Temporality and the Carer’s Experience in the Narrative Ecology of Illness: Susan Sontag’s Dying in Photography and Prose

Yianna Liatsos
School of English, Irish, and Communication, University of Limerick, V94 T9PX Limerick, Ireland; Yianna.Liatsos@ul.ie

Received: 24 June 2020; Accepted: 11 August 2020; Published: 16 August 2020

Abstract: This paper joins a discussion about the representational dissonance and commemorative ethics of two self-referential works that engage with Susan Sontag’s 2004 death from Myelodysplastic Syndrome: Annie Leibovitz’s A Photographer’s Life 1990–2005 (2006) and David Rieff’s Swimming in a Sea of Death: A Son’s Memoir (2008). Instead of approaching these two texts as testimonial accounts measured by standards of reliability and grace, this paper considers how the temporal dissonance produced by an incurable cancer diagnosis thwarts questions of personhood and ethical intention in Leibovitz’s photography and Rieff’s prose. By contextualizing these works as the caregivers’ experience of Sontag’s illness, this paper reads them as attempts at gauging two distinct temporal perspectives that confound identification—those of living through and of remembering terminal time.

Keywords: illness memoir; illness photography; cancer; prognosis; temporality

Susan Sontag’s 2004 death from Myelodysplastic Syndrome (MDS) is routinely addressed in publications on Sontag’s oeuvre and the Medical Humanities at large, mostly through reference to two texts: Annie Leibovitz’s A Photographer’s Life 1990–2005 (2006), which alongside some of Leibovitz’s commissioned work and family photographs displays intimate pictures of the two women’s fifteen year relationship, including ones from Sontag’s final days and death; and David Rieff’s Swimming in a Sea of Death: A Son’s Memoir (2008), which recounts in detail Sontag’s final year, from the time of terminal diagnosis (29 March 2004) to her death, nine months later (28 December 2004). One of the leading topics of discussion about these two works has to do with their alleged representational dissonance, whereby Leibovitz’s pictures of a barely recognizable and visibly expiring Sontag in a hospital room have largely drawn shock and condemnation, while Rieff’s memoir, following two years after Leibovitz’s book, has been primarily lauded as chronicling Sontag’s terminal illness with honesty and courage.

1 In her essay on Leibovitz and Rieff’s memoirs entitled “Cancer Narratives and an Ethics of Commemoration” Mary DeShazer gives the following breakdown of the photos in Leibovitz’s book: “Of the 341 images contained in the book, which Leibovitz calls “a memoir in photographs,” more than two-thirds are personal, and approximately a hundred of these depict Sontag” (DeShazer 2009, p. 217).

2 Not all reception of these two texts has echoed these sentiments. A general overview of the literature indicates that scholarship adopting a medical humanities perspective has tended to remain neutral in its reference to this tension between Leibovitz and Rieff’s memoirs—see (Conway 2007; Avrahami 2007; Burt 2009; Jurecic 2012; O’Mahony 2016), among others. Works that focus on Sontag herself or review Leibovitz’s album have tended to fall into this pattern—with several exceptions. The following list is an amalgamation of the ones offered in Mary K. DeShazer’s article “Cancer Narrative and an Ethics of Commemoration” (2009) and my own findings: critical of Leibovitz—(Smith 2006; Karnasiewicz 2006; Thomson 2007; Miller 2009), among others; supportive of Leibovitz—(Guthmann 2006; Garwood 2007; Wilson 2008; Jacobs 2017), among others; critical of Rieff—(Zuger 2008; Mars-Jones 2008; Rickett et al. 2015), among others; supportive of Rieff—implicitly, all publications that reference Rieff’s memoir as the default archive (perhaps in conjunction with Sontag’s diaries, which Rieff posthumously edited and published) of Sontag’s final cancer treatment and death.
The aim of this article is to contribute to these discussions by considering how the temporal dissonance produced by an incurable cancer diagnosis thwarts questions of personhood and ethical intention in Leibovitz’s pictures and Rieff’s prose. Specifically, I am interested in how a focus on temporality reframes how the experience of illness is endured and recollected, and how photography and prose engage this reframing process in distinct ways within the narrative ecology of terminal cancer. In the process, this paper also contributes to the discourse of illness narratives at large by shifting the focus from the patient and autothanatographical writing, which dominates the field, toward the primary caregivers and their distinct situatedness in the lived reality of terminal illness. By contextualizing Leibovitz’s and Rieff’s autobiographical records of Sontag’s death as the carers’ experience of her illness, this paper moves from approaching the two texts as testimonial accounts measured by the stick of ethical correctness, to reading them as uncertain materializations of two distinct temporal perspectives that confound identification—those of living through and of remembering terminal time.

Among Sontag’s reflections on how life-threatening illness in general, and cancer in particular, is understood and represented by interrelated social registers, the most cited one is the spatial metaphor that opens her acclaimed book *Illness as Metaphor* (1978). In a mythological, if patriarchal language, Sontag conceives of embodied consciousness as shaped by its situatedness into one of two kingdoms, the kingdom of the well and the kingdom of the sick, and she stresses the cognitive dissonance that an individual is subjected to when she is forced to leave the former kingdom to reside, indefinitely, in the latter. S. Lochlann Jain’s autoethnographic book *Malignant: How Cancer Becomes Us* (2013) turns to Sontag’s metaphor to describe the author’s grasp of her own cancer diagnosis, and expands Sontag’s scope for understanding the impact of such diagnosis by introducing, among other considerations, the variable of time to the discussion.

Calling the temporality that a newly diagnosed cancer patient inhabits “prognostic time,” Jain addresses the inherent disjointedness of its lived experience: “Living in prognosis,” she notes, “severs the idea of a timeline and all the usual ways we orient ourselves in time: age, generation, and stage in the assumed lifespan. If you are going to die at forty, shouldn’t you be able to get the senior discount at the movies when you are thirty-five?” (Jain 2013, p. 29). Furthermore, she continues: “Described by words such as _apoptotic_ and _runaway_, cancer inhabits a competing version of time . . . From cashing in the retirement savings to hours spent in the waiting room, from the prognosis to the too quickly dividing cells, cancer is always about time” (Jain 2013, p. 61). The protocol for gauging the cancer diagnosis, which entails the review of pathology reports and prognostic charts for the purpose of determining potential treatments (and for assessing malpractice claims, as it were), reveals the perplexity of cancer’s temporal countenance even further. If clinical encounters, according to Brian Hurwitz, “focus typically on temporal sequences, on relations of before and after, on discussions of beginnings and endings,” the exchange between oncologist and patient conjures temporal incongruities that undermine the rational omniscience traditionally projected onto and performed by medical authority (Hurwitz 2004, p. 414).

Jain explains:

In one swift motion, the cancer prognosis detonates time, which scatters like so many glass shards. Having harbored cancer in one’s body all that time before diagnosis, when one thought one was quite well, thank you, mystifies both past and future . . . unable to specify with certainty the behavior of any one particular cancer, oncology relies instead on statistics. One rarely knows if treatment has ended for good or if a next round with the “palliative” rather than the “cure” box checked on the medical treatment forms will be needed. A prognosis seems like a fact, if only a scrap of flotsam frenziedly bobbing in the rapids of cancer treatment. But its stunning specificity (“34.7%”) shields the bloodlessly

---

3 “Illness is the night-side of life,” begins Sontag’s *Illness as Metaphor*, “a more onerous citizenship.” Furthermore, she continues: “Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (Sontag 1978, p. 3).
vague platitude: in five years, you, yourself, will be either dead or alive. The prognosis purees the I-alive-you-dead person with the fundamental unknownness of cancer and glops it into the general form of the aggregate. The individual cookie cut from the dough is both prognostic subject and cancer object. (Jain 2013, pp. 28–29)

Jain’s insights into the experience of a cancer diagnosis broadens discussions about the power of social discourses and medical language to transform the individual subject from person to patient, by revealing temporality as an additional register of signification in the grammar of illness. Jain’s discussion of what she calls “prognostic skullduggery” shifts life-threatening illness from a solitary experience into a protracted exchange between the displaced individual, who has had her habits of subjectivity, along with her internal sense of time, interrupted; and the array of healthcare professionals and medical technologies that govern the kingdom of the sick while nonetheless operating under the normative temporality regiment of the kingdom of the well (Jain 2013, p. 27). The clinician, with the authority of expertise behind her and a partiality toward a linearly chronological storyline that fosters the potential of a restorative ending, assumes top billing within the narrative ecology of illness. In doing so she eclipses the patient’s temporal experience and the corresponding pulverized experience of the self. Before the healthcare worker, who is armored with clinical data and “the firing squad of statistics,” the patient, according to Jain, is rendered mute by a vernacular that swirls around in unrecognizable patterns (Jain 2013, p. 28). In his own memoir Rieff describes this experience as “infantilizing asymmetry” and recognizes himself, as his mother’s caretaker, to also fall in the purview of its administration (Rieff 2008, pp. 135–36). For the patient, this can be a source of great conflict—the medical discourse stipulates a narrative sense of time and self that does not correspond to the patient’s experience—and/or great comfort—the doctor’s coherent narrative, with its promise of potential restoration, or, minimally, of tending to the best care of the patient under the circumstances, functions as a reassuring scaffolding in an otherwise chaotic reality.

Irrespective of one’s response to the unresolvable temporal conflict at the heart of a cancer diagnosis, the signifying predicament of a life-threatening illness remains: insofar as it renders time indeterminately contingent and in so doing unravels one’s sense of self-as-patient, it becomes precarious at best to accommodate the experience of being sick in the conventional language of personhood—either for the purpose of tapping onto one’s sense of self-determination in choosing how to respond to the range of available treatments, or for reconciling oneself to one’s death, as the legacy of a “good death” has it. Put simply, the temporal perplexity of a life-threatening illness undoes one’s secure hold on futurity, that is, on the temporal horizon that gives the modern self one of its most fundamental endowments, that of agency. These incongruities also extend to the discourses of commemoration and ethics, which are directly linked to the normative identity-based language, and so fall short of effectively correlating with the experience of life-threatening sickness and its impact on those who live through it. Sontag’s terminal illness archive at our disposal allows us to reflect on the limits of signifying illness from the perspective of the primary caregiver, the “survivor” of prognostic time,

---

4 In The Wounded Storyteller (Frank 1995), one of the formative texts in the field of medical humanities at large and the subfield of narrative medicine in particular, Arthur Frank focuses on the individual change from a person to a patient, and names three types of autobiographical narratives that capture the lived experience of this transformation—the chaos, quest, and restitution narratives.

5 Jain quotes a poignant segment from the blog of a young woman dying of ovarian cancer: “The vernacular drones constantly. And for those who speak it, the task is loose, as it should be. Rendered mute, you can only listen to the din. It swirls around you, looping endlessly in patterns and figures you can’t quite recognize—a language you once studied, but cannot speak or master” (Jain 2013, p. 28).

6 While the medical humanities subfields of Narrative-Based Medicine and Narrative Medicine have sought to mediate the alienating experience that Evidence-Based Medicine tends to invoke for the patient by reducing her to a cog of a diagnostic algorithm, there are countless references made in illness memoirs to the comfort patients experience in relinquishing choice over treatment to doctors they deem competent and empathic. Among recent such memoirs see Nina Riggs’ The Bright Hour: A Memoir of Living and Dying (Riggs 2017) and Julie Yip-Williams’ The Unwinding of the Miracle: A Memoir of Life, Death, and Everything That Comes After (Yip-Williams 2019). Rieff’s own memoir makes such references on behalf of both himself and his mother.
as Rieff repeatedly characterizes himself in relation to his mother’s terminal illness (Rieff 2008). As the patient’s confidant the caretaker partakes in the patient’s prognostic temporality and identity fluidity. In the case of incurable diagnosis, however, the carer, unlike the patient, emerges from the kingdom of illness, marked in irrevocable ways by an experience she/he must integrate as she/he returns to a life of order and constancy. The constellation of Leibovitz’s and Rieff’s respective photographic and written memoirs provide us with a unique insight into this experience-of-incurable-illness-by-proxy by capturing both the discordant reality of living through prognostic time, and of coming to terms with its unsettled aftermath.

Leibovitz’s brief introduction to her photographic memoir makes repeated references to both her biological family and relationship with Sontag, thus assuming the well-worn dictum that all self-referential expression is relational. By specifying that A Photographer’s Life is “an archaeological dig” at the service of her grief over Sontag and her father’s deaths to cancer in the span of six weeks, Leibovitz directs us to read this composition of herself as the product of a particular identity transformation that reflects what Sandra Gilbert has described as “cross[ing] the ‘bitter river’ into death along with” a loved one (Gilbert 2006, p. 5). In Leibovitz’s case, this mnemonic effort at self-reflection is inherently informed by the caretaker’s experience of living in prognosis. If prognostic time, as Jain has suggested, “demands that we adopt its own outside ‘pre-posterous’ viewpoint, one in which the end, or posterior, seems to precede the story,” then the carers of terminally-ill patients are faced with the double task of mourning the loss of a loved one—and through her, an essential measure of reality—while also working through the affective holdover of prognostic temporality.

Photography, as a technology of temporal registration, may be uniquely positioned for this kind of memory work. Sontag herself, in her first book on the subject entitled On Photography (1973), called the medium “an elegiac art, a twilight art” (Sontag 1973, p. 15). “All photographs are memento mori,” she argued; “to take a photograph is to participate in another person’s (or thing’s) mortality, vulnerability, mutability. Precisely by slicing out this moment and freezing it, all photographs testify to time’s relentless melt” (Sontag 1973, p. 15). Roland Barthes built on Sontag’s insight by calling temporality the ur-punctum of photography. In Camera Lucida (1981), where Barthes famously coined and distinguished between the now quintessential photographic terms of the studium (the recognizable system of cultural sensibilities that allows the viewer to recognize the photographic subject matter and the photographer’s intentions in photographing it) and the punctum (the affect that exists in the detail of the photographic image and exceeds the logic of the studium in a way that pricks the viewer, overwhelming her comprehension/interpretation), he wrote of Time as another punctum which is not an integral aspect of the photographic form but rather of its intensity. Barthes called this other punctum “the lacerating emphasis of the noeme (“that-has-been”), its pure representation,” and wrote about it in terms that echo the temporal fold of Jain’s “pre-posterous” prognostic time:

[In seeing a photograph] I read at the same time: This will be and this has been; I observe with horror an anterior future of which death is the stake. By giving me the absolute past of the post (aorist), the photograph tells me death in the future. What pricks me is the discovery of this equivalence . . . Whether or not the subject is already dead, every photograph is this catastrophe . . . each photograph always contains this imperious sign of my future death.” (Barthes 1981, pp. 96–97)

Through her introductory reference to A Photographer’s Life as a grieving practice, Leibovitz evokes this kind of spectral—anterior future—reading of her memoir, which progresses mostly chronologically and whose earliest images precede the book’s 1990–2005 timeframe by two years, thus signaling the anarchic relationship of memory to chronological mandates even within the context of a personal archive. Photographs of Sontag, which make up approximately a third of the book, mainly document her private life in variant degrees of intimacy that capture her vitality, intellect, and physicality in the

At the same time, however, among these pictures there is a qualitatively different type of photograph to be found, that depicts Sontag’s cancer in ways that unsettle her otherwise venerating commemoration. This disruption is at the heart of the criticism Leibovitz’s book has received. Most photographic memoirs chronicling cancer, or other life-threatening illnesses, are auto-bio/thanato-graphical, so that the abject effect of their pictures is recognized as the patient’s chosen and conscious expression for the purpose of restoring agency in the face of complete objectification by the medical discourse—what Jo Spence called the process of “putting [one]self in the picture.” Insofar as Leibovitz’s photographs of Sontag’s three bouts of cancer cannot avail of this legitimating authorship, they have been criticized for not adhering to the moral code of photojournalism’s documentary aesthetic, thus compromising their photographic subject’s dignity and privacy. Mary DeShazer and Karen Jacobs have already offered insightful readings of these controversial images (as a practice of intimate witnessing and as part of a queer family album, respectively) that have gone a long way toward putting these criticisms to rest. My own reason for

---

7 In her 2006 interview to Edward Guthmann, Leibovitz addressed her relationship with Sontag whose status had been kept out of the public purview while Sontag was alive. According to Leibovitz terms like “companion” or “partner” were never used by the two women. “It was a relationship in all its dimensions,” said Leibovitz. “Call us ‘lovers’. . . I like ‘lovers.’ You know, ‘lovers’ sounds romantic. I mean, I want to be perfectly clear. I love Susan. I don’t have a problem with that. I just had a problem with ‘partner’ or ‘companion.’ It just sounds like two little old ladies” (Guthmann 2006).

8 In her photographic memoir entitled Putting Myself in The Picture: A Political, Personal and Photographic Autobiography, Jo Spence noted how her turn to photographic narrative in the face of a breast cancer diagnosis was for the purpose of reclaiming a modicum of agency: “Passing through the hands of medical orthodoxy can be terrifying when you have breast cancer. I determined to document for myself what was happening to me. Not to be merely the object of their medical discourse but to be the active subject of my own investigation”—(Spence 1988, p. 153). Similar efforts at reclaiming agency have been expressed by other memoirists who chose to document their experience with a cancer diagnosis (predominantly breast cancer) through the photographic medium—most famously Hannah Wilke and Lynn Kohlman (referenced and discussed in detail in Jain’s Malignant).

9 In her article “Retouching Queer Kinship: Sontag, Leibovitz, and the Ends of the Photographic Lens,” Karen Jacobs reflects on the debates about the ethics of representation in photographic albums of HIV-positive subjects and people with AIDS—specifically those by Nicholas and Babe Nixon (People With AIDS) and Thomas McGovern (Bearing Witness to AIDS)—in order to contextualize the “hostile response generated by Leibovitz’s hospital and postmortem images of Sontag” (Jacobs 2017, p. 10).

10 (DeShazer 2009; Jacobs 2017) have already come to Leibovitz’s defense by reading the effects of her photographic memoir in ways that go beyond Leibovitz’s own explanations. In her essay “Cancer Narratives and an Ethics of Commemoration’
referring to the disconcerting impact of these cancer images in Leibovitz’s memoir is in order to point out the affective discrepancy among photographs whose temporality is differently configured. Futurity bestows an elegiac punctum on all photographs that possesses identifying markers, as Sontag and Barthes suggest (we read Barthes exclaiming, upon seeing an old photograph of two little girls, one of whom is his now dead mother, “how alive they are! They have their whole lives before them; but also they are dead today”) (Barthes 1981, p. 96). Photographs that depict cancer’s material evidence on the body, however, possess a punctum that exceeds elegiac observations to deliver what Sontag has described as the intolerably realistic sight of death’s unruly viscerality (Sontag 2003, p. 63). In capturing what Jain describes as the terror of prognostic time and Rieff has described it as living with “the sword of Damocles” over one’s head, Leibovitz’s cancer photos of Sontag archive the caretaker’s similarly intolerable symbiotic attendance to the partner’s experience with cancer, through the photographic promise of what Mary Ann Doane calls “the storage and legibility of time” (Doane 2002, p. 25).

Already in the early part of A Photographer’s Life there is a two page tetraptych of pictures that depict Sontag naked in a bath in Leibovitz’s apartment covering the absent left breast that was removed after she was diagnosed with stage IV metastatic breast cancer (“My apartment in London Terrace, West 23rd Street, New York, 1992”). Unlike the effect of other tetraptychs that Leibovitz composes in her memoir so as to produce a filmic effect of flow and movement (“more like life,” Leibovitz calls it), these photographs convey both an iconographic stillness (Sontag’s face, photographed in profile from a high angle, is unemotional) and vulnerability (the three other pictures, along with the profile picture, depict Sontag with her hand protectively covering the scarred remainder of the radical mastectomy—Halstead—she had been subjected to in 1975). In 1992, when those photographs are taken, Sontag knew that the wager of the grueling cancer treatment she had pursued had already won her an eighteen-year remission, but in light of subsequent photographs in the collection those images convey the punctum of a death sentence postponed. As Jacobs suggests, within the larger context of Sontag’s subsequent bouts with cancer in 1998 and in 2004, these four pictures act as “as a poignant reminder that the Sontag of 1992 was already beginning to run out of time” (Jacobs 2017, p. 23).

The second set of Sontag’s illness pictures are found approximately halfway through Leibovitz’s memoir and document Sontag’s 1998 diagnosis of uterine cancer in three sets of tetraptychs that depict Sontag as resting in her hospital room (first tetraptych); lying on her side while a healthcare worker is administering a treatment that causes Sontag visible discomfort (second tetraptych); and out of the hospital room (“Susan receiving chemotherapy, 1998”; “Susan with Ben Yeoman at 24th Street, August 1998”; “Bertilda Garcia cutting Susan’s hair, West 24th Street, August 1998”—third tetraptych). Whatever pensive melancholy may be found in the first set of tetraptychs of this photographic sequence dissipates by the third set of the arrangement, which portrays Sontag busy at work with her writing, compliantly looking at the nurse who is organizing her chemotherapy session via the port on her chest; and matter-of-factly getting her hair cut short to presumably accommodate the aftereffects of the chemotherapy. The Sontag we see in these pictures is the one who Rieff describes as “a militant propagandist” who had figured out how to fight and beat cancer—by gathering “the right information, the right doctors, and the right follow-through, and above all the willingness to undergo any amount

DeShazer argues the ethical predicaments posited by the photographs in question are integral to the paradox that any witness of trauma faces: at once, the impossibility of not testifying to that which has been witnessed; and the futility of ensuring that the visual representation will escape the objectification of its subject—the crux of Sontag’s own dilemma in Regarding the Pain of Others. DeShazer insists that the sole resolution to this paradox must come from the audience’s response to these images. It is we who must decide how we will encounter these images—voyeuristically, or as reciprocal witnesses. Jacobs, on the other hand, reads Leibovitz’s book as the expression of a posthumous “coming out.” While focusing on Leibovitz’s postmortem photograph of Sontag and reflecting on it in relation to the longer history of the photographic genre, Jacobs argues that the memoir functions as a queer family archive that altogether challenges the normative spatial (private/public) and temporal (living/dead and past/future) frameworks of commemorative ethics, alongside the boundaries between intimate photography and photojournalism (Jacobs 2017, p. 3).

Much has been written on Sontag’s choice to proceed with a Halstead mastectomy in spite of a terminal diagnosis for which she was advised to go home and settle her affairs. As Rieff writes in his memoir “her principal doctor at Memorial Sloan Kettering Cancer Center in New York City never really expected her to live” (Rieff 2008, p. 25).
of suffering” (Rieff 2008, p. 39). These are photographs of living through prognostic time revisited after a twenty-three-year respite, and the sense of movement that the three tetraptychs beget reflect what Rieff describes as “the habits of hope” Sontag had extrapolated from her previous experience with cancer (Rieff 2008, p. 45). As DeShazer suggests, “these images reassure viewers in their ‘restorative’ movement . . . from diagnosis to treatment to healing—the dominant narrative endorsed by the American Cancer Society, whose discourse strives . . . to associate cancer not with death but with recovery” (DeShazer 2009, p. 222). Sontag here is thus depicted as the successful illustration of what Deborah Lynn Steinberg has dubbed the “good patient”: in the “representation economies of the cancer culture industry . . . the phantasmatic ‘good patient’ embodies distinctively neoliberal body-affective imperatives—imperatives of will, affect and action—that renounce vulnerability and loss, at least temporarily” (Steinberg 2015, p. 118). Like the bathtub photos, these images impart a punctum of a death forestalled and also foretold: in his own memoir Rieff notes that the treatment his mother received in 1998 for uterine cancer generated the terminal MDS with which she was diagnosed less than six years later (Rieff 2008, p. 71).

The third and final set of Sontag’s illness photographs come near the end of Leibovitz’s book and have stirred up great controversy precisely because they depict an unconscious Sontag in her hospital room at the Fred Hutchinson Cancer Research Center in Seattle as she is actively dying—what Sontag herself, in Regarding the Pain of Others has called the camera’s unique capacity “to catch a death actually happening and embalm it for all time” (Sontag 2003, p. 59). Writing about her own experience of viewing Eddie Adam’s famous shot from 1968 of the chief of the South Vietnamese national police shooting a Vietcong suspect in a street in Saigon, Sontag abandoned her earlier references of photography as elegiac art and articulated something more opaque and amoral in its stead: “one can gaze at these faces for a long time,” Sontag notes, “and not come to the end of the mystery, and the indecency, of such co-spectatorship” (Sontag 2003, p. 60). Leibovitz’s critics have echoed this precise denunciation, with Sontag’s son offering one of the most explicit castigations of these photographs, calling them “humiliating carnival images of celebrity death,” even as he—unconsciously?—composed the most ekphrastically faithful description of these images in his own memoir, describing his own perception of his mother’s “excruciating pain” and “physical agony” during her cancer treatment:

Bedridden in the aftermath of her bone marrow transplant, her muscles soon so flaccid and wasted that she was unable even to roll over unaided, her flesh increasingly ulcerated, and her mouth so cankered that she was often unable to swallow and sometimes unable to speak, she dreamt (she spoke, when she could speak, that is) of what she could do when she got out of the hospital and once more took up the reins of her life. The future was everything. Living was everything. And though her mind was fuzzy from chemicals—“chemo brain,” as cancer patients call it—and she was often disoriented and wild-eyed, seemingly in focus and out of her head, she counted the days until she might be released. (Rieff 2008, pp. 104–5)

Unlike Rieff’s retrospective description of his mother’s state, Leibovitz’s own explanation for taking the controversial pictures, arranged as a single triptych, has an oracular quality: “Susan’s last illness, in 2004,” she notes in her introduction to her book, “was harrowing, and I didn’t take any pictures of her at all until the end . . . I forced myself to take pictures of Susan’s last days. Perhaps the pictures completed the work she and I had begun together when she was sick in 1998. I didn’t analyze it then. I just knew I had to do it” (Leibovitz 2006). In relinquishing the attempt to reflect on the 2004 hospital photographs through a conscious contextualization of her intentional agency, Leibovitz’s photos illuminate the carer’s experience-qua-gaze of living through her loved one’s prognostic time. I would argue that even the brief rationalization Leibovitz offers of “taking pictures of Susan’s last days” is informed by a retrospective observation, much like the entirety of Rieff’s memoir which is haunted, in its own right, by the mystery of prognostic time.

Indeed, from Rieff’s description we know that Leibovitz’s photographs of what we came to know as a dying Sontag were in fact of a Sontag caught in prognostic time’s limbo, and that Leibovitz as a carer reaching for the camera in that instant, much like her photographic subject, had no sense of
where in the prognostic time’s trajectory they were to be found. Leibovitz writes in her introduction that she took pictures of Sontag in her dying days, but this kind of temporally-configured awareness is only retrospective—so that knowledge of the temporal character of those days was determined only after Sontag died. It is only through the future retrospective gaze that Leibovitz could gauge what exactly she was witnessing at the present moment when she was taking the controversial photographs of Sontag after her bone-marrow transplant. As Jerome Groopman, one of Sontag’s doctors, explains in harrowing detail in his essay “A Healing Hell” (Groopman 1998), bone-marrow transplants are not only a treatment of last resort because they are the most devastating regiment the human body can be subjected to, but also because their success is unpredictable—so that it is only belatedly that the suitability of undergoing such a grueling cancer treatment can be measured. As Rieff recounts, the days after her transplant, and for the duration of her hospitalization in Seattle, Sontag herself anticipated recovering and so hoped her doctors (Rieff 2008, p. 115). It is only belatedly that Sontag and her carers understood that her bone-marrow transplant failed and that her prolonged suffering was, as Rieff says, “for nothing: she gambled everything on a transplant, but [she] lost” (Rieff 2008, p. 104).

The work that Leibovitz’s photographs do, thus, within the greater narrative ecology of cancer, is that of indexing the experience of cancer-treatment-onto-death in a way that illuminates the lived experience of adhering to the “good patient” protocol of what Jain dubs the cancer complex” (Jain 2007, p. 89). In the caretaker’s hands the camera becomes the means of capturing the singular brutality of indeterminate cancer treatments. As Leibovitz attests, this impulse to arrest time need not be conscious. In her book Photography, Trace, and Trauma Margaret Iversen describes photography’s idiosyncratic affordance to register lived experience in the moment “without consciousness of registration” (Iversen 2017, p. 5). A photograph of a failing treatment for a terminal cancer restores in the narrative ecology of illness the otherwise occluded experience that is not processable at the moment one is living through it. Leibovitz’s subconscious instinct to pick up the camera and capture this moment reveals something of the caretaker’s aporetic experience with prognostic time, a nebulous temporality without signposts to orient patients and their caretakers where in the trajectory of terminal illness the present moment fits. Where prognostic time is mystifying (“having harbored cancer in one’s body all that time before diagnosis … mystifies both past and future,” Jain asserts), photography grants intelligibility by organizing lived experience in distinct frames of being.

If the photographic capture of this moment offers any assurance of a potential belated comprehension, and thus redemption of the trauma the loved one and/or the caretaker is living through here and now, such a compensating temporal trajectory is not intrinsic to the picture. Freezing a moment photographically opens up the possibility of a belated visitation and a different kind of reckoning with prognostic time, but this reckoning need not be inherently redemptive—some kind of cathartic reconciliation with the terror at the heart of prognostic time. The work that it would take to produce such a reconciliation would be to translate the photographic capture of prognostic experience into the kind of awareness that befits a coherent narrative temporality—which is to say not only translate between contrasting temporali
ties, but more importantly between distinct affective registers, whereby the one belongs to the here-and-now present, the other to the mnemonic motivation to grasp the present through re-reading the past. This kind of translation work is not necessarily precluded. Irrespective of how it is processed, the memory of the carer works to probe the limits of agency and personhood and renders the carer precarious. In recounting her motivations for picking up the camera and taking pictures of Sontag, her dying partner, Leibovitz remains unclear. The dying photos, as part

---

12 In her own acclaimed caregiver’s illness memoir entitled The Iceberg, Marrion Coutts has captured the force of this unknowingness by addressing the experience of caring for her husband who is given a terminal diagnosis of Glioblastoma: “How many times do I think, Now we are really in trouble … And this time I mean it more than all the previous times. But there will surely be another time when I will mean it more still and this time will seem … manageable or benign in retrospect” (Coutts 2014, pp. 122–23). As Rieff suggests, if his mother “had been offered the possibility of an immortality that consisted of nothing but consciousness … the science-fiction immortality of the disembodied head, she would have accepted it with relief and gratitude—perhaps even with appetite” (Rieff 2008, pp. 73–74).
of a larger sequence of grief, have been revisited and translated into a chronologically-configured sequence of images, while nonetheless guarding their uniquely haunting punctum of forever looking at death, in all the undiminished agony that such a stare elicits. In Rieff’s book it is graphic memories that evoke this kind of abject piercing to different effect.

Rieff’s memoir of his mother’s death, much like Leibovitz’s work, is inspired by a grieving process that follows his immersion in prognostic temporality. In many ways that are typical of the two distinct recording mediums used by Leibovitz and Rieff, respectively, where her final set of cancer photographs seize the present moment of prognostic time in its full obliviousness of what awaits, his writing engages prognostic time retrospectively in a way that generates room for critical reflection of its toll. In so doing Rieff’s memoir goes beyond the expected and potentially cathartic introspection that the genre promotes. “If life writing,” as Paul John Eakin has suggested, “has the power to confirm our status as persons” (Eakin 2004, p. 5), Rieff’s memoir instead observes the limits of such a project by disclosing the continuing discombobulating impact of prognostic time on the caretaker, well after he exits its domain. For while Rieff’s perspective on his mother’s terminal illness does possess the savvy of retrospection, it does so in a manner that unsettles the pillars of personhood, such as certainty or at minimum, acceptance. This challenge is produced by the memoir’s subject matter but also by its multifocal perspective, the caretaker’s rendition of which jars the rearward orientation of retrospection. I will return to this part later. For now, I want to delineate some of the other foci in Rieff’s book, especially as they illuminate the vicissitudes of the larger narrative ecology of terminal cancer and the effects of its unsettling imperviousness on both the patient and the carer. These perspectives are interspersed along the straightforward, linearly developed description of what Rieff calls “the catastrophic verdict” of his mother’s cancer diagnosis until her death nine months later (Rieff 2008, p. 69).

The storyline is simple: Rieff returns to New York City from a month-long assignment abroad and is asked by his mother to accompany her to a meeting with a leukemia specialist who, upon reviewing the latest results of her routine biannual scans and blood tests, delivers a terminal diagnosis while insisting on the unavailability of treatment options. In spite of the doctor’s verdict Sontag implements the tried-and-tested strategy used during her previous two cancer diagnoses, which is to gather available information and seek out the latest and most radical treatments available for her case. Notwithstanding the gathering chorus of dismal prognoses for her latest diagnosis, Sontag and her “accompany-ers,” as Rieff calls the group of employees, friends and loved ones who gather around her, persist and grab onto the slim possibility that a bone-marrow transplant, if successful, could give her another lease on life (Rieff 2008, p. 80). Sontag, escorted by her cohort, goes to Seattle to undergo the grueling treatment, which fails. Injured beyond recognition by the procedure, she returns via an air ambulance to the Memorial Sloan Kettering Cancer Center in New York City, where she continues to receive an experimental treatment for another month and a half until her death. The memoir concludes with Sontag’s burial in the Montparnasse Cemetery in Paris.

Onto this bare-bones and dispassionately communicated account Rieff interweaves multiple narrative threads that convey both the chaotic and the terrifying character of cancer’s prognostic temporality. The one that begins early in the memoir and continues to unfold well after Rieff pronounces his mother’s passing pertains to one of the foundational relationships in the narrative ecosystem of illness, that of patient and clinician. Rieff’s book tells of two types of doctors and two types of patients: the glass half-empty clinicians who give disconsolate prognoses, versus the glass half-full ones who “let the hope back in” in spite of gloomy statistics associated with a particular diagnosis; and the pessimistic patients who accept their dismal fate and surrender to the worse-case prognoses, versus those who are willing to suffer anything and everything for a chance at remission (Rieff 2008, p. 111).

Sontag, as the latter kind of patient, crosses paths with both kinds of doctors during her three bouts with cancer. While Rieff’s memoir centers on Sontag’s last diagnosis, it nonetheless cross-references her previous experiences with cancer in a manner that mediates what he belatedly perceives as his own
complicity in his mother’s grueling and also, ultimately, futile fight against MDS. In the process, these
earlier references also trouble his assessments of the clinicians who handled his mother’s final case.

Rieff writes disparagingly about his mother’s encounter with the first oncologist who delivers her
terminal diagnosis in 2004, Dr. A., a clinician who responds to Rieff and his mother’s befuddlement
over his diagnostic pronouncement of “myelodysplastic syndrome” (MDS) by “lecturing” them “as if
he had a family of village idiots sitting in front of him… taking refuge in acronyms and pedagogy”
(Rieff 2008, p. 7). Rieff describes Dr. A. as mindlessly cruel for stating that palliative care and “quality
of life” were the only plausible considerations Sontag should have about her future—a verdict that
generated crippling panic attacks that would not be assuaged by the anti-anxiety medication Sontag
was prescribed (Rieff 2008, p. 66). To Sontag’s clinical encounter with Dr. A. Rieff counterposes those
with Dr. Stephen Nimer and Dr. Jerome Groopman, both of whom supported Sontag’s determination
to fight her terminal diagnosis by undergoing a bone-marrow transplant, and when that treatment
failed, to proceed with yet another experimental drug treatment until she died. Rieff describes Nimer’s
and Groopman’s capacity “to reel” his mother “back from the black well into which she had fallen”
time and again during the last months of her life as “nothing short of magic” (Rieff 2008, p. 110).
This acknowledgment however does not appear to absolve Rieff of the guilt he has over the physical
agony his mother suffered in pursuit of medical treatments whose promise, in retrospect, appear
to have been driven by magical thinking themselves. Rieff quotes palliative care physician Diane
Meier’s rebuke of clinicians’ efforts to prevent their patients from facing head on the terror of a
terminal diagnosis:

As a physician, you don’t want to impose your quantitative, Cartesian view of probabilities
on an individual person who says, ‘That’s probabilities, that’s not me. I’m a fighter. I want
that thousand to one chance and who are you to say that it’s not worth it?’ The result is that,
as doctors, we end up through that kind of thinking becoming unwitting participants in a
folie à deux with patients and family of caving to the desire to live, because it is respectful of
the patient and who she or he is and their perception of the right way to live, while realizing,
in the other part of your brain, that there’s essentially no chance that this is going to help,
that it’s definitely going to cause harm and side effects, that it’s hugely expensive out of
the public trough, and it is a very wearing kind of cognitive dissonance. (Meier quoted by
Rieff 2008, p. 114)

Meier’s insight complicates Rieff’s early criticism of Dr. A.’s callous exchange with Sontag
and her son, intimating a principled bearing behind his refusal to encourage unjustified wishful
thinking. Similarly, Meier’s words contradict the valor Rieff himself grants to Nimer and Groopman for
“saving [Sontag’s] sanity during the time that remained to her,” irrespective of the prognostic statistics
associated with her case (Rieff 2008, p. 118). When Rieff recounts the email he received from Nimer
after his mother’s death that read “we have to do better,” he expresses gratitude but also hesitation:
“of course we have to do better,” he notes, “and I have no doubt that great doctors like Stephen Nimer
will do better. But with the greatest respect, the brute fact of mortality means that there are limits on
how much better we can realistically expect to do” (Rieff 2008, p. 166).

At the same time Rieff’s repeated references to his mother’s diaries and longer history with cancer
complicates Meier’s critical insight and its implications. Rieff recounts Sontag’s first bout with what
was at the time perceived to also be a terminal diagnosis—Stage IV breast cancer that had metastasized
to her lymph nodes. Back in 1975 the Dr. A. of 2004 was Dr. William Cahan, Sontag’s principal
doctor who “never really expected her to live” (Rieff 2008, p. 25). The only difference in the two
doctors’ comportment with their patient had to do with their adherence to the cultural practices of their
respective times—whereby, as Rieff suggests, in the 1970s “it was standard practice for doctors to lie to
cancer patients” and only convey the full gravity of the prognosis to family members (Rieff 2008, p. 25).
Rieff recalls how at that time he decided to remain quiet about the terminal prognosis Dr. Cahan
confided in him, thus mirroring both the doctor’s and his mother’s silence, who “chose not to speak of
it” even though “she knew how dire her situation was” (Rieff 2008, p. 27). When later in his memoir
Rieff speaks of his, his mother’s and her doctors’ silence in “the sick room” where Sontag was visibly dying in 2004, it is “the silence of impotence” he is referencing, the silence “of the powerlessness of feelings to change anything, of the vanity of human wishes” (Rieff 2008, p. 134). However, back in 1975 a comparable silence inadvertently germinated the kind of magical thinking that allowed Sontag, and her then partner Nicole Stéphane, to seek out Dr. Lucien Israël and Dr. Gianni Bonadonna (the Dr. Nimer and Dr. Groopman of the time in Europe), who prescribed an improbable and ultimately life-saving experimental treatment for Sontag. The treatment entailed a highly toxic regimen of chemotherapy and immunotherapy whose “effects bordered on the unbearable”—not unlike the treatment Sontag was subjected to in 2004. “My body is invasive, colonizing,” Sontag writes in her diary from that time, likening her experience to the Vietnam War: “They’re using chemical weapons on me. I have to cheer” (Rieff 2008, p. 35). In 1975 both the silence and the horrendous “magic bullet” treatment, as Rieff calls it, prove lifesaving insofar as they help put Sontag’s cancer into remission for twenty-three years (Rieff 2008, p. 30).13 “Of course statistically she should have died. But she didn’t,” repeats Groopman of Sontag’s first cancer diagnosis, thus contextualizing his support of Sontag’s refusal to accept the death sentence she received in 2004 (Rieff 2008, p. 30). The puzzling affinities and discrepancies that are evoked through these contradicting episodes in Sontag’s life with cancer, both of which revolve around denial, wishful thinking, and doggedness, exemplify the bewildering effects of prognostic time’s unpredictable endpoint.

The maddening uncertainty of cancer treatments that makes prognostic time terrifyingly arbitrary is compounded by the wide circulation of medical literature, which often assumes an inconsistent, if confusing tone.14 If “information mean[s] control,” as Rieff suggests of his mother’s approach to her cancer diagnoses, then the multiple sources of medical knowledge, especially since the advent of the internet, have pushed this fantasy of control to its limits (Rieff 2008, p. 45). From scientific papers to the culture industry circulation—and normalization—of case-specific cancer stories that become universal in their reach (Rieff references CNN’s broadcast of Lance Armstrong’s Livestrong foundation); and from the diagnosis-specific booklets published by cancer societies that are sponsored by biotech firms, to brochures published by the National Cancer Institute, the amount of material that can be amassed on any particular cancer is as massive as it is stupefying. Rieff recounts how both himself and his mother felt that they had become “functional illiterate” in trying to discern the “largely unintelligible” information that scientific articles imparted, finally abandoning the effort and with it the fantasy of medical accessibility (Rieff 2008, p. 83). Rieff also notes the emotional impact of the official cancer brochures on his mother and on her support network which gathered and organized the data, noting how the information either “read like print versions of Dr. A. [or] went to lengths to try to cushion the blow” (Rieff 2008, p. 49). The former kind of narrative often used gratuitously terrifying terminology to describe MDS, such as “smoldering leukemia,” thus compounding “the choking haze of [Sontag’s] own panic” over her prognosis (Rieff 2008, pp. 46–47). The latter kind of narrative was “written in lowest-common-denominator language” that imparted information in ways that were “crushingly, unnecessarily obtuse . . . written in the language of hope [while] in fact offer[ing] almost none to anyone reading it with care” (Rieff 2008, p. 55).15 Indignant over the mocking quality of the language and its adverse impact on Sontag, Rieff nonetheless admits to have no sense of “what the best alternative would be” (Rieff 2008, p. 57).

13 In his Pulitzer Prize winning book The Emperor of All Maladies: A Biography of Cancer, Siddhartha Mukherjee names Paul Ehrlich, the “father of chemotherapy,” as the person who first coined the term “magic bullet”—“a phrase with an ancient, alchemic ring that would sound insistently through the future of oncology” (Mukherjee 2011, p. 86).
14 Both Jain (2013) and Steinberg (2015) have described in detail how medical knowledge is represented by the cancer culture industry in ways that shape illness subjectivity and the social imaginary.
15 Angrily Rieff offers as an example a write up under the “Need for Treatment and Treatment Approaches” section of a Leukemia brochure that reads “In the very small proportion of patients who are under 50 years of age with a severe form of myelodysplastic syndrome, intensive radiation and/or chemotherapy followed by allogeneic stem cell transplantation can be considered.” To this Rieff notes “Here is the worst news being given in the language of the best case” (Rieff 2008, p. 57).
When he addresses his own place within the narrative ecology of his mother’s illness Rieff portrays it as a precarious one. “The contrast between the assurance I felt I had to not just feign but incarnate . . . when speaking with my mother and the sense of being an ignorant fool I had when I would speak with her doctors would have been comical in almost any other context,” he admits (Rieff 2008, pp. 129–30). In spite of his mother’s famous argument against it, Rieff turns to metaphorical language to describe his experience of undergoing “psychological intubation” for the duration of his mother’s illness, so as to cope with his inability to assuage her terror and his powerlessness before medical authority (Rieff 2008, p. 101). The metaphor Rieff uses is the same one that gives his memoir its title: swimming in a sea of death: “As she died,” Rieff says of his mother, “we swam alongside her, in the sea of her own death, watching her die. Then she did die. And speaking for myself, I find that I am still swimming in that sea” (Rieff 2008, pp. 161–62). The metaphor of swimming resonates with an insight by John Berger that Rieff quotes elsewhere in his memoir, namely that “We are always between two times: that of the body and that of consciousness” (Rieff 2008, p. 78).

Rieff references this quote to address his mother’s body/mind split that endowed her with the will to undergo any amount of physical torture in the form of a cancer treatment in order to hold on to her consciousness for a little while longer (Rieff 2008, p. 73).16 Berger’s dualistic understanding of lived temporality, however, also illuminates the dynamics of the memory work that Rieff’s own writing is performing especially where his place in the narrative ecology of his mother’s illness is concerned. Part of that remembering process is consciousness-driven, in that it revolves around the more traditional dynamic associated with life-writing, that of hindsight and introspection (consciousness-time). Another part, however, fixedly, almost photographically, replays instances from the nine months between his mother’s diagnosis and her death, when language either purposefully betrayed or failed to capture the visceral intensity (body-time) of living in prognosis.

Thus, when Rieff speaks of his mother’s reply to Dr. A. after he finishes lecturing her about the terminal nature of her cancer (“So what you’re telling me . . . is that in fact there is nothing to be done”), he notes how her response “makes [him] gasp even remembering it” (Rieff 2008, pp. 10–11). When he recalls “a catch in her voice” after Sontag reads a brochure on MDS that says the disease is “also known as ‘smoldering’ leukemia,” he adds that “the catch in her voice is what I really remember” (Rieff 2008, p. 47). Similarly, his recurring reference to her overall zest for life and terror of death inform his also repeated desire to “temporize” with his mother so as to “grant her some tiny sliver of acceptance of death, or, if not that, perhaps at least confer upon her some flake of Buddhist indifference to extinction” (Rieff 2008, p. 14). Furthermore, his abject memory of her painful death gives rise to fantasies of alternative endings, his mother dying “suddenly from a massive heart attack—the death that all of us who, like my mother . . . are crippled by the fear of extinction must yearn for” (Rieff 2008, p. 150).17 “I still cannot believe there was nothing I could do to help,” Rieff says at the end of his memoir’s penultimate chapter, echoing his earlier dismissal of a possible “closure” for the death of a loved one (Rieff 2008, p. 170).

Much like Leibovitz’s photographs, these references to Rieff’s own remembering process situate the reader in the thick fog of prognostic time, and convey to us what it is like for the carer to feel his way through the replay of those memories in real time. Rieff’s writing illuminates the traumatic character

---

16 As Rieff suggests, if his mother “had been offered the possibility of an immortality that consisted of nothing but consciousness . . . the science-fiction immortality of the disembodied head, she would have accepted it with relief and gratitude—perhaps even with appetite” (Rieff 2008, pp. 73–74).

17 Ending the pain, emotional suffering and physical indignities of the end-stages of prognostic time, however elusive they are to demarcate, is at the heart of the argument raised by proponents of assisted dying/physician-assisted suicide (PAS). PAS is legal in parts of Australia, Belgium, Canada, Luxemburg, the Netherlands, Switzerland, and parts of the United States. Each country has similar criteria of qualification of PAS, and they revolve around individuals of sound mind, with a diagnosed terminal illness, seeking to gain some control over their impending death so as to alleviate intolerable suffering. See “Concept of unbearable suffering in context of ungranted requests for euthanasia: qualitative interviews with patients and physicians” (Pasman et al. 2009) and “Unbearable suffering and requests for euthanasia prospectively studied in end-of-life cancer patients in primary care” (Ruijs et al. 2014), among others.
of prognostic time on the caretakers, and the persistent shock that is experienced when memories from that time flash into consciousness voluntarily, or involuntarily, to reproduce a visceral response and/or invite corrective revisions of the past in the survivor’s imaginary. In this way Rieff’s memoir exceeds the conciliatory demands of the genre whereby the past, in the form of a memory, is integrated into the normative world of meaning and identity. Instead, Rieff’s writing delivers punctum-like jolts by capturing the abject quality of living through prognostic time, even as his memoir’s temporal distance from the events it recounts, and critical reflection that its belatedness permits, undercut the text’s capacity to transmit the abject intensity of living in this time in the way that Leibovitz’s photographs do. Still, much like the memory work that Leibovitz’s controversial photos perform in her memoir, which is to pierce through grief’s resigned facade so as to restore the jarring materiality of death, Rieff’s writing records the efforts made by the caretaker to come to terms with the terminal illness of a loved one, so as to reveal the failure of reaching mourning’s end.

In this way both Leibovitz’s and Rieff’s attentiveness to the effects of prognostic time on the caretakers, makes their works resistant to the kind of chronological closure expected from grief memoirs. Instead, the only consolation that they offer is to turn their attention to different timeframes altogether: Leibovitz, who bookends her memoir with the vast and timeless landscapes from trips to Jordan and Italy that she took with Sontag in the early years of their relationship, offers photographs of ecological deep time that unsettle both the studium and punctum expectations of the viewer and serve as an uncanny antidote to the anthropocentric experience of prognostic time (Wadi Rum, Jordan, 1994; Mount Vesuvius, Naples, 1992; Monument Valley, Arizona, 1993). Rieff, loyal to the “family olive oil business,” as he calls his and his mother’s love of words, turns his attention to mythopoetic time, quoting his mother’s own lyrical consolation to the angst of living in prognostic time when she was being treated for breast cancer: “In the valley of sorrow, spread your wings” (Rieff 2008, p. 179). If these alternative temporalities offer any respite from the anxiety of prognostic time, it is not in the guise of restored control, but of revised perspective.

Funding: This research received no external funding.

Conflicts of Interest: The author declares no conflict of interest.

References


