Article

Exploring Intimacy in Collaborative Photographic Narratives of Breast Cancer

Agnese Sile

School of Design, Edinburgh College of Art, University of Edinburgh, Edinburgh EH3 9DF, UK;
agnese.sile@ed.ac.uk

check for updates

Abstract: A life-limiting illness brings about heightened awareness of mortality and reshapes close relationships. Couples must often negotiate and adjust their actions to sustain intimate bonds. Through analysis of two projects—Dorothea Lynch's and Eugene Richards's collaborative project *Exploding into Life* (1986) that documents Lynch's experience living with breast cancer through photographs and text, and Angelo Merendino's e-book *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* (2013), I explore how couples make sense of and communicate illness experience. *Exploding into Life* and Merendino's project are not only explorations of Lynch's and Jennifer's experiences living with breast cancer; the works also question what it means to be seen through the eyes of the other. The projects share similar experiences; however, they are situated in two different historical moments. Taking Arthur Kleinman's argument of illness experience as social and political as a starting point, I question the limits of experience and examine how the photographs and the accompanying text articulate and mediate private expressions of illness, and what motivates the participants of the photographic act to make their experiences public. The study is informed by Arthur W. Frank's dialogical narrative analysis and some of the writings by Thomas G. Couser, Roland Barthes, and Michel Foucault.

Keywords: breast cancer narrative; photography; text; photographic illness narratives; intimacy; collaboration

1. Introduction

Illness is commonly defined as a lived experience of physical and mental disease—"a patient's interpretation of his or her disease, the feelings that accompany it, the life events it turns into" (Mol 2002, p. 9).[1] However, illness is not experienced in isolation. As anthropologists Arthur Kleinman and Don Seeman argue, the illness experience "is not bounded by the bodies or consciousness of those who are ill"; it also encompasses families and social networks (Kleinman and Seeman 2000, p. 231). For Kleinman and Seeman, "[i]t is the irreducible 'sociosomatic' quality of illness experience, rooted in the infrapolitics of everyday life as well as the more encompassing political, economic, and cultural realities of the societies we live in" (Kleinman and Seeman 2000, p. 231). Being considered as ill involves complex strategies of awareness, negotiation and recognition. A person's experience of illness can be significantly shaped by cultural orientation, medical and social support, or a lack thereof (Thorne et al. 2013). Similarly, people who are either biologically related to or intimately involved with the ill person are also affected in multiple ways (Taylor 2014; Robinson 2016; Lee and Roberts 2018). The experience

---

[1] In this paper I define illness as lived experience of physical and mental disease. Disease, as defined by Kleinman, is 'the practitioner's construction of patient complaints in the technical terminology of a particular healing system' (Kleinman and Seeman 2000, p. 231).

of illness and the heightened awareness of mortality that it brings about call for a renegotiation of close relationships and re-evaluation of the time spent together (Sile 2018). Through two case studies—Dorothea Lynch and the American social documentary photographer and her long-term partner Eugene Richards' collaborative project *Exploding into Life* (1986), and Angelo Merendino's e-book *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* (Merendino 2013a)—my aim is to explore how couples make sense of and communicate illness, how photographs and text allow them to sustain intimacy, and what motivates the participants in the photographic act to make their experiences public.

The projects were both published posthumously; *Exploding into Life* was published three years after Lynch's passing, and *The Battle we Didn't Choose* two years after Jennifer's death. The two photographers, Richards and Merendino, are witnesses, carers, co-storytellers and editors, as well as caretakers of their collaborative stories of breast cancer experiences. Their skills as photographers are used "in the service of conferring on the sufferer a dignity to which she can lay claim" (Radley 2002, p. 16). The projects do, however, raise a range of ethical questions about representation, the dynamics of collaboration and authorship.

One of the leading scholars in life-writing and disability studies, G. Thomas Couser, states that "those cases in which the completion and publication of the narrative devolve upon a survivor who narrates another's terminal illness" are particularly susceptible to power imbalance (Couser 1998, p. 336). The subjects of these collaborative works have no control over editing, or how and where these projects are disseminated. If illness is understood as a social and public experience, then collaborative or relational narratives pose questions about whose life story is being represented and how illness is constructed.

Exploding into Life includes Lynch's autobiographical writings on her experience with breast cancer, which are presented alongside Richards's photographic record. Here Lynch and Richards each provide a separate narrative that is articulated through different forms of media. The text and image occupy an equal amount of space within the book. In Merendino's *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer*, the writer and photographer is one and the same person (apart from a short text written by his wife, Jennifer, and an introduction by her oncologist). Couser refers to single-author projects as "auto/biographies" (Couser 1998, p. 338) and memoirs of intimate others. Although Jennifer is an active participant in this project, the story is predominantly shown and told through Merendino's standpoint. While the e-book contains video and sound files, as well as text, the photographs are privileged over other forms of media.

W.J.T. Mitchell argues that it is a utopian endeavour to discern differences between text and image, as "all media are mixed media, and all representations are heterogeneous" (Mitchell 1994, p. 5). In photographic essays, however, as Mitchell points out, the interaction of image and text is particularly prominent and "[t]he relation of photography and language is a principal site of struggle for value and power in contemporary representations of reality" (Mitchell 1994, p. 281). Each medium has its own ideology; there is a struggle between the temporality of the text and the spatiality and permanence of an image, between dialogue and spectacle. Each media has its own limitations with regard to what can be revealed and articulated. In photographic essays, when one medium reaches its boundary, the other extends into yet another meaning. This does not mean that text and image circle in an enclosed loop and engage in a straightforward exchange of information; rather, each medium creates tension and unpredictability in relation to each other. Susan E. Bell claims that "photographs represent a complex movement from presence to absence" (Bell 2002, p. 10). It is not just about what is represented in a frame or described in text, but also what is not shown and not told. This movement between presence and absence can not only be sensed within images, but also between images, as well as between images and text, creating what Peter Wagner calls "in-between spaces" (Wagner 1995). This space is relational and dynamic and has the potential to connect imaginative, sensual and emotional elements and experiences. The text also punctuates the rhythm of viewing photographs, thereby slowing down the rate at which these images would otherwise be approached. In collaborative visual

essays on illness experience, this movement between "the seeable and the sayable, the visible and the articulable, display and discourse, showing and telling, perception and conception or symbol and concept" (Alù and Hill 2018, p. 2), between presence and absence, is particularly significant and will be explored further in this paper.

There are notable similarities between the two projects, both aesthetically and thematically. Both include black and white photographs and follow an objective documentary style. The unflinching portraits of Lynch and Jennifer not only disclose pain, suffering and loss, but also the joy and beauty of shared moments of togetherness. On the surface, the projects share similar experiences; however, they are situated in two different historical moments. The way these stories are communicated and shared depends on the photographers' individual choices; but, I argue, it is also affected by the medium they use, as well as the historical, social and cultural contexts in which these works are situated. The concerns raised about visual and textual representations of breast cancer in 1986 are different from those posed in recent years. For this reason, before engaging in detailed analysis of these projects, I will provide a brief overview of breast cancer activism.

2. Breast Cancer Activism

The mid-1970s and early 1980s marked the beginning of a surge of memoirs, biographies and studies of pain and suffering, as well as exhibitions and public discussions by, and about, people who were living with life-threatening illnesses, particularly cancer and AIDS. Lisa Diedrich claims that during this time a new figure arose, a "politicized patient", and with this politicisation of illness experience there emerged "techniques for *doing* illness in new ways, and [. . .] new forms of *writing* illness" (Diedrich 2007, p. 26 (italics added)). The breast cancer activism that began in the mid-1970s led to one of the first narratives to document a radical mastectomy: Rose Kushner's iconic book *Breast Cancer: A Personal and Investigative Report* (Kushner 1975). This activism continued throughout the 1980s and marked a cultural shift from silence and shame to speaking out about personal experiences, reclaiming women's bodies from medical interventions and enabling women to obtain control of their own fates. As Andre Lorde states in her autobiographical narrative and critique, *The Cancer Journals*: "If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies must become visible to each other" (Lorde 1980, p. 61). Language here becomes a political act; as Diedrich claims: "Language as action and action as language" (Diedrich 2007, p. 41). This call for visibility was echoed not only in writing, but also in photography. For Judith Butler, "'materiality' designates a certain effect of power or, rather, is power in its formative or constituting effects" (Butler 2011, p. 34). Through language, and more significantly through photographic practice, ill bodies come into being, they materialise, claiming their rights and acquiring meaning.

One of the first photographic works to depict a mastectomy wound is the American poet and writer Deena Metzger's portrait *The Warrior* (1977) taken by Hella Hammid. Metzger is depicted with her chest bare, arms outstretched and with a clearly visible mastectomy scar covered by a tattooed tree branch. Similarly, in 1982 (the same year she was diagnosed with breast cancer), the British photographer Jo Spence posed in a photograph with a bare chest and writing across her left breast: "Property of Jo Spence?". In her book *Putting Myself in the Picture: A Political, Personal, and Photographic Autobiography,* Spence writes: "Through photo therapy, I was able to explore how I felt about my powerlessness as a patient, my relationship to doctors and nurses, my infantilisation whilst being managed and 'processed' within a state institution" (Spence 1986, p. 156). A similar demand to be seen and resistance to breast reconstruction can be observed in the activist and model Matuschka's cover of the *New York Times Magazine* from 15 August 1993.[2] In the photograph, Matuschka wears an elegant white gown and a headscarf; her mastectomy wound is clearly visible. Her gaze is directed to the right;

---

[2]   The image can be viewed here: http://www.beautyoutofdamage.com/index.html.

the photograph is purposefully posed in such a way that the viewer has no choice but to look and observe the mastectomy scar. Jo Anna Isaac claims that these early photographic representations "are triumphant, not because the women win the battle; for the most part they don't. They are triumphant in their challenge to society's obsession with masking loss, in their willingness to look steadily at the 'disappearance that everybody denies' (Žižek 1991, p. 79)" (Isaac 2002, p. 221). Through a complex representation of the sick body, and a critique of medical objectification, these photographic works question what kind of body is "fit to be seen" (Dykstra, cited in DeShazer 2013, p. 122). Through visual representations, as well as text, these works helped to transform "the individual illness experience into a politicised collective illness identity" (Brown et al. 2004, p. 68), thereby affirming that breast cancer is not only a personal health concern; it cannot be separated from "the social and or physical environment, nor from sexism, racism, and classism" (Diedrich 2007, p. 43).

Since the 1990s, there has been a significant proliferation of cancer stories, both textual and visual (including photography, film and graphic novels), that provide a testimony of suffering as well as of revelations that the disease brings about. In her book *Mammographies,* Mary DeShazer states that the works produced this millennium differ from the earliest accounts in several important ways. As well as questioning the environmental risk factors, genetic testing and preventative mastectomy, these works act as counter-narratives to the mainstream breast cancer culture, which tends to give prominence to triumphant rhetoric, pink iconography, and commercialisation of the breast cancer movement (DeShazer 2013, p. 1).[3] As the poet, writer and breast cancer survivor, Anne Boyer, writes: "the challenge is not to speak into the silence, but to learn to form a resistance to the often obliterating noise" (Boyer 2019a, p. 8). In consumer-orientated cancer culture, with what Samantha King calls its "tyranny of cheerfulness" (King 2010, p. 287), lived experiences of breast cancer, suffering, grief and, often, death are largely ignored and not recognised. Emilia Nielsen argues that contemporary breast cancer narratives not only resist but, most importantly, disrupt mainstream breast cancer culture and, by doing so, they create "important emotional, political, and cultural knowledge" (Nielsen 2019, p. 22). These counter-narratives, drawn from lived experience, can offer ways for healing through writing, visual representation and reading, as well as providing space for knowledge exchange and "strategies for mourning and commemorating the women whose lives have been lost to this disease" (DeShazer 2013, p. 261). One such work is Annie Leibovitz's photographic memoir *A Photographer's Life, 1990–2005* (2006) in which, amongst other events in her life, Leibovitz documents her relationship with her partner Susan Sontag and Sontag's experiences living with breast cancer. The project depicts not only Sontag's struggles with a terminal illness, but also reveal a range of emotions that those living towards death and their close ones must often grapple—fear, anger, grief, and despair. As DeShazer argues, Leibovitz's work, published after Sontag's death, provides "a needed corrective to death denial or to facile idealizations of the cancer experience" (DeShazer 2013, p. 273). Other collaborative examples of photographic breast cancer narratives include Charlee Brodsky and Stephanie Byram's *Knowing Stephanie* (2003), Annabel Clark and Lynn Redgrave's *Journal: A Mother and Daughter's Recovery from Breast Cancer* (2004) and Amy S. Blackburn's *Caring for Cynthia: A Caregiver's Journey through Breast Cancer* (2008). These collaborative illness narratives not only document one person's lived-life experience, but also give space to the role of witness and/or caregiver. The photographic act can reinforce the reciprocal bonds between the participants, however, more importantly, it offers space for self-reflection and exploration of the self in relation to the other.

Digital technologies and social media also provide new avenues for self-expression and communication for people with breast cancer. The internet has made photographic breast cancer narratives more accessible, and also facilitates public engagement through commenting on and sharing

---

[3] In the US the funding for breast cancer research has rapidly increased from just under $100 million in 1990 (Lerner 2002, p. 227) to $721 million in 2018 (NIH Categorical Spending 2019). Although the survival rate of breast cancer since the 1980s has improved, its causes are not fully understood and despite medical advances, existing treatments are still just as aggressive and toxic, and more mutilating than the illness itself.

such representations. However, the proliferation of digital information does not necessarily grant new ways of listening, recognising and responding to such stories.

Below, I will explore how these social and political changes are reflected in *Exploding into Life* and Merendino's projects.

3. Exploding into Life

The project begins with Lynch's discovery and ultimate diagnosis of breast cancer in 1978, when she was 34 years old. She writes: "So there is something worse, after all, than your man turning away from you. Your own body turning away, running away with a crazy new life of its own" (Lynch and Richards 1986, p. 10). As the title suggests, *Exploding into Life* marks a beginning.[4] There is a strong sense of origination, a violent shattering, a sudden eruption that signifies simultaneously both emergence and destruction. Here, emergence, also "the process of becoming visible after being concealed" (OED), can be understood as a breaking of taboos that surround illness and death, shattering barriers that stand between strictly private and public expressions. Explosion into life in this narrative can also point toward the cancerous cells' " 'unlimited' overproduction of life" (Thomas 2013, p. 198). Lynch's body cells have taken on a "crazy new life" of their own.

After several chemotherapy treatments, Lynch describes her reflection in the mirror: "I am dried up, older than ancient, sexless. My body is unfamiliar territory to me, and if I have any great sorrow it is that my body is unreliable now" (Lynch and Richards 1986, p. 58). Yet, in the same year, just before her 35th birthday, she writes:

> I don't even feel like the same person. [. . .] I can never remember being so happy. [. . .] The woman who was terrified of death and what she thought its ugliest manifestation—cancer—of changes, of being without choice or will has survived the confrontation. Cancer is a disease of life, not death.
>
> (Lynch and Richards 1986, p. 60)

Here grief, mourning and exaltation oscillate with one another. Each of these are followed by a new realisation: "I do not know what will survive from this strange new knowledge" (Lynch and Richards 1986, p. 60). The text and photography become spaces in which this knowledge can be formulated, shared and communicated. The disruption caused by "a non-assimilable alien" (Kristeva 1982, p. 11), or the "other", also provides a space for potential.

The idea of visually documenting the disease started when Lynch was asked to make a decision on her treatment. The project grew as a protest against the lack of information and the silences that surrounded breast cancer. After endless searching for visual materials that would explain and show "what a woman with one breast looks like", all Lynch and Richards (in Lynch's text referred to as Gene) could find were "books of a senile old man dying of starvation, young children with distended bellies crying with hunger, men and women blown apart by bombs" (Lynch and Richards 1986, p. 17). The American Cancer Society refused to give them access to images with the excuse that "books with pictures of cancer treatments aren't considered suitable for nonmedical people" (Lynch and Richards 1986, p. 16). Lynch writes that the women are "in the dark" about their bodies: "we ask in whispers, in the corner at a party or on the telephone, what does a breast lump feel like?" (Lynch and Richards 1986, p. 17). In her sharp observations and witty writing, she criticises her own and other women's lack of knowledge (Thomas 2013, p. 207). Despite prohibitions from doctors who are "horrified at the idea of our making 'intimate' photographs'" (Lynch and Richards 1986, p. 71) within the hospital, Lynch

---

[4]   The book received the 1986 Nikon Award for photographic book of the year. In the same year, Eugene Richards's photographs of Lynch were shown at the Théâtre Antique in Arles, France. When the book was published, not all reviews were positive. As Richards discloses in an interview: "It became, in time, a book that helped women talk about their bodies, and their explorations of self. At the time, the American Cancer Society didn't want it. People trashed it" (Richards and McCullin 2011, para. 30).

and Richards decide to photographically document Lynch's mastectomy wound, the procedure of chemotherapy and her reactions to treatments, as well as other patients' stories. The initial idea for the book was to publish other patients' stories as well as those of Lynch; however, this project was never completed due to increased resistance from hospital authorities (Lynch and Richards 1986, pp. 132, 137–41). *Exploding into Life* is not only a book about one individual's private struggle, but an attempt to create a dialogue amongst cancer patients, as well as with others who are affected by the disease.

On page 21 Lynch describes their initial agreement: "Gene says looking upset: 'No I couldn't. [. . .] a camera would be in the way when I'm with you'", to which she replies: "'Come on,' I bully him. 'You're always criticizing me and our friends for not recording the important events in our lives'" (Lynch and Richards 1986, p. 21). In this narrative, breast cancer becomes what Diedrich calls "an illness event" (Diedrich 2007, p. 25), something worthy of being narrated and documented. Lynch resists the "isolation imposed by illness" (Singer, cited in Diedrich 2007, p. 26) and "being a textbook cancer patient" (Lynch and Richards 1986, p. 38). This event not only marks personal transformation, but, most importantly, through their shared venture, illness experience obtains additional public and political dimensions (Couser 1997, p. 57).

The book is divided into seven chapters; their sequence and described events mark the passage of time. The first chapter starts with the discovery of a lump in Lynch's breast, which is followed by examinations, tests, confirmation, diagnosis and mastectomy. The second chapter describes and documents her ordeal of having to undergo chemotherapy. The third and fourth chapters of *Exploding into Life* introduce other patients Lynch and Richards meet on the Cancer ward (in which the word "cancer" hardly gets mentioned) (Lynch and Richards 1986, p. 80). Chapter five leaves the hospital behind and describes other events, such as the birth of Richards's friends' baby, and Richards's assignment on protests at the Seabrook Station nuclear power plant.[5] However, these events in the context of Lynch's illness emphasise the poignancy of the story. Lynch enthusiastically follows the news, and stories such as Three-Mile Island, genetic manipulation and toxins found in the air and drinking water deeply resonate with her own questions and search for a meaning for her illness (Lynch and Richards 1986, p. 123). Perhaps pollution is to blame for her cancer? Can she do anything to have a say in her future?

In the last two chapters, the focus shifts back to the recurrence of Lynch's disease. The text occupies considerably less space than previously. In between panic and questioning her own contribution to the spread of the disease and trials of alternative medicine, the double page spreads of her images fill the gaps that the brevity of her text leaves.

Dialogic Space and Scenes of Intimacy

In the published book, Lynch's text occupies 79 pages; there are 49 photographs that fill 76 pages. A marginal divide questions the respective importance of and relationship between text and image. Can words reveal what is behind the image? Where does the body stand in this text-image interaction? In his analysis of *Exploding into Life* project, Couser observes that the photographs do not reveal anything more than the text does (Couser 1997, p. 59). Yet, each medium adds another layer of meaning.

Lynch's narratives are written in the present tense. This stylistic choice allows her to expand the moment, but also situates the reader in a never-ending temporal circle, a loop. In present tense the events gain a particular vividness. Her writing invites the reader to perceive the world through her experience of reality. In this simultaneous first-person narrative, the difference between "the narrating I" and "the experiencing I" becomes blurred (Huber 2016, p. 71). Although Lynch occasionally looks back at the past ("Prosthesis. I used to think it was a word for something dirty" (Lynch and Richards 1986, p. 38)), these passages are very brief and she quickly switches back to the present tense ("Sarah

---

5   The images of the occupation of the Seabrook, New Hamphire nuclear power plant and the birth of his friends' child, alongside Lynch's text, were published in a book, *50 Hours*, in 1983.

places a prosthesis over my bandages so I can see 'how natural it looks'" (Lynch and Richards 1986, p. 38)). Her text talks to us from a moment that once was, but that is not grammatically separated from now. Suzanne Fleischman calls this "atemporality", which "makes it possible to detach events from a particular historical moment and endow them with a sense of timelessness" (cited in Huber 2016, p. 74). The textual entries, and the photographs that are placed between them, are not dated, which creates a sense of uncertainty; although the event is situated within a specific timeframe that is punctuated by temporal markers like "tomorrow", "afternoon", "tonight" and "six o'clock in the morning", we are forced to search for connections. In her analysis of the use of the present tense in contemporary literature, Irmtraud Huber points out that synchronous narratives that deal with "radical change, destruction and the disappearance of a way of life [allow] for a perspective that largely avoids nostalgia" (Huber 2016, p. 74). Illness can radically alter one's experience of time (Morris 2008). The sense of timelessness here perhaps signifies a disturbance and dissociation in the usual relation between time and one's body. David Morris claims that "[c]hronic illness is thus kin to Angst (anxiety)"— a heightened sense of awareness of experiences that unfold (Morris 2008, p. 411). In *Exploding into Life*, apart from short recollections, Lynch does not dwell in the past for long. The focus here is on capturing the moments that are already slipping away.

The same can be found in the photographs. Apart from six snapshot images in the front page of the book that depict Lynch as a child with her mother, with her brother and Richards, and on what seems to be a journalistic work assignment, there are no images included from before the diagnosis. Photographs problematise temporal and spatial boundaries. André Bazin writes that photography has a power to halt lives "at a set moment in their duration, freed from their destiny" (Bazin 1960, p. 8). For Bazin, "photography does not create eternity, as art does, it embalms time, rescuing it simply from its proper corruption" (Bazin 1960, p. 8). Laura Mulvey develops this idea further by arguing that time is not only "'embalmed' in the photograph, it persists, carrying the past across to innumerable futures as they become the present" (Mulvey 2007, p. 56). In Lynch's texts and Richards's photographs the past is not a separate entity, but rather a time that constantly interferes with the present and the future. The present is a process of constant reconstruction and composition of consequences and connections.

At the end of chapter 1 in *Exploding into Life*, Lynch has undergone mastectomy and she is waiting to be discharged from the hospital for Christmas. She explains that she is the last patient to be discharged; they are waiting because a doctor has been held up by another patient's prolonged childbirth. The two of them have been waiting for hours; Eugene is silent. She writes: "He makes me nervous. There doesn't seem to be anything to say" (Lynch and Richards 1986, p. 41). Here, she is voicing the silence using the passive voice; it is a silence of both of them who are unable to speak. In her conversation with Nancy, Ann Smock claims:

> Maybe in between the communication of disappointment and the disappointment of communication, there is speaking—there where the voice breaks, where the words part and divide in two—in two misunderstandings—where one is able only by mistake to turn away and depart from speaking, failing the obligation that speaking is, but unable, after all, to do that either; unable even to do that; unable to do anything but let the differing of language be—its division, its splitting between two.
>
> (Nancy and Smock 1993, p. 313)

However, what is the response when language is failing? How to speak "when the power to speak departs from you" (Nancy and Smock 1993, p. 311)? In *Exploding into Life*, photographs often enter the space when language is inadequate (in the last two chapters of the book there are more photographs than text, for example). However, how do photographs speak in silence? For Roland Barthes, photographs contain *studium*, their cultural context, and an "element which rises from the scene, shoots out of it like an arrow, and pierces me"—the *punctum* (Barthes 2000, p. 26). The *punctum* for Barthes is this "blind field" (Barthes 2000, p. 57) that is inaccessible via language, "a kind of subtle beyond" (Barthes 2000, p. 59) the visible frame that disturbs and "cries out in silence" (Barthes 2000,

p. 53). It extends the visible and often reveals itself *after* the image is observed. "Absolute subjectivity," Barthes states, "is achieved only in a state, an effort, of silence (shutting your eyes is to make the image speak in silence)" (Barthes 2000, p. 55). Through temporal delay, the image extends the conversation, and creates an affective response.

On the following page, after Lynch's text, there is a double-page spread of a photograph that depicts her (Figure 1). Her body opens up and stretches itself across the two pages, breaking out from the limitations and constraints of the page and the constraints of the empty hospital corridor. Lynch is wearing a patient's hospital gown—a depersonalised and uniform garment worn by all the patients on the ward, separating and indicating who belongs and who does not belong to the ward, hospital and disease. She is not allowed to go, as her text makes clear. Yet the image portrays a rebellious spirit; she is laughing, dancing and moving. She is facing the onlooker and the viewers of the image. There is a rhythm in the photograph, a sharpness of her face and knee, in contrast to the rest of her body and surroundings, which are slightly blurry, suggesting movement. The image feels spontaneous, it captures that one moment in between all the others: the moment of joy and nervousness, between inability to leave and inability to stay still. This image shows her in contradictory roles—the role of the patient and the role of the companion and lover, the role of the sick and that of the healthy. The presence of the photographer is acknowledged and through this so is the presence of the viewer. For Jacques Lacan, looking and being looked at are indistinguishable processes; he states: "things look at me, and yet I see them" (Lacan 2004, p. 109). Similarly, for Barthes, the lover's gaze constitutes several acknowledgments: "in this relation [. . .] I see only the other, I scan the other, I want to penetrate the secret of this body I desire; and on the other hand, I see the other seeing me" (Barthes 1985, p. 241). Yet, he emphasises that "by the other's all-powerful gaze" one cannot grasp that the other knows that "I see him: I see myself blind in front of the other" (Barthes 1985, p. 241). The subject of the photograph clearly occupies the visual field of the image, but Richards's presence is also there in the sense of being-with and his own desire to be seen and therefore loved by Lynch.

Figure 1. Courtesy Eugene Richards, *Exploding into Life.*

The shared vocabulary of their intimacy, in-jokes, silliness, gestures, tensions, obscure references, are meaningless to outsiders; they are untranslatable to strangers. For W.J.T. Mitchell, intimacy "implies collectivity, a circle of acknowledgment and recognition. [. . .] [i]t requires a third as witness or participant" (Mitchell 2005, p. 230). Intimacy, in this case, is constructed from overlapping layers or spaces of inclusion and exclusion, belonging and alienation. As readers and viewers, we transform the dialogic space into a scene of intimacy (Mitchell 2005, p. 230), as I will illustrate further below.

The majority of the photographs are taken in a hospital whilst Lynch is undergoing tests, treatments and, later, during conversations with other patients. The close-ups of Lynch's face, her body and the mastectomy wound are posed and captured within the confined and secluded spaces of hospital rooms, corridors and doctor's offices. Michel Foucault writes that: "Institutional codes can't validate these relations with multiple intensities, variable colors, imperceptible movements and changing forms. These relations short-circuit it and introduce love where there's supposed to be only law, rule, or habit" (Foucault 2000, p. 137). For Foucault, love is a highly political issue. In his text he is referring specifically to homosexuality within the army, yet the same can be applied to healthcare settings. The space of the hospital is designed to allow patients to be treated close to each other, devoid of any meaningful privacy, whilst also eliminating any meaningful contact (Frank 1997, p. 36). Similarly, hospitals and hospices do not acknowledge the need for intimate contact between patients and their close ones (Taylor 2014). Visiting hours are restricted, and the hospital beds are too narrow to allow any personal contact, sexual or otherwise. Here, photography provides the space for intimacy that is otherwise denied.

In a portrait of Lynch that appears towards the end of the book, she occupies the left side of the image, her hair and face are in movement, the light touches the side of her neck and hair (Figure 2). The background is sharp, contrasting with her blurry figure. She is leaning against the wooden bars of what seems to be a balcony. A pigeon is peacefully resting next to her. She is not looking at the camera; her eyes are closed and her head pointing upwards. The light, the blurriness of her body and hair and her upwards-directed pose resemble a religious painting. On the next page her text reads:

> After Gene shuts off the lights, he puts his arm around my head, so I roll against him. He kisses me, his lips big and soft against mine. The bristles of his beard scrape against my throat. I feel my stomach flutter, and lower down, the insides of me open. It is always thrilling, always new, this response of mine.

> (Lynch and Richards 1986, p. 154)

Richards's sensual, ethereal image of Lynch converses with her writing. The photograph also reflects a need to be desired. Their intimacy extends here into being-with, and not a sense of "being-present". Nancy describes this as the sense of "a present" that is not a being, instead "a coming and a passing, an extending and a penetrating" (Nancy 2007, p. 13) that communicates through resonance. The image and text converse here in a suspended virtuality.

Figure 2. Courtesy Eugene Richards, *Exploding into Life.*

I will now turn to Merendino's *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* and explore how a dialogue is created not only between image and text, but also between image and voice. I will also discuss the ways wider audiences shape and reproduce this narrative and the impications of this.

4. The Battle We Didn't Choose

Jennifer Merendino was diagnosed with breast cancer in February 2008, at the age of 36, just five months after her and Merendino's wedding. After undergoing a double mastectomy, chemotherapy and radiation treatment, the prognosis was promising. However, two years later, in April 2010, further tests revealed that the cancer had metastasised. At this time, Merendino began taking photographs of Jennifer to communicate their daily realities to their family and friends. If *Exploding into Life* started as a protest against the lack of visual representation of cancer, then Merendino's project grew out of a desperate need to communicate lived illness experience in a society that is largely oblivious to the realities of the disease, and where breast cancer is seen as an "enriching and affirming experience during which women with breast cancer are rarely 'patients' and mostly 'survivors'" ([King 2010](#), p. 286). Merendino recollects that after Jennifer's cancer metastasised, their friends and family did not understand the severity of Jennifer's condition: "Often people would tell us, 'You'll be ok. You're getting treatment at one of the top cancer hospitals in the world and you just have to stay positive'" ([Merendino 2013e](#), para. 9). On his blog, Merendino writes: "Our words were failing as we struggled to make known that we needed help so I turned to the only other form of communication I know—my camera" ([Merendino 2013b](#), para. 14). Similarly to *Exploding into Life,* when language is inadequate, photography here also "cries out in silence". The photographs here not only capture moments of togetherness, but, most importantly, they demand recognition, attention, and validation of Jennifer's and Merendino's experiences. As the cancer progresses, via the photographs Merendino calls upon the viewer to be with Jennifer in the pain of illness and fear of "nearness to death" ([Charon 2006](#), p. 135). Azoulay claims that "a photograph produced in the course of an encounter between photographer and photographed is created and inspired by a relation to an external eye, the eye of the spectator" ([Azoulay 2008](#), p. 129). In the photographic act the photographer and the photographed "acknowledge that they are not alone in front of the other" ([Azoulay 2008](#), p. 129). Although the photographs depict private and intimate moments shared by Merendino and Jennifer, they are created or enacted for public viewing.

At first the photographs and short texts published on Merendino's blog were meant to communicate Merendino and Jennifer's everyday realities to their close friends and relatives; however, soon the images began to attract a wider audience. Merendino recollects that one woman contacted them to say that "because of Jen she faced her fear and scheduled a mammogram. That's when we knew our story could help others" ([Merendino 2013c](#)). By making their story public, their experience gains meaning and there is a hope that the story can help others beyond their temporal and spatial bounds.

After Jennifer's death in December 2011, Merendino continued to share photographs and his recollections online. He notes that the "anonymous world of blogging" gave him a voice and kept him from "falling apart" ([Merendino 2013c](#)). For Merendino, the photographs "have been a bridge back to a time in my life that I am trying to not only understand but also never let go of" ([Merendino 2013d](#), para. 3). The images help Merendino situate "the illness disruption into a temporal framework" ([Hydén 1997](#), p. 53). Merendino, however, does not reflect upon this time in purely negative terms. Despite the horrors, struggles and fears, it is also a time that he tries not to "let go of". Each of the photographs "mechanically repeats what could never be repeated existentially" ([Barthes 2000](#), p. 4) and in this process, as Ulrich Baer claims, they "can provide special access to experiences that have remained unremembered yet cannot be forgotten" ([Baer 2005](#), p. 7). If, for Lynch, writing is a tool that helps her "sort out ideas and emotions and find out what I really feel" ([Lynch and Richards 1986](#), p. 35), then for Merendino, organising, editing, posting and sharing photographs and texts is a dynamic sense-making process and an essential part of managing his grief.

The project *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* was published in digital book format in September 2013, in celebration of Merendino and Jennifer's sixth wedding anniversary (Merendino 2013d, para. 1). The e-book consists of 98 black and white photographs, an introduction by Jennifer's oncologist, Dr. Tiffany A. Traina, a short text by Merendino that includes details about how he and Jennifer met, their struggles, fears and revelations after the diagnosis, and acknowledgements at the end of the book. The set of images is accompanied by a short text written by Jennifer, and nine images include audio recordings in which Merendino reflects on their relationship and his despair facing Jennifer's demise. The book also includes two short videos: one depicts Jennifer whilst they are on holiday, swimming in the Atlantic Ocean, and in the other Jennifer addresses the viewer and explains her aims and hopes for this project. The book includes transcripts of Merendino's recordings, and his and Jennifer's writings translated into Spanish, French, German, Italian and Russian. The photographs in the e-book are not dated, and although a timescale is given, the images do not follow a linear narrative. The viewers are forced to make sense of the events—to search for connections—and are "caught in a process of constant 'fulfilling' rather than, say, of ever 'completing' a whole picture" (Bate 2013, p. 49). There are hyperlinks to portfolios of other photographers, including the work of Eugene Richards, and charities and initiatives that raise awareness of breast cancer. *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* is not a stand-alone story; rather, it is embedded in a larger narrative that is created and shaped by readers/viewers, as I will illustrate further. The story can be accessed through horizontal scrolling (temporal arrangement), but the hyperlinks also allow observers to access new information spaces (spatial arrangement). George Landow states that:

> Electronic links connect lexias 'external' to a work [. . .] and thereby create text that is experienced as nonlinear, or, more properly, as multilinear or multisequential. Although conventional reading habits apply within each lexia, once one leaves the shadowy bounds of any text unit, new rules and new experience apply.
>
> (Landow 2006, p. 3)

Barthes defines "lexia" as "a series of brief, contiguous fragments" and "blocks of signification" (Barthes 1992, p. 13). The text here exceeds its meaning as material text printed on a page; instead, it is "a process of demonstration", and "experienced only in an activity of production" (Barthes 1977, p. 157). It could be argued that images and voice recordings are also part of this text. For Barthes: "The Text is not a co-existence of meanings but a passage, an overcrossing: thus it answers, not to an interpretation, even a liberal one, but to an explosion, a dissemination" (Barthes 1977, p. 159). It allows infinite permutations of signification. The concept of "text" as an explosion and dissemination is particularly relevant in the context of Merendino and Jennifer's visual narrative.

The information about the story is available on multiple platforms, including a photographer's website (https://www.angelomerendino.com/my-wifes-fight-with-breast-cancer) and a blog (https://www.mywifesfightwithbreastcancer.com/), Jennifer's blog (https://mylifewithbreastcancer.wordpress.com/), Twitter and Facebook accounts, a YouTube channel, multiple interviews with Merendino in online and offline media outlets, art gallery exhibitions, and two TEDx talks—*Photo Greater Than 1,000* (2013) and *Community on Social Networks Sharing Experiences and Healing* (2014).[6] The story thus circulates across several platforms and most of its elements, images and blog entries can be freely accessed, shared and remediated (Matthews and Sunderland 2017, p. 47). The story is circulated, analysed, read, watched, observed and "liked" (or otherwise reacted upon); it resonates with new

---

6   Notably, the word "fight" does not appear in the title of Jennifer's blog. Although the words "fight" and "fighting" appear in entries on her blog several times, the main focus here is on the everyday experience of living with cancer—doctor's appointments; treatments and her reactions to them; her fears, revelations and joy at seeing her friends and family. As much as the project *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* is about Jennifer's lived experience of breast cancer, it is also about Merendino's fight to not let go of her. Photography, as externalised memory, plays a part in this fight to capture and behold.

audiences and, through sharing and remediation, it unfolds over time. The users contribute to the story by adding their comments and conversing amongst each other. However, in their analysis of multimodal digital storytelling, Nicole Matthews and Naomi Sunderland argue that Jennifer's voice is not easy to hear; it gets lost within the multiplicity of stories (Matthews and Sunderland 2017, p. 49). This raises questions about ethical issues, such as power, ownership, consent and integrity. Although Jennifer is an active participant in the photographic act and a collaborator in this project, the circulation of the images and texts online occurs in unexpected ways, and their intentionality is subject to alterations.

In his text *Letting Stories Breathe: A Socio-Narratology*, Arthur W. Frank claims that: "Stories and humans work together, in symbiotic dependency, creating the social that comprises all human relationships, collectivities, mutual dependencies, and exclusions" (Frank 2010, p. 15). For Frank, stories do not, or do not only, reveal the private expressions of the storyteller but, most importantly, they produce and construct different subjectivities: "Those stories are never theirs [storyteller's and story listeners'] except as reassemblies of fragments on loan" (Frank 2010, p. 14). The concept of stories as social actors resonates with W.J.T. Mitchell's analysis of images as "not merely signs *for* living things but signs *as* living things" (Mitchell 2005, p. 6 (original emphasis)). Similarly, Ariella Azoulay argues that photographs cannot be considered finished works or objects (Azoulay 2008, p. 137). Referring to Hannah Arendt's definitions of work and labour, Azoulay states that photographs are rather acts that indicate a new beginning without a possibility of knowing the result. She writes: "The photo acts, thus making others act. The ways in which its action yields others' action, however, is unpredictable" (Azoulay 2008, p. 137). In this process, the authorship of the story, as well as the boundaries and limits of experience, are questioned and blurred. The story and images cannot exist without the storytellers, here Merendino and Jennifer. However, text, voice recordings and images also create an experience, as the anthropologist Cheryl Mattingly argues: "Experience is, at best, an enactment of pre-given stories" (cited in Frank 2010, p. 21). The ending of Merendino's and Jennifer's story becomes a beginning of yet other stories.

Multi-Sensory Engagement

Similar to Lynch and Richards' project, in *The Battle we Didn't Choose* project, photography and texts provide an intimate space that can be accessed through the visual, tactile and auditory senses in which relationships are played out. The voice recordings by Merendino that accompany nine images are short and contain a few sentences at most. The tone has a certain neutrality, the integrity of "a written text that speaks with the impersonality of the printed page" (Chion 1999, p. 54). However, the voice not only reveals the message, but also, through its timbre, accent, pitch, intonation and texture—which Barthes describes as "the grain of the voice" (Barthes 1977, p. 182)—the presence of a material body. The gaps between words and sentences on a page become breathing spaces. For Adriana Cavarero, voice is dynamic and transient, whilst image is subject to "a spatial, linear, analytical, and permanent process" (Cavarero 2005, p. 81). Similarly, in his text *Listening* (2007), Jean-Luc Nancy questions the relationship between the visual and the auditory: "Why in the case of the ear, is there a withdrawal and turning inward, a making resonant, but, in the case of the eye, there is manifestation and display, a making evident?" (Nancy 2007, p. 3). For Nancy, the sonorous reveals interiority, whilst the visual is more concerned with the surface. In between the two media there is "[a] continual relinking which takes place over the irrational break or the crack" (Deleuze 2006, p. 55). The text and image cannot be observed at the same time; there is physical as well as conceptual space between them. The voice, on the other hand, surrounds the image. Although the photographs in Merendino's project can be observed without the voiceover, allowing the viewer to create their own interpretations, once the voice button is clicked, the voice overlays the image, tainting it, giving it a specific meaning. Cavarero states that "[d]estined for the ear of another, the voice implies a listener—or better, a reciprocity of pleasure" (Cavarero 2005, p. 7). Through the emission of his voice, Merendino reveals himself to the viewer/listener and reiterates his position in relation to his wife.

An image towards the end of the e-book depicts Jennifer looking at the camera with a faint smile (Figure 3). There are no wounds visible in the photograph, but the image is not easy to look at. We see a woman with a bald head and a complexion that bears the marks of suffering and pain, her face swollen by medications. There is no pretence or denial: Jennifer is a woman marked by cancer, moving towards her death. As Boyer writes, "The cancer pavilion is a cruel democracy of appearance [. . .]. We resemble a disease before we resemble ourselves" (Boyer 2019a, p. 49). The blurred figure of a friend or relative is sitting to the right of her, leaning over a bed tray with a plate, smiling and holding her hand. Merendino's voice explains: "I can't think of many things in this world that made me as happy as seeing Jennifer smile. Especially, when Jen was smiling because of something I did" (Merendino 2013a). The past tense here signifies that the action is complete and the recording was most likely made after Jennifer's death. The image in relation to the voice allows two moments to encounter each other: one that once was and one that is enacted in the process of looking and listening. The photographic act here signifies the rite of passage towards death, as Sontag claims: "Photographs state the innocence, the vulnerability of lives heading toward their own destruction" (Sontag 1979, p. 70). At the same time, the voice and its message draw the attention back to Jennifer's face and her smile, as well as Merendino's position. Here Merendino has captured a moment of intimacy, a fleeting glance that provides a glimpse of their relationship. We see Jennifer through Merendino's eyes. Is she smiling because Merendino has said or done something? Barthes argues that a portrait contains two meanings or codes: "rhetorical order (declaration and detail) and an anatomical cataloguing (body and face). [. . .] when two codes function simultaneously but according to unequal wavelength, they produce an image of movement, an image of life" (Barthes 1992, p. 60). The photograph of Jennifer and the voice overlay and communicate the presence and intimacy that once was. The disruption in time and space that the various modalities cause opens up space that could be likened to what Foucault refers to as heterotopia—a space or a "counter-site" that does exist, yet this is a space that simultaneously reflects, contests and inverts real sites (Foucault 1984, p. 3). "These spatio-temporal units, these space-times, shared the fact of being places where I am and yet I am not", which, as Daniel Defert argues, transform ordinary existence and "ritualize splits, thresholds, and deviations, and localize them as well" (Defert 1997, p. 275). Images, voice recordings and text in Merendino's project formalise this space, yet this space is neither here nor there; it does not belong to the past, nor the present, it is neither real nor imaginary. This space, however, is critical in reconnecting with moments that are no longer present.
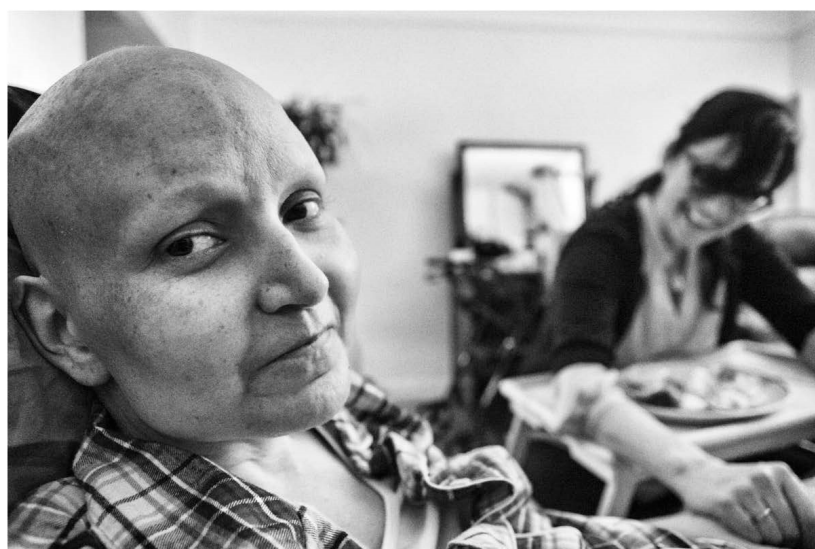
Figure 3. Courtesy Angelo Merendino, *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer*.

One of the last images in Merendino's e-book depicts an empty transferrable hospital bed (Figure 4). This last image feels hollow and silent. The hospital bed is detached from the sofa, gesturing towards a

physical separation. The cover is smoothed out, a bedsheet is folded, and two pillows are placed in the middle of the bed. There is a similar arrangement on the sofa-bed—three pillows are placed on top and some folded sheets or towels are visible in the right-hand corner of the image. The two beds mirror each other. The photograph is taken from a high angle, giving the illusion that the photographer and the viewer are hovering above. At the top centre of the image there is a photograph of Jennifer with an elderly man, presumably her father, looking back at the viewer. The image of Jennifer here "answers the need to include the virtual presence of those who are otherwise absent" (Batchen 2004, p. 12). The bed reveals what was once there, the void. The presence here contrasts with absence. Despite Jennifer's death, her presence can be felt in the image that looks back at us. In the absence of Jennifer, we must draw sense from absence, making absence a presence.

Figure 4. Courtesy Angelo Merendino, *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer*.

5. Conclusion

Exploding into Life and *The Battle we Didn't Choose—My Wife's Fight with Breast Cancer* are not only books about one individual's private struggle, but, most importantly, attempts to create a dialogue between the person living with breast cancer and their close other, as well as with a wider community. In the two projects illness is experienced not in isolation, but in relation. The photographs and text construct intimacy through aesthetic style, references to emotions, images and descriptions of everyday life and situations that would otherwise not be accessible to the viewer/reader. Intimacy here also unfolds in spaces that open up between photographs, photographs and text, and photographs and voice. The photographic act in *Exploding into Life* allows Lynch and Richards to challenge and reconfigure the institutional and formal space of the hospital and to establish intimacy between themselves and other patients on the cancer ward. Merendino's photographs capture the moments of togetherness and provide support after Jennifer's death. The sites in which Merendino and Jennifer's story is located act as public grieving spaces. Grief in this context is not a state, but a dynamic process that embodies participation, recognition and reflection. Intimacy here is a dynamic process that folds and unfolds over a period of time and space and in a relationship between the subject, photographer and the viewer/reader. The photographs and texts are created in response to different needs, including individual emotional needs, as well as to seek recognition and attention.

The photographs and texts provide meaning to the lives of Jennifer and Lynch, as the last entry of Lynch's text states:

No one is special, are they, when all is said and done? And, of course, each of us is very special, very singular, carrying weight. I matter. [. . .] I would like to open the window tonight and yell that outside. <u>I matter.</u> Or go down and lie next to the plants and whisper it.

<div align="right">

(Lynch and Richards 1986, p. 161 (original emphasis))

</div>

Despite their biological death, Jennifer and Lynch still exist to those with whom their lives have been interconnected and also to the readers and observers who have been touched by the images and text. Here, Boyer's concept of "undying" comes to mind (Boyer 2019a). Boyer describes her experience of surviving yet "dying along with the death of my cells, and not entirely losing myself as I lost the parts of me I associated with me—my memories, my looks, my capacity to think as I once did, my body parts, even the certainty of my own existence" (Boyer 2019b). Similarly, in these projects, life and death is described as unravelling, as the boundaries of existence and experience are challenged and reshaped.

References

Alù, Giorgia, and Sarah P. Hill. 2018. The Travelling Eye: Reading the Visual in Travel Narratives. *Studies in Travel Writing* 22: 1–15. [CrossRef]

Azoulay, Ariella. 2008. *The Civil Contract of Photography*. New York and Cambridge: Zone Books.

Baer, Ulrich. 2005. *Spectral Evidence: The Photography of Trauma*. Cambridge and London: The MIT Press.

Barthes, Roland. 1977. *Image. Music Text*. London: Fontana Press.

Barthes, Roland. 1985. *The Responsibility of Forms: Critical Essays on Music, Art, and Representation*. Berkeley and Los Angeles: University of California Press.

Barthes, Roland. 1992. *S/Z*. Translated by Richard Miller. Oxford: Blackwell Publishers.

Barthes, Roland. 2000. *Camera Lucida: Reflections on Photography*. New Edition. London: Vintage Classics.

Batchen, Geoffrey. 2004. *Forget Me Not. Photography & Remembrance*. New York: Princeton Architectural Press.

Bate, David. 2013. The Emancipation of Photography. In *The Versatile Image: Photography, Digital Technologies and the Internet*. Edited by Alexandra Moschovi, Carol McKay and Arabella Plouviez. Leuven: Leuven University Press, pp. 37–52.

Bazin, André. 1960. The Ontology of the Photographic Image. *Film Quarterly* 13: 4–9. [CrossRef]

Bell, Susan E. 2002. Photo Images: Jo Spence's Narratives of Living with Illness. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine* 6: 5–30.

Boyer, Anne. 2019a. *The Undying: A Meditation on Modern Illness*. London: Allen Lane.

Boyer, Anne. 2019b. Undying and Reparative Magic: A Conversation With Anne Boyer. Interview by Shoshana Olidort. *Poetry Foundation*. September 23. Available online: https://www.poetryfoundation.org/harriet/2019/09/anne-boyer-undying-interview (accessed on 13 March 2020).

Brown, Phil, Stephen Zavestoski, Sabrina Mccormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior Altman. 2004. Embodied health movements: New approaches to social movements in health. *Sociology of Health and Illness* 26: 50–80. [CrossRef] [PubMed]

Butler, Judith. 2011. *Bodies that Matter: On the Discursive Limits of 'Sex'*. New York: Routledge.

Cavarero, Adrianna. 2005. *For More Than One Voice: Toward a Philosophy of Vocal Expression*. Palo Alto: Stanford University Press.

Charon, Rita. 2006. *Narrative Medicine: Honouring the Stories of Illness*. New York: Oxford University Press.

Chion, Michel. 1999. *The Voice in Cinema*. New York: Columbian University Press.

Couser, Thomas G. 1997. *Recovering Bodies: Illness, Disability, and Life Writing*. Madison: University of Wisconsin Press.

Couser, Thomas G. 1998. Making, Taking, and Faking Lives: The Ethics of Collaborative Life Writing. *Style. Literature and Ethical Criticism* 32: 334–50.

Defert, Daniel. 1997. Foucault, Space, and the Architects. In *Politics- Poetics: Documenta X—The Book*. Edited by Catherine David and Jean-François Chevrier. Ostfildern-Ruit: Cantz Verlag, pp. 274–83.

Deleuze, Gilles. 2006. *Foucault*. London and New York: Continuum Books.

DeShazer, Mary K. 2013. *Mammographies: The Cultural Discourses of Breast Cancer Narratives*. Ann Arbor: University of Michigan Press.

Diedrich, Lisa. 2007. *Treatments. Language, Politics, and the Culture of Illness*. Minneapolis and London: University of Minnesota Press.

Foucault, Michel. 1984. Of Other Spaces: Utopias and Heterotopias. Architecture Mouvement Continuité. Available online: http://web.mit.edu/allanmc/www/foucault1.pdf (accessed on 5 February 2020).

Foucault, Michel. 2000. *Ethics: Subjectivity and Truth: Essential Works of Michel Foucault 1954–1984*. London: Penguin, vol. 1.

Frank, Arthur W. 1997. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.

Frank, Arthur W. 2010. *Letting Stories Breathe: A Socio-Narratology*. Chicago and London: The University of Chicago Press.

Huber, Irmtraud. 2016. *Present Tense Narration in Contemporary Fiction: A Narratological Overview*. London: Pelgrave Macmillan.

Hydén, Lars-Christer. 1997. Illness and Narrative. *Sociology of Health and Illness* 19: 48–69. [CrossRef]

Isaac, Jo Anna. 2002. *Feminism and Contemporary Art: The Revolutionary Power of Women's Laughter*. London and New York: Taylor & Frances e-Library.

King, Samantha. 2010. Pink Diplomacy: On the Uses and Abuses of Breast Cancer Awareness. *Health Communication* 25: 286–89. [CrossRef] [PubMed]

Kleinman, Arthur, and Don Seeman. 2000. Personal experience of illness. In *The Handbook of Social Studies in Health and Medicine*. Edited by Gary L. Albrecht, Ray Fitzpatrick and Susan C. Scrimshaw. London: Sage Publications Ltd., pp. 230–42.

Kristeva, Julia. 1982. *Powers of Horror: An Essay on Abjection*. New York: Columbia University Press.

Kushner, Rose. 1975. *Breast Cancer: A Personal History and an Investigative Report*. New York: Harcourt Brace Jovanovich.

Lacan, Jacques. 2004. *The Four Fundamental Concepts of Psycho-Analysis*. London and New York: Karnac Books.

Landow, George. 2006. *Hypertext 3.0: Critical Theory and New Media in an Era of Globalization*. Baltimore: The John Hopkins University Press.

Lee, Eunjin, and Linda J. Roberts. 2018. Between Individual and Family Coping: A Decade of Theory and Research on Couples Coping with Health-Related Stress. *Journal of Family Theory and Review* 10: 141–64. [CrossRef]

Lerner, Barron H. 2002. Breast cancer activism: Past lessons, future directions. *Nature Reviews/Cancer* 2: 225–30. [CrossRef] [PubMed]

Lorde, Andre. 1980. *The Cancer Journals*. Argyle: Spinsters, Ink.

Lynch, Dorothea, and Eugene Richards. 1986. *Exploding Into Life*. New York: Aperture in association with Many Voices Press.

Matthews, Nicole, and Naomi Sunderland. 2017. *Digital Storytelling in Health and Social Policy: Listening to Marginalised Voices*. Abingdon and New York: Routledge.

Merendino, Angelo. 2013a. The Battle We Didn't Choose—My Wife's Fight with Breast Cancer. Apple Books. Available online: https://books.apple.com/gb/book/the-battle-we-didnt-choose/id714342247 (accessed on 13 March 2020).

Merendino, Angelo. 2013b. Our Story. The Battle We Didn't Choose—My Wife's Fight with Breast Cancer (blog). Available online: https://www.mywifesfightwithbreastcancer.com/home#.XZC5KyV7lN0 (accessed on 13 March 2020).

Merendino, Angelo. 2013c. Photo Greater Than 1000: Angelo Merendino at TEDxUSU. Available online: https://www.youtube.com/watch?v=KeT221skphw (accessed on 15 September 2019).

Merendino, Angelo. 2013d. The Battle We Didn't Choose. *Breast Cancer Consortium. Critical Thinking on Breast Cancer*. Available online: https://breastcancerconsortium.net/the-battle-we-didnt-choose/ (accessed on 10 September 2019).

Merendino, Angelo. 2013e. 'Interview with Angelo Merendino—My Wife's Fight with Breast Cancer'. Interview by Angela Butler. *PHLEARN*. January 29. Available online: https://phlearn.com/magazine/phlearn-interviews-angelo/ (accessed on 13 March 2020).

Mitchell, Thomas W. J. 1994. *Picture Theory: Essays on Verbal and Visual Representation*. Chicago: The University of Chicago Press.

Mitchell, Thomas W. J. 2005. *What Do Pictures Want? The Lives and Loves of Images*. Chicago and London: The University of Chicago Press.

Mol, Annemarie. 2002. *The Body Multiple: Ontology in Medical Practice*. Durham: Duke University Press.

Morris, David. 2008. Diabetes, Chronic Illness and the Bodily Roots of Ecstatic Temporality. *Human Studies* 31: 399–421. [CrossRef]

Mulvey, Laura. 2007. *Death 24x a Second: Stillness and the Moving Image*. London: Reaktion Books Ltd.

Nancy, Jean-Luc. 2007. *Listening*. New York: Fordham University Press.

Nancy, Jean-Luc, and Ann Smock. 1993. Speaking Without Being Able To. In *The Birth to Presence*. Edited by Werner Hamacher and David E. Wellbery. Stanford: Stanford University Press, pp. 310–18.

Nielsen, Emilia. 2019. *Disrupting Breast Cancer Narratives: Stories of Rage and Repair*. Toronto: University of Toronto Press.

NIH Categorical Spending. 2019. Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC). In *National Institutes of Health*. Available online: https://report.nih.gov/categorical_spending.aspx (accessed on 17 November 2019).

Radley, Alan. 2002. Portrayals of Suffering: On Looking Away, Looking at, and the Comprehension of Illness Experience. *Body & Society* 8: 1–23.

Richards, Eugene, and Don McCullin. 2011. Interview: Heroes & Mentors: Don McCullin and Eugene Richards. *PhotoDistrict News*. July 20. Available online: https://pdnonline.com/features/photographer-interviews/heroes-mentors-don-mccullin-and-eugene-richards/ (accessed on 15 February 2020).

Robinson, Carole A. 2016. Trust, Health Care Relationships, and Chronic Illness. A Theoretical Coalescence. *Global Qualitative Nursing Research* 3: 1–11. [CrossRef] [PubMed]

Sile, Agnese. 2018. Echo and the Failure of Knowing in Judith Fox's Photographic Project 'I Still Do: Loving and Living with Alzheimer's'. *Journal of Medical Humanities* 39: 361–75. [CrossRef] [PubMed]

Sontag, Susan. 1979. *On Photography*. Harmondsworth: Penguin.

Spence, Jo. 1986. *Putting Myself in the Picture: A Political, Personal, and Photographic Autobiography*. London: Camden Press.

Taylor, Bridget. 2014. Experiences of Sexuality and Intimacy in Terminal Illness: A Phenomenological Study. *Palliative Medicine* 28: 438–47. [CrossRef] [PubMed]

Thomas, Helen. 2013. Breast Cancer Autopathography: The Laws of the Body and the Body of the Law. In *Scenes of Intimacy: Reading, Writing and Theorizing Contemporary Literature*. Edited by Jennifer Cooke. London and New York: Bloomsbury Academic, pp. 191–210.

Thorne, Sally E., John L. Oliffe, Valerie Oglov, and Karen Gelmon. 2013. Communication Challenges for Chronic Metastatic Cancer in an Era of Novel Therapeutics. *Qualitative Health Research* 23: 863–75. [CrossRef] [PubMed]

Wagner, Peter. 1995. *Reading Iconotexts. From Swift to the French Revolution*. London: Reaktion Books Ltd.

Žižek, Slavoj. 1991. *Looking Awry: An Introduction to Jacques Lacan through Popular Culture*. Cambridge: MIT Press.