quality of other cancer narratives. People, especially women, with cancer are exhorted in public discourse to be positive, strong, attractive, sexy – and funny” (ibid. 294). Although this last remark is generally true about the cancer memoirs that proliferate today, it is hard to see how this is the case with Engelberg. At no point in her book does she pose as any of these things, apart from funny, and then still I would argue that she does not *pose* as funny – she *is* funny. Most importantly, her humor, her funniness, operates in different ways and on different registers to accomplish various functions that pertain to significantly more than merely her own person, or projecting herself as a smart and funny breast cancer patient who essentially tells us: “I haven’t lost my sense of humor. (I am pretty great)” (ibid). But let us have a closer look.

## The Satirical and The Lyrical

Engelberg positions herself outside the normative models of socially approved breast cancer performances right from the outset of her memoir. She is outside the neoliberal, Bildungsroman narrative plot, and she fixedly remains there. If she treats things with humor, this happens for a variety of reasons and purposes. To begin with, this is her way to cope with an unbearable experience. Her “lifeline” (Engelberg 2006: xii), as she tells us in her introduction, was, to an extent, drawing her comics, and her humor was part and parcel of this comics. It was, in fact, an essential element of Engelberg as a person. It had already manifested itself in her as an artist who did stand-up comedy based on autobiographical material. It was also one of the things that appealed to her strongly when she first started reading autobiographical comics: “I’ve always enjoyed memoirs, but there was something about the way Kuper<sup>32</sup> turned moments from his life into cartoons that I found both hilarious and touching. He wasn’t afraid to laugh at his own foibles, and the self-deprecating tone struck a chord with me” (ibid: x).

What is more, Engelberg’s humor is never the I-will-get-through-this-with-a-smile-on-my-face-and-good-cheer kind of humor, but quite the opposite. It is against cheerfulness, against optimism: ultimately, against doing what they expect you to. Her humor is negative, bitter, sarcastic, mordant, ironic, satiric, and wry. Engelberg uses this humor not only to cope emotionally, but also, and predominantly, to resist to narrative pressures and to castigate oppressions and injustices, and surely not to tell other breast cancer patients to put on a brave face and be pleasant and funny. This is a well-known function of humor and well-researched, too, in widely varied contexts. From the 2016 presidential elections in the US, to protest graffiti at the Gezi park in Turkey, to examining pathology and deviance from a ludic perspective, to anti-racist comedy (Kersten 2019;

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<sup>32</sup> Peter Kuper is an award-winning American illustrator and alternative comics artist. Kuper is best known for his autobiographical style and for his political and social commentary.

Yanik 2015; Cardena and Littlewood 2006; Weaver 2010), and many more. Engelberg's humor operates in similar subversive ways. Theorists such as Emily Waples (2014), Martha Stoddard Holmes (2013), and Mary DeShazer (2013) find that it functions as a tool of disobedience and have highly praised it. DeShazer argues that it is "rebellious", operating in a way that "deflat(es) the culture of optimism" (2013: 92), and combining "self-deprecation" and "cultural critique" (ibid: 103). Waples asserts that Engelberg "extends the generic logic of the cancer narrative" and "brushes against the grain of the breast cancer memoir" (2014: 176). And Stoddard Holmes appreciates the ways in which the artist resists accepted notions "of illness and disability as bleak and deeply ennobling conditions, most often operating in a satiric mode" (2013: 158).

This overarching satiric mode enables Engelberg's socio-political, socio-cultural criticism, which is one of the dimensions of satire (Griffin, 1994), and rather its core, fundamental dimension and most defining trait (Boler, 2006; Baumgartner & Lockerbie, 2018; Sweigart-Gallagher, 2019). As McClennen and Maisel confirm, "[s]atire speaks truth to power and it does so in a way that demands critical thinking and creates community, while entertaining us and inspiring us. Its wit allows us to avoid falling into cynical apathy or downright depression; its exposure of social flaws helps us open our eyes and become more aware; and its style can coax a broad audience to question the status quo" (McClennen and Maisel, 2014: 190).

In her comic strips, Engelberg, like a good satirist, exercises such a "rhetoric of inquiry and provocation" as she "raises questions, provokes doubts, and draws attention to social problems" (Tang & Bhattacharya, 2011: 2). She targets taken for granted assumptions, neoliberal common-sense thinking, power and influence. She persistently points to political and cultural failings through humor and irony in ways that arguably show her memoir to be a clear "site of resistance to cultural and political hegemony" (Connery & Combe, 1995: 11). And it is all the more relevant that precisely such work is done in the accessible form of a comic book, since "it is in the everyday iterations of popular culture where the battle over hegemony is continuously waged" (Day, 2011: 21).

This argument is in line with what Richard Delgado claims in "Storytelling for Oppositionists and Others: a Plea for Narrative" (Delgado 2000), where he maintains that ideology works through all kinds of narratives that make oppression pass while not looking like oppression at all (2000: 62) and he makes a plea for counter-stories that "can shatter complacency and challenge the status quo" and which "are frequently ironic or satiric" in character (Delgado 2000: 61; see also McKenzie-Mohr and Lafrance, 2017). Significantly, Delgado refers to the picaresque as an example (2000: 61), which further supports the case for Engelberg's comic book, to the defense of which comes, as well, James Phelan (2020).

In a chapter titled, "Irony, Ethics, and Lyric Narrative in Miriam Engelberg's *Cancer Made Me a Shallower Person*" (2020), Phelan addresses precisely Segal's objections to Engelberg's memoir. He begins by warning that "we should be cautious about assessing individual narratives in terms of a priori political conditions about what those narratives should and shouldn't do" (Phelan, 2020:

312), and proceeds to examine the ethical dimensions of Engelberg's "diverse irony" (ibid: 313) and "her use of serial narration to construct an innovative hybrid lyric-narrative form" (ibid: 312). Phelan presents and analyzes specific examples from the book, beginning from the introduction, with the clear intention to articulate a different perspective to that of Segal and more in line "with other appreciative treatments, especially those of Martha Stoddard Holmes, Emily Waples, and Mary K. DeShazer" (ibid).

However, a few pages later, while discussing Engelberg's visual style, Phelan seems to share part of Segal's point. Surely not the siding-with-the-master-narrative part, but the I-am-great part. He writes: "Engelberg can also use her visual style in combination with the verbal track for a range of non-humorous, even deadly serious communications. In addition, she can use it to fluctuate between the humorous and the serious on the same page. And of course, she can use it to communicate the message that Segal attributes to the memoir: I haven't lost my sense of humor (I am great)" (ibid: 315–316). This tendency seems to be a component of the memoir which, nevertheless, does not define its character, since Phelan concludes:

"As these analyses suggest, Engelberg is very much the cancer patient with a sense of humor, but she harnesses her diverse ironies not to indirectly assert her own greatness but to honestly explore the ethical and experiential dimensions of her experience and to do so in ways that lead to ethical critiques of aspects of that experience, including the pressure of the master narrative. These ethical critiques undergird her political stance against that master narrative. These conclusions suggest that Segal should recognize Engelberg as an ally rather than another perpetrator of the master narrative" (ibid: 320).

We understand, then, that perhaps at times Engelberg does perform a persona who thinks, "I am so funny and great", but that this – and telling other women to be like her – is very far from being the reason why she created her book. It is, moreover, very far from expressing her ethico-political position. A position, which, as her irony and social critique proves, covers areas much bigger than such self-centered concerns. A self-congratulatory tone, which one might detect at times, expresses rather an "and... and" quality, which exists in all narrative without compromising the minoritarian character of a counter-story.

In connection to the particular case of satire, such an element has been discussed before in scholarly research as one of its potential dimensions. For example, Dustin Griffin's analysis of satire casts it as a rhetoric of "display and play" (Griffin, 1994: 71–94), which can "win the admiration and applause of a reading audience not for the ardor or acuteness of its moral concern but for the brilliant wit and force of the satirist as rhetorician" (ibid: 71). As Tang and Bhattacharya write, "[s]atirists play with words and ideas and enjoy it. Perhaps they enjoy displaying their brilliant wit even more" (Tang & Bhattacharya, 2011: 1–2). Griffin refers to Northrop Frye who makes a distinction between ornamental and persuasive rhetoric (Frye, 2000 [1957]: 245). The first type leads people "to

admire its own beauty or wit”; the second “tries to lead them kinetically toward a course of action” (ibid). Frye, however, does not seem to share Griffin’s reluctance regarding satire’s political power, as he (Frye) defines satire as “militant irony” the “moral norms” of which “are relatively clear” (Ibid. 223). “Two things”, states Frye, “are essential to satire; one is wit or humor founded on fantasy or a sense of the grotesque or absurd, the other is an object of attack” (ibid: 224).

In Engelberg’s account all the above are present to perform a minoritarian, micro-activist gesture that does not deny its sprouting out of a specific, bigger, and variegated pool of stories. Moreover, one that “plays and displays” different tendencies without forgetting or betraying its goal, which is, ultimately, to expose and castigate oppression and injustice. And finally, one that, instead of trying to lure its readership into accepting neoliberal logics of selfhood, rather reaches out in an effort to potentially inspire solidarity and create “oppositional counter-publics” (Day, 2011: 14), as Engelberg intimates in her introduction, and in this way to foster “a community in opposition” (ibid: 13).

### **Writing-and-Drawing in a Minor Key**

To sum up what I have discussed so far, at the same time as being an anti-hero and an oppositionist – depressed, stubborn, and militant, with a very critical attitude – Engelberg is also a person who is very much fun-loving and “shallow”, when that can be on her own terms and not in any socially prescribed sort of way. That is what urges her to indulge in trying on all those wigs and in playing around with different looks for herself. She did not do this to be sexy, nor to explore different, never before tried paths in her femininity (we see no such tendency anywhere in the book), nor to re-invent herself. She did it, like with some of her jokes, because it was fun, pure and simple fun – it was something in the here and now, and it was also a very much-needed distraction. She did it because she decided it was a pretty cool idea.

Other women activists would not do it. Barbara Ehrenreich would not do it. Audre Lorde would not do it. They have a different stance. They see the commodification, the aggression, the abuse, the deception, the fraud that directs women to compare wigs and head scarfs instead of uniting and fighting against what kills them. Engelberg, however, does it because it gives her some rest from the constant anxiety she experiences. She does it without taking herself too seriously. She does it and mocks it right after. The hybridity and ambiguity that define her as a character urge her to protest when something strikes her as oppressive, offensive, and unfair, and simultaneously they make her go for it when something promises lightness and entertainment. The one element does not exclude or disqualify the other. As it happens in life, antithetical tendencies coexist in one and single form, in one and single expression of being. Engelberg is a funny breast cancer patient who cracks the one hilarious joke after the other and tries on blue and red wigs, while simultaneously giving us a socio-political

commentary of minor activism, showing her vulnerability, her critical and independent spirit, as well as her keen observation of the world around her. We tend to imagine that the real political action is elsewhere and in a different shape – big, loud, self-conscious, and with a very concrete agenda. Erin Manning writes:

“The unwavering belief in the major as the site where events occur, where events make a difference, is based on accepted accounts of what registers as change as well as existing parameters for gauging the value of that change. Yet, while the grand gestures of a macropolitics most easily sum up the changes that occurred to alter the field, it is the minoritarian tendencies that initiate the subtle shifts that created the conditions for this, and any change. The grand is given the status it has not because it is where the transformative power lies, but because *it is easier to identify major shifts than to catalogue the nuanced rhythms of the minor*. As a result, these rhythms are narrated as secondary, or even negligible” (Manning, 2016:1; my italics).

Marcelo Svirsky, in his examination of activism from a Deleuzian perspective (2010), makes a similar point. “Rather than understanding activism as supporting or leading social struggles”, he pursues a definition that presents it “as an open-ended process and stresses the role of *investigation* in relation to practices within the social situations to which activism addresses itself” (ibid:163, my italics). Activism, then, is doing this investigation, looking at things with critical eyes, interrogating the ethical aspects of practices, arrangements, and processes, asking questions, asking “why”. This is what makes further action possible and the most revolutionary part of all political action – the moment of negation and of the interruption of an old rhythm; before the organized struggle begins; before the new order is established: “[i]t is in the insolence and intensity of the challenge posed against constituted power (whatever its form or mode), and its associated way of life, that activism is located, and not necessarily on the barricades or protest marches” (ibid:169). It is in “failing”, as Halberstam suggests in *The Queer Art of Failure* (2011), to be a compliant subject and to act according to the social requirements, and in using the subversive power of failure to “escape the punishing norms that discipline behavior and manage human development” (ibid:3), to “preserve some of the wondrous anarchy of childhood and disturb the supposedly clean boundaries between adults and children, winners and losers” (ibid), and to employ “disappointment, disillusionment, and despair... to poke holes in the toxic positivity of contemporary life” (ibid). This is activism as a form of escape, “not concerned with changing the world, but (that) rather would like ‘to produce it anew’” (Svirsky, 2010: 169), which is reminiscent of Ian Williams’ statement regarding the world-building power of comics.

## Minor Literature

Based on the features of Engelberg's memoir that I have presented so far (its negativity, its refusal to conform to majoritarian discourses, its dissonance), I would like now to examine it as an instance of minor literature, a work of literature that encourages and performs minoritarian becomings. Deleuze and Guattari, in their book on Kafka (2006), define three main characteristics of minor literatures: First, language becomes deterritorialized, dislocated, and displaced, it is removed from its homeland or what is taken to be its natural lodgings (2006:17). Second, "everything (in a minor literature) is political" because "its cramped space forces each individual intrigue to connect immediately to politics" (ibid). Third, "everything takes on a collective value," since "what each author says individually already constitutes a common action, and what he or she says or does is necessarily political, even if others aren't in agreement" (ibid).

Major literature begins from an already given content and proceeds to put that content in a suitable literary form, that is, it starts from something already known to present it through, or invest it with, aesthetic means. It is about the representation of lived experience – it is a type of literature that speaks of what exists out there in our cultural and social world as we know it and, in that sense, it reproduces this world. The author puts herself on the side of language as it is and as it is habitually used to convey thoughts and desires to which readers are used, as well. In short, it is about the familiar and about communicating the familiar in familiar terms. For example, in the case of illness stories, one conventionally talks about those times when, while feeling lost or in agonizing pain, she stuttered or screamed; one needs to find a reason for all the suffering; and one needs to learn how to be a better person, or what the gain out of all this hardship can be. A minor literature author, on the other hand, instead of describing stuttering or screaming, makes the language itself stutter and scream (the way Kafka or Beckett did); instead of searching for the comfort of a certain meaning and for the reassurance of becoming "better", she shuns what is socially expected of her, as is the case with Engelberg. Instead of starting from a pre-given content, she starts from an overwhelming encounter or an encounter with something affective (such as Burrough's encounter with drugs, or Kerouac's with travel; or, indeed, like Engelberg's encounter with breast cancer). The author, in creating minor literature, does not reproduce common knowledge or habitual ways of thinking; does not represent and does not repeat what is already there. On the contrary – and effectively, in an activist way – she challenges and upsets not only notions of how things are supposed to work or thought of or written about, but language and expression itself.

Becoming-minoritarian, which constitutes an activist micro-political move, is a process that develops and unfolds between the *ethic* and a certain kind of the *aesthetic*. And that, in our case, would be the use Engelberg makes of the specific aesthetics and the structural expressive affordances that become possible in the genre of comics. On this, I will give an example from Engelberg's graphic memoir. In a gag strip that is entitled "The Undead" (2006), when she comes

across an acquaintance who is quite surprised to see that she is still alive, she feels herself to have metamorphosed socially – in the eyes of this person – from a normal human being shopping at the grocery store into a zombie-like creature, something in-between the living and the dead, something abject, abortive, and monstrous. By that time, Engelberg had already had surgery, chemotherapy, radiation, she had lost her hair, and in general, she had been living with breast cancer for quite some time. When this acquaintance is so surprised to see her still around, her reaction is not to explain to us readers how this made her feel, particularly after all the trials she experienced, nor is it to describe her thoughts about being seen as a piece of sick and decomposing flesh which is, startlingly enough, not quite dead yet. She could have done that, but she doesn't. Instead, she uses the vocabulary of comics to give another type of response. In what I find one of the best frames of this book, she writes, "... when suddenly I became The Undead", and draws herself under this caption as a zombie figure with a deformed face, melting and falling apart, eyes popping out of their sockets, drooling, her curls rigid and unbending, as if she has been electrocuted, her fingers extended and stiff. To the right of this drawing, two words stand for sounds, as it oftentimes happens in comics: "glug", "gurgle". These two sounds and the drawing are Engelberg's reaction to a culture that turns cancer into a metaphor inspiring horror and disgust for the diseased body, rotting from the inside (see: Sontag, 1983). By showing herself to be transforming – in a frame that transports us from the real to the imaginary – into a zombie making zombie-like sounds, she makes her chosen language, that is, comics, "stutter and scream" in a way that is simultaneously satirical, caustic, and highly emotive. Her gesture constitutes a powerful critique that not only works much more effectively than if she had chosen to explain, panel after panel, in a conventional narrative manner her position, but also functions as a surprise tactic strategically performing a twist on a power level. For Engelberg turns her body into a mirror and confronts this cancer-dreading culture with the very zombie image that is projected on her. So far as textual narrative goes it's "glug" and "gurgle", but in its directness and compactness, together with the drawing, Engelberg's choice works far better than pages and pages of explanatory text.

The fact that comics make use of both language and images constitutes it as a compellingly hybrid genre whereby the intermixing of these two different registers enables an intermedial mode of communication, one "rich in possibilities for complexity, irony, and genre disruption" (Stoddart Holmes, 2014:148). Once language and images are put together, they are both transformed as they participate in the process of the comic book (see: Kukkonen, 2011; McCloud, 1993). Language becomes deterritorialized, imagined and employed differently, taken to different territories, connecting to different things, as we have seen in Deleuze and Guattari's analysis of what is minor literature<sup>33</sup>. Language and images in their becoming-a-comic-book turn into writing-and-drawing, and manifest a new kind

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<sup>33</sup> This is not to say that all works from the genre of comics are works of minor literature, but only that there is a strong potential in this specific genre for the creation of such a literature.

of materiality, since many times the drawings present themselves as words, and written text performs as image. In a sense, then, the uses of each form of communication (visual and verbal) are re-negotiated and re-imagined. This takes place in ways that dislocate and deterritorialize their properties while assigning to them new creative tasks, granting them novel potentials, and enhancing (as in Engelberg's memoir) the possibilities for an ethics of resistance, in a blurred, material, warm space that melts abstraction and concreteness into new expressive forms. On this, I will give two examples.

Under the heading, "Everything is my Enemy", Engelberg presents the reader with a page-long frame where she enumerates all the bigger or smaller everyday carcinogenic sources (or those that she thinks of as carcinogenic, with her usual dose of satire), like the hole in the ozone, pesticides in the park, having too much cheese, or eating hot dogs when she was a kid. A lot of the text in that frame, though, escapes the confinements of the conventional text bubbles to mix with the drawings and to engage, to interact with them in a more free relationship. This serves two purposes. First, to convey Engelberg's generalized and oppressive feeling of being threatened and made vulnerable in a world where innocent-looking, everyday, functional objects that felt like home have now turned into something uncanny, something that can make her sick or kill her (her water filter, her coated cookware). Second, to demonstrate how thoughts of cancer have spread all over her habitual micro-interactions with objects and things (the material world), and how they have become attached to these things, like rapidly multiplying weeds that are now suffocating her environment and all that used to be familiar in it. This text, then, is not only part of the frame as language, but it functions *as image* because the way it is positioned, the way it is employed actually draws (depicts) Engelberg's anxiety and fear as these emotions now lie beside, pop out of, or hover over the drawings of things that used to be trusted, or, at least, not consciously thought of as enemies.

Another instance of text functioning as image is the following: in the gag-strip "The Disposition of Doctors", after her radiologist tells her that the size of her tumor seems to be about two centimeters "but it could be larger", she finds herself returning to the waiting room in a panic. In this particular frame, we see Engelberg with tears rolling down her cheeks while over her head, in the shape of a halo, the words of the radiologist seem to reverberate in a sinister triple repetition, "it could be larger... it could be larger... it could be larger...", like dark and ominous vibrations – like a black cloud or evil spell that shrouds her and holds her captive under its terrible power. These written words in that frame, they are text, sure enough, but far from being *only* text they are part of the frame *as image* since they are employed in such a manner that they communicate the artist's emotional state, her agony, in a pictorial way, and just as much as her tearful face does.

The qualities that are given by Deleuze and Guattari as characteristic of minor literature (the deterritorialization of language, the connection of the individual to the political, the collective value) are manifest in *Cancer Made Me a Shallower Person*. Engelberg's book is a personal story of resistance that speaks to the

reader in a minor key, opening up some space for negation and revolt. It allows for and acknowledges the validity and authenticity of what might be regarded as shallow in a consumerist, neoliberal culture which seems to value ready-made patterns of human experience that emerge, in this culture's context, as deeper or more profound. To follow the patterns is to try and see what has gone wrong with your choices and fix it. It goes hand in hand with the mentality of self-help, self-improvement, self-discipline – the idea of the positive thinking, successful individual that reconciles, says yes to life, can see the grand (major) picture, and, learning along the way, win the battle and save herself. To follow a direction such as the one Engelberg points to, is to be able to see through and denounce the political oppression of normative discourses based on the false and punishing concept of individual responsibility, obliterating community, and distributing socially accepted roles for people to play. It is to have the grit to fail, to be minor, childlike, stubborn, unwilling to conform and do the “right” thing. It is, finally, to speak up for your rights and against the injustice you are subjected to. It is to expose the dishonesty and mock it; it is to say no.

### **Critique – The People Who Are Missing**

So far, I have discussed Engelberg's breast cancer memoir as a minoritarian narrative of resistance to dominant tropes of entrepreneurial selfhood of learning and growing out of one's cancer experience; as a counter-narrative undermining toxic positivity, compulsory spirituality, and all the lying that presents cancer treatment as manageable and living a healthy life as possible. Furthermore, as a minor political gesture, and as a work of minor literature. I have defended Engelberg's work against criticisms that I found unfounded, but I have offered no criticism of my own. In this last section, I intend to do so, and I have selected to present it here, at the end, not because I attribute to it small importance, but because, on the contrary, I believe it is of great significance, and I would like the reader to finish this chapter with these specific thoughts.

For all its merits, Engelberg's book does not include women whose life and breast cancer experiences, in the context of this life, differ from those of the artist. Women who are underprivileged, poor, colored, unemployed, uninsured (Kasper, 2000), and live in toxic neighborhoods (Conroy et al., 2017), exposed much more to environmental and social injustices, and dying at a much higher rate than white middle/upper class women (Bassett & Krieger, 1986). Women who, due to their sometimes radical financial limitations, might not even make it to the hospital (Bowen, 2013). Or make it there, and get sent away by the doctors when the latter find out that their patients are uninsured. Or have some insurance, and wait for hours at the hospital for breast cancer appointments without any money to buy lunch. “The people who are missing” are missing here, too. While Engelberg's sharp social critique does not miss bigger structures and discourses of violence and their interactions in creating and sustaining what Lochlann Jain calls in *Malignant*, “the cancer complex” (2013: 223), while it exposes “the constituent

parts of this experience (which) spin the web that we call cancer and, unless we are vigilant, entrap us in it” (ibid), it does miss other realities, much darker and more violent than the author’s own. The connections Engelberg makes between her state/health and broader oppressive, necropolitical arrangements always begin from her own experience – how these arrangements affected her, personally – and they end there, as well. Even though she must have been well aware of the very different situations of underprivileged women diagnosed with breast cancer, she looks at wider systems applying themselves in her own life, but *not at people with much more difficult lives and how these systems might be affecting them*. That is reminiscent of the majoritarian narratives of white middle/upper class women who typically omit the breast cancer Others in their tales, but, definitely does not undo all of Engelberg’s outspokenness, and courage, and keen critical attitude, offering dissident alternatives in a suffocating, neoliberal breast cancer world – all that she has accomplished in her genuinely minoritarian, satiric and defiant comic book. It does, nevertheless, remind us of the fact that there can be no justice unless it is justice for all, and that *this is something we need to keep speaking about*, and never cease problematizing and putting it in the foreground. It also brings to mind minoritarian-activist works that, actually, do this, such as Anne Boyer’s award-winning book, *The Undying* (2019).

Boyer, a poet and essayist, who was diagnosed with triple negative breast cancer at the age of forty-one, examines the breast cancer landscape in the U.S. from a feminist-Marxist perspective. In her incisive, merciless, angry, and lyrical text, a hybrid between a memoir and a manifesto (Hermann, 2020), she keeps “mov(ing) between different registers” and “shifting scales of focus”<sup>34</sup> (Jain & Stacey, 2015: 2 and 5), taking us from the personal to the communal, to the religious, to the technological, to statistics, to poetry, and always to politics. She writes: “I was a single mother without savings who existed in a world of profit, had no partner to care for me or family nearby in a world that privatizes survival, (and) had to work all through my treatment at a job where I was advised to never let on I was ill” (2019: 130). Only days after her surgery, she has to go to her teaching job “with surgical drainage bags stitched to my tightly compressed chest, expected to be bravely visible as a breast cancer survivor while my students have no idea what has been done to me or how much I hurt” (ibid: 157).

Boyer does not let us forget that the “semi-eradicat(ion)” of women gets all the more “deepened by class, race, and disability” (ibid: 118), and that those outside a family network, the poor, the black, the non-productive, are “rarely considered worth enough to keep alive” (ibid: 150). Regarding black women, disproportionately afflicted by triple negative breast cancer, like hers, “the last breast cancer left with no targeted treatment” “because of medicine’s institutionalized racism” (ibid: 173), she states: “[t]hese women’s deaths are racist and unnecessary, and our grief over them should tear open the earth” (ibid).

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<sup>34</sup> Jackie Stacey and Lochlann Jain do something similar in their books, *Teratologies: A cultural study of cancer* (1997) and *Malignant: How cancer becomes us* (2013), respectively.

## Conclusion

Activism begins from a denouncement, from speaking up for your rights, and from exposing hypocrisy and injustice. “Always starting as a wound of alterity within the habitual” (Svirsky, 2010: 167), which is precisely what Engelberg does: opening that wound. *Cancer Made Me A Shallower Person* stands out among other breast cancer narratives because it is in *movement*. Its movement is precisely the position, different from that of the majority, which Engelberg takes regarding her illness, as a complex cultural-political phenomenon, as well as towards what is socially expected of her. This movement is an outward one, taking the artist (and the reader) outside of and away from understandings of the dominant center, and towards a much less populated place in the margins. It keeps her out of fixed, pink scenarios prescribing how a woman who “fights” breast cancer does this – cheerfully, gracefully, and gratefully for this “gift” – out of the club of the noble and the turned-spiritual, and of the appreciative-of-the-grandeur-of-life. It takes her to areas of variation and critique of a violent world, perhaps darker ones, but much more ethical and worthy of a thinking person, because from there she can consistently negate ready-made ideas, expose lies, remain real, do some good by speaking the truth, and look for her own way.

Engelberg’s memoir, at the same time as performing valuable activist functions in a cultural landscape and literary genre dominated by survivors and winners who find nothing wrong with the world, is also a work of mixed tendencies, hybridity, omissions, and, at times, manifestations of lightheartedness that can be, occasionally, misunderstood. In the midst of all this, however, the in-betweenness, the antithetical traits, the indignation, and the desire to poke fun, one thing is certain: the established order does not fare well at all in the witty satire of *Cancer Made Me a Shallower Person*. And, as George Orwell has famously stated, “every joke is a tiny revolution” insofar as it “upsets the established order” ([http://www.nonsenselit.org/Lear/essays/orwell\\_2.html](http://www.nonsenselit.org/Lear/essays/orwell_2.html)). Dissecting different situations as she goes along, Engelberg mocks, critiques, and subverts, eliciting from the audience of her graphic performances reactions of recognition, but also raising doubt over certainties, and pointing towards desperately needed socio-political change. Her penetrating humor is a tool of resistance and a rescue-boat that keeps her afloat, for as long as this can be the case. Engelberg, herself a hybrid creature, both vulnerable and detached, a trickster and truth-teller who strategically targets things oppressive and unjust, has offered us a minoritarian narrative of resistance that takes a very serious look at the contemporary breast cancer cultural landscape. As Lawrence Michael Bogad remarks in his book on creative activism, *Tactical Performance: The Theory and Practice of Serious Play* (2016), “[s]ometimes you need to take a situation seriously enough to make fun of it” (Bogad, 2016: 62).

## CONCLUSION OF THE DISSERTATION

In this dissertation, I addressed the issue of neoliberal breast cancer stories currently written and published in the U.S. and following a coming-of-age pattern that emphasizes personal responsibility, survival and triumph, and ignores broader contexts of violence, oppression and injustice, which are suffered most acutely by precarious women who do not get to describe their experience in best-selling memoirs. To this end, I examined a number of factors (elements in a network of material structures, objects, and meanings) acting as influential agents in the formation of contemporary understandings of breast cancer, of social attitudes, and of the general, current socio-political state of affairs. These include: Narrative Medicine, an important area of medical humanities promoting literary/narrative ways of communicating and understanding the experience of illness and of improving the quality of doctor-patient relationship. International publishers coaxing people who have experienced illness and trauma to engage in the therapeutic process of writing their memoirs following the instructions of manuals made available by the same publishers, and send their manuscripts for publication. A therapeutic culture that fosters and sustains an image of people as fundamentally vulnerable and in need of constant healing. Spiritual practices such as yoga and meditation, extracted from their original community-oriented context, and made to fit neoliberal ideas of coping in a swim-or-sink world. As well as, a narrative genre (*Bildungsroman*) which evolved together with the advent of modernity and the rising forces of capitalism, and which, promoting neoliberal values of constant self-improvement and of adjusting oneself to the world, has currently become the prominent way we understand reality and narrate the self.

Subsequently, I turned my attention to counter-narratives: critical stories which narrate personal experience intertwined with inquiry on structural social issues, and foregrounding this way the connections between the personal and the political. These accounts, often bearing elements of the master narratives, complicate the relationship between majoritarian and minoritarian, as well as that of center and margins, while simultaneously performing minor activism of refusal-and-resistance, and offering alternatives to neoliberal ways of thought and life. Making a case for such activist gestures and for stories that undermine individualism, linearity, and completeness by favoring fragmentation, collective narration, and performative modes of writing as antidotes to the neoliberal tales, I examined three accounts: “The Gift of Disease” (1979) and “Eurydice in the Underworld” (1997) by Kathy Acker, and *Cancer Made Me A Shallower Person: A Memoir in Comics* (2006) by Miriam Engelberg. Three very different from each other texts that function – as my analysis has shown – as *micro-political acts of refusal/resistance* and as *minor counter-narratives*, contesting majoritarian norms, making political claims, and subverting the narrative models of master narratives. Written by women often excluded from notions of marginality but who embody a nuanced, outsider position within the dominant social structure these works are not canonized or celebrated as unequivocal acts of resistance.

Instead, they have been met with skepticism, dismissal, or marginal recognition, raising questions about their activist potential.

My goal in choosing this type of narratives was to expand the minoritarian landscape by highlighting the breadth and diversity of minoritarian voices and by challenging preconceived notions of what qualifies as “minoritarian” showing that resistance can emerge from unexpected sources. My goal was also to unveil micro-transitions and to encourage a sensitivity to subtle shifts and mixed tendencies in narratives and to propose that these micro-processes can serve as precursors to broader social change. Finally, I sought to amplify resistance by advocating for the recognition of under-acknowledged voices and by suggesting that fostering dialogue around such narratives can help build solidarities and networks for change across different types of oppression and violence.

In the course of my research, I gathered and synthesized information and scholarly knowledge from a variety of fields, such as comics studies, narrative studies, and research bringing together activism and academia. What stayed with me the most, however, what affected me the most on an intellectual and emotional level, is the brutal reality described in statistics and studies which present life and death in the margins of society, as well as inevitable death also for those who did not have to struggle within a vulnerable mode of existence. For example, consulting the webpage of the American Cancer Society ([www.cancer.org](http://www.cancer.org)), one encounters the following estimates for 2024, which, by the time of submission of this dissertation, will have been already realized:

- About 310,720 new cases of invasive breast cancer will be diagnosed in women.
- About 56,500 new cases of ductal carcinoma in situ (DCIS) will be diagnosed.
- About 42,250 women will die from breast cancer.

Such numbers make words stop. And they do, or should, make one think twice before deciding what they’d like to use words for. Certainly, as well, along with these numbers, the racist character of so many of these deaths is daunting. As the American Cancer Society reports:

- Black women have the highest death rate from breast cancer. This is thought to be partially because Black women have a higher risk of triple-negative breast cancer – more than any other racial or ethnic group.
- At every age, Black women are more likely to die from breast cancer than any other race or ethnic group.

The American Cancer Society website does not mention that triple-negative breast cancer, as well as other types of cancer disproportionately affecting black people “receive less research funding than those cancers with high incidence rates among white patients” (<https://consultqd.clevelandclinic.org>; see also: Haghghat et al., 2023), nor does it comment on the role of non-biological factors such as

access to health-care, socioeconomic background, and higher exposure to chemicals that cause breast cancer.

In this light, it becomes an urgent ethical issue to advocate for anti-neoliberal, anti-individualist, alternative stories that cannot be turned into things to be consumed or overlooked, thrown in the whirlwind of the current hyper-production of words and images, at the end meaning very little and making no difference. I don't believe that this can happen with the stories I have examined. These are stories that cannot be appropriated and time has already proven that. There are and there can be many more such narratives that cannot be co-opted by neoliberalism or by any other system that might be interested in taming them. These are stories that serve a crucial political purpose and it is hopeful that they have been written and published. They have surely had impact on the people who read them, slowly effecting minor changes at least on the thinking of women who would not necessarily pursue a more openly or directly activist response (for example, by connecting to the grassroots activist organization Breast Cancer Action).

Changing the stories means changing the thinking and this, in turn, can change the doing. These processes take time, too. Critiquing oppressive, inauthentic, market-oriented illness stories, in a context in which massive death is involved, such as is the case of breast cancer, became for me an imperative and the main purpose of this thesis. Of course, narrative, in different forms (written or otherwise) can be very helpful to many people who have been through illness or trauma, and it can offer considerable support to their recovery. This fact is not problematic or contestable, and for this reason I did not dedicate much space to it in my work. But in the face of suffering, injustice, exploitation, greed, hypocrisy, and death going on for decades on end in a place where vulnerable women don't even have the basic right of health insurance and are abandoned to their fate, while privileged women write stories of journeys, perseverance, and triumph, one needs to take a critical stance, bring to foreground the dissident stories of oppositionist, and make a case for more critical-activist work. I hope to have accomplished this and to be able to engage again in this type of activist-scholarly work in the future.

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## SUMMARY

In this dissertation, *Breaking Free of Cancerland: Changing the Stories We Tell About Breast Cancer*, I examine autobiographical narratives written by women with breast cancer in the U.S. These stories, looking at breast cancer from a neoliberal, individualist perspective, constitute a big contemporary cultural phenomenon as well as part of an extensive network (of objects, structures, and meanings) that determines people's perception of breast cancer and, consequently, what happens or does not happen on a broader level about it. In my research, I found that mainstream breast cancer narratives mostly emphasize survivorship and positive thinking, personal responsibility and heteronormative/middle class values of life. In doing so, they obscure different realities and modes of existence, and preclude people from considering different responses to this storytelling epidemic, such that might foreground its links to economic-political interests and circumstances, and elicit more ethical and community-oriented approaches. Alongside my critique of mainstream breast cancer stories and a discussion of various factors that shape them and keep them in currency, I suggest turning to counter-narratives – critical autobiographical breast cancer stories that resist the storytelling pattern of winners'/heroes' tales. I analyze three such narratives that stood out for me and I look at them in connection to their own specific features and with respect to their activist qualities.

In the introduction, I discuss the broader cultural tendency to compose one's own memoir as well as how common this practice has become, historically stemming from an identification of self and self-narrative, and gradually considered to be an essential practice particularly for ill people, bringing coherence to a disturbed identity and life. Subsequently, I inspect three main agentic forces involved in the making of the breast cancer memoir boom: therapeutic culture (current notions of the individual as vulnerable and in constant need of healing as well as socio-economic structures that support this healing), Narrative Medicine (an area of the medical humanities promoting engagement with the writing and reading of literature for doctors and patients), and a specific part of the publishing industry (inviting people who go through illness or trauma to send their manuscripts). I, then, examine the entrepreneurial-neoliberal-heterosexual pattern most mainstream breast cancer stories follow (a *Bildungsroman* type of story) and give specific examples of memoirs. I explain the reasons why such texts operate in ways that are socially harmful and I suggest looking at the network of connections among meanings and technologies that sustain this reality, as well as at alternative, critical stories.

In the first chapter, titled "Breast Cancer Under Neoliberalism", I look in more detail at certain elements of this network, upon which I touched in the introduction. I discuss Narrative Medicine (critiquing some of its premises and suggesting alternatives), and look at the evolution of illness narratives as a genre from the early 70's to the 90's. I delve into the pervasive nature of neoliberalism and its change from an economic system to an ontological issue, as well as that

of the *Bildungsroman* – the narrative genre which has become the dominant storytelling type of our times. I look into the practices of yoga, meditation and mindfulness and the ways they serve neoliberalism, and go on to look at research on master and counter-narratives, which demonstrates that people’s accounts are never pure and uncontaminated discourses, and that diverse and oftentimes opposing elements co-exist in the same narrative. I end the chapter considering the concept and practice of refusal along with that of resistance (which had been my main thinking lens for counter-narratives), and identify my case studies as moving between refusal and resistance, a fact that endows them with positive, bonding, community-building qualities.

In the second chapter, I analyze two textual accounts (counter-narratives) by the avant-garde writer Kathy Acker describing her experience with breast cancer. The first one, “The Gift of Disease”, is a matter-of-fact story written for The Guardian, in which the author exercises critique on the breast cancer industry and details her encounters with spiritual healers after her decision to abandon mainstream medicine. The second, “Eurydice in the Underworld”, is a performative, poetic text that mixes genres, employs the myth of Orpheus and Eurydice, and prepares Acker for her imminent death while addressing an activist call to the reader, whose cancer-death in current necropolitical times might not be far away. I look at the first case through the *Bidungsroman* and picaresque type stories, as well as of the concept of counter-narrative, which is always entangled with elements of master-narratives. In the second case, I compare Acker’s “Eurydice” to the Greek oral poetry tradition of *moirologia* (laments) and find many common features establishing “Eurydice” as a textual performance of protest making mourning public – a protest that includes those who exist in the margins, and creates bonds with other women.

In the third chapter, I examine the best-selling graphic novel “Cancer Made Me A Shallower Person” by Miriam Engelberg, a self-taught cartoonist who documented her breast cancer experience in comics. Engelberg’s graphic memoir bears elements from the *Bildungsroman* type story but stands more on the side of the picaresque, giving the story in episodic form and featuring a protagonist who will not learn lessons and change, but who retains the status of an outsider wanting at the same time, in certain ways, to belong. The artist uses satire and humor to exercise critique on commonly held perceptions of breast cancer as an opportunity to become a better person and change your life, or to become deeper and more spiritual. She refuses to participate in the culture of meditation, yoga, and journaling, and speaks openly about constant involuntary exposures in an unsafe world, and about the environmental causes of cancer. Her memoir emerges as an activist counter-narrative debunking neoliberal ideas of individual responsibility and stands out in the genre of graphic pathographies, in which it belongs.

In the conclusion, I bring together some of the strands I dealt with in my examination of breast cancer narratives in the U.S. as a multiple phenomenon that describes and stems from neoliberal systems and structures of life, and argue again for different stories resisting and refusing necropolitical, individualist

models of greed, cancer, and death. I maintain that different stories (not emphasizing coherence and the hero's self-development, not told from a strictly individualist point of view, not following the instructions of writing courses and manuals on how to write a successful memoir today) can slowly and gradually make the minoritarian voices heard and, over time, lead to more ethical ways of existence.

## SUMMARY IN ESTONIAN

### Vähimaast lahtiütlemine: Rinnavähist räägitavate lugude muutmine

Käesolevas doktoritöös “Vähimaast lahtiütlemine: Rinnavähist räägitavate lugude muutmine” uurin Ameerika Ühendriikides rinnavähki haigestunud naiste autobiograafilisi narratiive.

Rinnavähki neoliberaalsest ja individualistlikust perspektiivist vaatlevad lood moodustavad olulise kaasaegse kultuurinähtuse ning on osa ulatuslikust objektide, struktuuride ja tähenduste võrgustikust, mis määravad inimeste arusaamu rinnavähist ning selle üle toimuvaid arutelusid laiemalt. Uurimistöös selgus, et peavoolu rinnavähinarratiivid asetavad enamasti rõhu ellujäämisele ja positiivsele mõtlemisele, isiklikule vastutusele ja heteronormatiivsetele/keskklassi väärtustele, varjutades seega tegelikkuse ja eksistentsi mitmekesisust ning takistades inimestel kaalumast teistsuguseid jutustamisvõimalusi, mis tõstaksid esile taoliste jutustamispraktikate seoseid majandus-poliitiliste huvide ja olukordadega ning kutsuksid esile eetilisemaid ja kogukonnale suunatud lähenemisi. Lisaks peavoolu rinnavähinarratiivide kriitikale ja diskussioonile erinevatest teguritest, mis neid kujundavad ja neile kaalu annavad, panen ette pöörduda kriitiliste autobiograafiliste rinnavähilugude ehk vastandnarratiivide poole, mis tõrguvad vastu “võitjate“ ehk “sangarite“ loojutustamise muustrile. Analüüsin kolme sellist narratiivi ning vaatlen neid seoses nii nende eripära kui ka ’aktivistlike’ omadustega.

Sissejuhatuses käsitlen memuaarikirjanduse laiemat kultuurilist suundumust ja seda, kuidas levinuks on taoline praktika muutunud. Ajalooliselt on selle alged enese ja enesekirjelduse identifitseerimises ning praegusel ajal peetakse enesekirjutust järjest olulisemaks praktikaks just haigete puhul, mis aitab luua sidusust häiritud identiteedis ja elus eneses. Järgnevalt uurin kolme peamist rinnavähi memuaaribuumi teket mõjutanud tegurit: teraapiakultuur (arusaamad inimesest kui haavatavast ja pidevalt paranemist vajavast olendist ning sotsiaalmajanduslikud struktuurid, mis seda paranemist toetavad), narratiivne meditsiin (meditsiiniliste humanitaarteaduste valdkond, kus arste ja patsiente julgustatakse pöörduma kirjutamise ja kirjanduse lugemise juurde) ning kirjastustööstuse haru, mis kutsub haigus- või traumakogemusega inimesi oma käsikirju saatma. Seejärel uurin ettevõtlus-neoliberaalset-heteroseksuaalset muustrit, mida enamik peavoolu rinnavähilugusid järgib (*Bildungsroman*-tüüpi lood) ja toon konkreetseid näiteid memuaaridest. Selgitan põhjusi, miks sellised tekstid toimivad sotsiaalselt kahjulikel viisidel ja kutsun vaatama tähenduste ja tehnoloogiate vahelist seoste võrgustikku, mis seda tegelikkust toetab, ning ühtlasi alternatiivseid, kriitilist laadi lugusid.

Esimeses peatükis pealkirjaga “Rinnavähk neoliberalismi tingimustes“ vaatlen lähemalt selle võrgustiku teatavaid elemente, mida käsitlesin sissejuhatuses. Arutlen narratiivse meditsiini üle (kritisereides mõningaid selle eeldusi ja pakku-des alternatiive) ning käsitlen haigusnarratiivide kui žanri arengut 1970ndate algusest kuni 1990ndateni. Süvenen neoliberalismi olemusesse ning muutumisse majandussüsteemist ontoloogiliseks probleemiks, ning käsitlen *Bildungsroman*’i narratiivset žanri, millest on saanud meie aja domineeriv loojutustamise tüüp. Vaatlen jooga, meditatsiooni ja *mindfulnessi* praktikaid ning nende võimalusi neoliberalistlike käsitluste uurimisel peavoolu ja vastandnarratiivide kohta, mis näitab, et inimeste jutustused ei ole kunagi puhtad ja saastamata diskursused ning et samas narratiivis eksisteerivad kõrvuti erinevad ja sageli vastandlikud elemendid. Lõpetan peatüki, kaaludes keeldumise mõistet ja praktikat koos vastupanu mõistega, ning määratlen oma juhtumiuuringud keeldumise ja vastupanu vahel liikumisena, mis annab neile positiivseid, sidusaid ning kogukonda arendavaid omadusi.

Teises peatükis analüüsin avangardistliku kirjaniku Kathy Ackeri kahte teksti (vastandnarratiivi), milles ta kirjeldab oma kogemust rinnavähiga. Esimene neist, “The Gift of Disease“, on ajalehele *The Guardian* kirjutatud faktilist laadi lugu, milles autor kritiseerib rinnavähitööstust ja kirjeldab üksikasjalikult oma kohtumisi vaimse ravitsejaga pärast otsust loobuda peavoolumeditsiinist. Teine, “Eurydice in the Underworld“, on performatiivne, poeetiline tekst, mis segab žanre, kasutab Orpheuse ja Eurydike müüti ning valmistab Ackerit ette peatseks surmaks, esitades samal ajal üleskutse lugejale, kelle vähktõve-surm praegusel nekropoliitilisel ajal ei pruugi olla kaugel. Vaatlen esimest juhtumit *Bildungsroman* ja pikareskse (kelmiromaan) jutustuse tüüpide läbi, samuti läbi vastandnarratiivi mõiste, mis on alati põimunud peanarratiivide elementidega. Teise loo analüüsis võrdlen Ackeri “Eurydice“-i kreeka suulise luule *moirologia* (leinaamise) traditsiooniga ning leian palju ühiseid tunnuseid, mis kehtestavad “Eurydice“-i leina avalikuks muutva protesti tekstilise etendusena – protesti, mis hõlmab neid, kes eksisteerivad marginaalis, ja loob samas sidemeid teiste naistega.

Kolmandas peatükis uurin Miriam Engelbergi, iseõppinud karikaturisti menukit “Cancer Made Me A Shallower Person“, kus ta on dokumenteerinud oma rinnavähikogemuse koomiksites. Engelbergi graafiline memuaar kannab *Bildungsromani* loo tüübi elemente, kuid kaldub pigem pikareski poole, kuna lugu on esitatud episoodilises vormis ja kujutab peategelast, kes ei võta õppust ega muutu, vaid säilitab autsaiideri staatuse, tahtes samal ajal teatud viisil kuhugi kuuluda. Autor kasutab satiiri ja huumorit, et avaldada kriitikat üldlevinud arusaamadele rinnavähist kui võimalusest saada paremaks inimeseks ja muuta oma elu või muutuda sügavamaks ja vaimsemaks. Ta keeldub osalemast meditatsiooni-, jooga- ja päevikupidamiskultuuris ning räägib avalikult pidevatest tahtmatutest kokkupuudetest ebatavalises maailmas ja vähktõve keskkonnast tulenevatest põhjustest. Tema memuaarid toimivad aktivistliku vastandnarratiivina, mis

lükkab ümber neoliberaalsed ideed individuaalsest vastutusest ning paistab silma graafiliste patograafiate žanris, kuhu see ka kuulub.

Kokkuvõttes toon välja mõningad suundumused, mis ilmneseid ameerika autorite rinnavähinarratiivide uurimisel mitmekesise nähtusena, mis kirjeldab neoliberaalseid süsteeme ja elustruktuure ja lähtub neist. Väidan taas, et need erinevad lood osutavad vastupanu ning keelduvad nekropoliitilistest, individualistlikest ahnuse, vähi ja surma mudelitest. Väidan, et erinevad lood (mis ei rõhuta sidusust ja kangelase enesearengut; ei räägi rangelt individualistlikust vaatepunktist; ei järgi kirjutamiskursuste ja käsiraamatute juhiseid, kuidas kirjutada tänapäeval edukat memuaari) võivad aeglaselt ja järk-järgult kuuldavaks teha marginaliseeritute hääled ja aja jooksul viia eetiliseimate eksistentsiviisideni.

## CURRICULUM VITAE

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### Honors and Awards

June 2019 The Moving Image Award of the Association for Medical Humanities for the ethnographic film *The Red heelbarrow* (student competition).

### Publications

Kirey-Sitnikova, Y., Böcker, J., Werner, A., Tzouva, P., Clay, S. (2021) “What Do We Talk About When We Talk About Queer Death? /4 Queering Death in the Medical and Health Humanities”, In: *Whatever: A Transdisciplinary Journal of Queer Theories and Studies*, 4, 615-644.  
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**Projects**

2018–2021 Participation in the research project *The Role of Imaginary Narrative Scenarios in Cultural Dynamics* (University of Tartu), under the leadership of Professor Marina Grishakova.

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## Publikatsioonid

Kirey-Sitnikova, Y., Böcker, J., Werner, A., Tzouva, P., Clay, S. (2021) “What Do We Talk About When We Talk About Queer Death? /4 Queering Death in the Medical and Health Humanities”, In: *Whatever: A Transdisciplinary Journal of Queer Theories and Studies*, 4, 615–644.  
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**Projektid**

2018–2021 Osalemine uurimisprojektis “The Role of Imaginary Narrative Scenarios in Cultural Dynamics” (Tartu Ülikool), professor Marina Grishakova juhtimisel.

**DISSERTATIONES LITTERARUM  
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