The Cancer Imaginary:
Body, Community and Image in Life Writing

A thesis submitted to the University of Hyderabad in partial fulfilment of the requirements for the award of the degree of

DOCTOR OF PHILOSOPHY

in

ENGLISH

Submitted by

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DECLARATION

I, **Meenakshi Srihari**, hereby declare that this dissertation titled **"The Cancer Imaginary: Body, Community and Image in Life Writing"** submitted by me under the supervision of Professor Pramod K. Nayar and Professor Anna Kurian, Department of English, University of Hyderabad is a bonafide research work. I also declare that it has not been submitted previously in part or in full to this University or any other University or Institution for the award of any degree or diploma.

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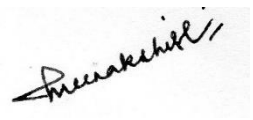

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CERTIFICATE

This is to certify that the thesis titled **"The Cancer Imaginary: Body, Community and Image in Life Writing"** submitted by **Meenakshi Srihari** bearing the registration number **17HEPH04** in partial fulfillment of the requirements for the award of Doctor of Philosophy in English is a bonafide work carried out by her under our supervision and guidance. The thesis has not been submitted previously in part or in full to this or any other University or Institution for the award of any degree or diploma.

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Further, the scholar has the following publications in the area of her research and has produced evidence for the same in the form of the contents page or reprint:

1. Srihari, Meenakshi. "Data Matters: The Informatized Body in Cancer Narratives." *Media Watch*, vol. XII, no. 1, Jan 2021, pp. 20-32.
2. Srihari, Meenakshi. "Sound and the Fury: Affect, Disability and Sound in Christine Wilks's *Tailspin*" *gnovis Journal: Communication, Culture, and Technology*, Georgetown University, vol. 20, issue 1, Spring 2019.

The scholar has presented papers in the area of her research as:

1. Srihari, Meenakshi. "Xenotransplantation and Borders: Two Indian Narratives" organized by the CHCI Medical Humanities Network Summer School, Columbia

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2. Srihari, Meenakshi. "The (Bio)Social Network: Narrative, Trauma and the Digital" in the Three-Day International Conference cum Workshop on Narrative Medicine called "The Enigma of Story: Lived Experience, Time and Narrative" organized by the Balvanth Parekh Centre, Baroda.

The scholar has undertaken the following courses for a total of **16 credits** as part of mandatory coursework to fulfil the UGC criteria for PhD submission.

1. Course Code: EN 801
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   Credits: 4
   Course Instructor: Girish Pawar and Sindhu Menon
   Result: Pass

2. Course Code: EN 802
   Course Title: Research Methods and Dissertation Writing
   Credits: 2
   Course Instructor: K. Narayana Chandran
   Result: Pass

3. Course Code: EN 824
   Course Title: On Narrative
   Credits: 4
   Course Instructor: Gopika Sankar U
   Result: Pass

4. Course Code: EN 812
   Course Title: Reading Right(s): The Culture of Human Rights
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   Course Instructor: Pramod K. Nayar
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Lastly, I often think of the people I have written about and the ethics of clinically and critically analysing these texts written by very real, dying lives. The written word leaves us with varying shades of and relations to empathy, and there is still a long way to go to understand the minds of the dying.

List of Illustrations

Chapter 2: The Everyday and the Extreme

Chapter 3: "Technologised Terrain"

Chapter 4: The Public-ation of Illness

To Appa and Amma, for letting me go.

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Contents

Chapter 1

Introduction: Approaching the Illness Narrative

Synopsis

1. Introduction

This study is a critical analysis of auto/biographical representations in the form of prose memoirs, graphic narratives and digital narratives that explore the lived experiences of cancer. Illness and disability have always been a prominent part of literature, both in western and eastern narrative traditions. Illness as a theme finds particular resonance in life writing at least since the twentieth century, where it does not merely serve as an object of interest to supplement the narrative[1], but concentrates on the *lived* experience of the ill. The project studies the ways in which advances in technology have bettered the faculty of observation and changed how people interact with and question the body. In the narratives under study, the ill person expresses one's self and relationships in bodily terms. Their narratives attempt to articulate the experience of illness through both conventional and newer modes of expression, merging the visual and the verbal, the analog and the digital, reflecting the

[1] For instance, David Mitchell and Sharon Snyder show in their work on Narrative Prosthesis (2001) that though the disabled/ill have always been prominent figures in literature, their presence has only served to be of interest because of their "marks of difference" (xii), without emphasis on the lived experience of disability.

blurring of various dualisms such as mind/body, health/sickness, self/other, and inside/outside that occurs in illness – the narrative mode and the illness both linger on the borders between linearity or continuity (life) and discontinuity (death).

The Literature, Arts and Medicine Database of New York University (also called LitMed, http://medhum.med.nyu.edu) on their website, calls the Medical Humanities "an interdisciplinary field of humanities (literature, philosophy, ethics, history and religion), social sciences (anthropology, cultural studies, psychology, sociology), and the arts (literature, theater, film, multimedia and visual arts) and their application to healthcare education and practice". Located in the Medical Humanities and finding its methodological grounding from Literary and Cultural Studies, this project studies 21st century verbal, visual and digital representations of cancer written/produced in English. The questions this dissertation explores are – *how do representations of illnesses help define the boundaries between the 'self' and 'not self' of an ill person*? *How does the ill person utilise mode and medium to build a public persona and a community?* And finally, *how can we study the entanglements between narratives and biomedical culture through literary ways of seeing?* In the course of delving into these questions, this dissertation will explore culture's demand for borders – between/within species, bodies, spaces, etc - and how these borders are defined and confronted in and through narrative.

Perhaps the most obvious instantiation of health and borders is the contagion of disease and its containment. Quarantine was begun as a process of safeguarding one's borders from diseases: this included inspection, marking and preventing the transmission of diseases through air or sea bodies in national border crossings[2]. The project studies how the cancerous body serves as a microcosm of this fear of the invasion of boundaries while being wary of

[2] The history of the quarantine in America shows how the fear of contagion led to measures including detainment, medical examinations and governmental intervention in the form of surveillance in border crossings between nations (https://www.cdc.gov/quarantine/historyquarantine.html)

strangers within the corporeal self itself. This is also an acknowledgement of the work of Laura Otis and others who study these boundaries, not as "natural" phenomena, but ones that exist because "the eye seeks boundaries, and language constructs . . . these differences so that there may be vision and communication" (Otis 7).While quarantine and the epidemic appear only in a figural manner in the body of the thesis, the concluding chapter studies cancer narratives written during the pandemic in its current instantiation of the SARS coronavirus II, situating the cancerous body in the present moment, the Covidian age.

In her essay on the antiheroic cancer narrative, Lisa Diedrich lists the various meanings of the word 'treatment,' choosing to focus on treatment as "a discussion of arrangement of terms, negotiation" (137), and drawing attention to how narrative form plays an important role in enabling this negotiation to take place. Taking its cue from Diedrich's definition, this project shows that the ill person's 'treatment' is not only shaped by the medical institution, society and culture but also by the form of the narrative. The twenty first century cancer narrative demonstrates that illness narratives interact with biomedical modes of communication, utilizing a more 'corporeal' narratology to articulate various facets of the illness, including but not limited to personhood, patienthood, activism, and community formation. Illness is not one or many of these facets, but all of them existing as a process. In many of these narratives, thus, we will find that the narrative is shaped not only by a now-familiar cancer-schema comprising of the moment of diagnosis – treatment options – chemotherapy – and finally healing/death, but also several everyday and extreme interactions and interventions: insurance schemes, the positioning of furniture, games and play, data, activism, and sartorial choices, to name a few. These narratives look at newer forms of expression, enabled by emerging modes of communication. As Elizabeth Grosz has pointed out in *Volatile Bodies*, "subjectivity can be thought. . . in terms other than those implied by various dualisms" (vii). That the subjectivity of the ill person constantly oscillates between

the dualisms and occupies a border between them will form one of the study's main focuses. *As illustrated through the 21st-century cancer narrative, the lived body represented in illness narratives serves as a site to study both, the ill person's subjectivity and their embeddedness in and interaction with the environment. While the cancerous body navigates the binaries of inside/outside, extreme/everyday, man/machine and private/public, the illness narrative constructs these navigations by 'negotiating' between or even trying to determine various modes of representation: the visual/verbal, data/experience, and science/art. The dissertation argues that the ill person is well aware of their entanglements with nonhumans and studies the borders that are defined and confronted through illnesses.* The dissertation contributes to the existing literature on narrative frameworks and ways of seeing enabled by literary studies to approach questions of genre, identity and relationality in illness narratives, by extending, for example, the definition of 'Biomedia' to include emerging genres of representation of the ill body, by studying the rhetoric of narrative biosocial communities through the lens of transmedia, and studying ekphrasis as it operates in responses to science or medicine.

I am defining the limits within which the analysis operates. The texts I study have been chosen due to their popularity and aesthetic inventiveness, and have all been written by American or British writers who respond to western medicine situated in the 21st century, though at least one of them (*Stitches*) responds to methods used in the 20th century by account of it being a retrospective account of the writer's tryst with cancer during his childhood. Hence the critical studies and theorization I use are also those that respond largely to 'western' medicine. Secondly, while cancer literature has emerged in the last century as a subgenre of its own within the corpus of illness literature, these narratives also serve as case studies for narrative themes and techniques employed in other chronic illness accounts. Hence the imaginary is not unique to cancer narratives (though more suited to them), and the thesis has been organized to reflect universal textualizations of the illness experience, such as

the reconfiguration of space and time, response to medical imaging and community formation.

The introduction is divided into three parts: contexts, texts and methods.

2. Contexts

Humanity has always incorporated the human body in its rhetoric. This is easily seen in how metaphors used as part of conversational language are directly influenced by the body's posture: "I am feeling *up*" or "I am feeling *low*" derive from an erect versus a drooping posture signifying health and sickness/death (Lakoff and Johnson, 22). This tendency has been amplified by developments in science that allow us to observe, transform and question bodily functions and boundaries. As Stephen Wilson says in *Information Arts*, "The body is a 'contested site' where many of our culture's discourses are played out. The times are exciting and confusing" (149). The blurring of the boundaries between organic categories such as body, death and time, and posthuman categories like the body in cyberspace has led to a new vocabulary of the body that demands study: a vocabulary that is corporeal but questions the limits of the corpus. At the same time, the need to humanize the sick body, and transcend its 'posthumanization' to focus on the person and the person's vulnerability is enabled by literary studies – the study of written texts that are themselves regarded as bodies, the term *corpus* is thus shared between the body and the text. While this dissertation does not espouse the view that narratives of illness can be used to instil compassion into medical education, thereby already assuming a binary between medicine and compassion, it *is* interested in how these narratives portray identity and meaning in terms of relationality.

While I consider the health humanities the right site to foster/find a common ground for the study of science and the arts, the particular study of illness narratives is also for me an effort to locate the 'human' in today's technologised world. The study of the illness narrative

serves as a prime example of the 'engaged humanities', especially with fields such as *Narrative Medicine* that attempt to look at the ill person beyond being merely a medical object, and the study of representations enabling pedagogical and social awareness in health practices. Though the pedagogical implications of such studies are beyond the scope of this dissertation, it studies the illness narrative as playing an important part in defining and redefining the idea of the person, human suffering and connectedness. The study finds its grounds in the following disciplinary and generic contexts:

2.1 The (Critical) Medical Humanities/ Health Humanities

While the project is situated in the broad field of the Medical/ Health Humanities, it is cognizant of the shift towards a more inclusive development within the field. It adheres to the principles of the *Critical* Medical Humanities that tend to complicate the narrative emphasis of the medical humanities and consider in equal measure the "thing-hood" of the patient (Evans 339). The arc of development between the medical humanities and the more preferred *health* humanities is thought to be a shift in the *raison d'etre* of the discipline itself. The Medical Humanities was initially established around the assumption that the introduction of humanities disciplines into the medical curriculum would result in more compassionate and empathetic doctors and practitioners, with the hope of bringing those in medicine "who are concerned with issues involving human values into close discourse with those . . . in the disciplines outside of medicine who have interest in, and perhaps a desire to help us with, the human problems that arise in medicine for the patient and the physicians" (Pellegrino, qtd in Jones et al, 2014). This was Edmund Pellegrino, the clinical bioethicist and physician who pioneered the introduction of the humanities disciplines into the medical institution. The issue with this formulation of the discipline soon became its confinement to the medical institution itself, and scholars of the medical humanities began to prefer the broader term "health humanities," that could include not just the work of physicians but also

of other healthcare workers, researchers, caregivers, patients and artists. A special issue of the BMJ journal *Medical Humanities* in 2015 anchored the critical medical humanities in place as a means to extend the scope of the field to critical 'entanglements' between the arts, humanities and social sciences with biomedical culture. While the authors acknowledge the medical humanities' "sensitivity to narrative-based interventions and their limitations" (2), the critical medical humanities tends to "address not only the meaning and historico-cultural contexts of health and illness, but their very production, concrescence and dispersal across the precarious, unequal and environmentally degraded societies in which we live" (Callard et. al 2). The questions that Anne Whitehead and Angela Woods add in *The Edinburgh Companion to the Critical Medical Humanities* (2016) to the solely narrative and humanistic approach that the conventional medical humanities espouse, to study, for example, the scene of cancer diagnosis, help us realise the underpinnings of this project as well. The scene of diagnosis, especially in the case of cancer, has been a principal scene of inquiry in the Medical Humanities through a focus on the lived body. Whitehead and Woods complicate these analyses by asking "*How might we account for non-human objects and presences, for belief systems, and even for the diagnosis itself – what, for example, is its history, or its status as a performative act? Where and when else might the scene be situated, and what difference would this make?"* (2, emphasis mine). In this dissertation, the cancer patient and her/his lived body are studied not only for their communication with the doctor and within the hospital but taken out of the clinic to study their situatedness in public spheres of communication and their interaction with their own bodies in relation to nonhuman agencies. The third mode of inquiry within the dissertation, and perhaps the most important, is to look at the narrator's critique of the conventional cancer narrative and their use of biomedicine as part of their narrative. The danger of an abundance of illness stories in the mediascape is that to readers and other storytellers, they make encompassing or dominant claims, make models

out of themselves and that tend to crowd out different stories, and hence present the real issue of typecasting the ill into one particular illness model. The narratives studied are already antagonistic towards this sort of typecasting, as is evident in the memoirs about breast cancer, for example, that are against brightsiding - a term introduced by Barbara Ehrenreich to refer to the culture of being surrounded by an overly optimistic wave of positive thinking that engulfs the American cancer patient (2001). This inherent criticism enables us to make meaning of the lived experience of living at risk, and treat the memoirs as important cultural work. The Critical Medical Humanities attempts to go beyond "service as an 'educational good' to nurturing good clinicians" and instead focuses on "an openness to wonder [that] animates our sense of the vibrancy of matter, including the matter that is ourselves – in and as our bodies – as patients, well or ill" (Evans 352). The texts that have been chosen for study display this attentiveness to materiality in different forms, be it Marisa Marchetto's graphic re-imagination of cancer cells in her body, Tom Corby's imitation of the conventional medical record to present an affective account of his illness, or ePatient Dave's activism for data rights. The narratives offer an inherent critique of simplistic portrayals of illness, making them apt texts for study using the approaches offered by the Critical Medical Humanities, which are discussed in Section III.

2.2 The Contemporary Memoir and its Forms

While memoirs were once projects of the 'elite', the last few decades have seen a remarkable rise in the production of 'ordinary' memoirs, a development that Andrea Kohler attributes to three reasons: "sadness, triumph and therapy" (qtd. in Lahusen 630). Experiences with illnesses contribute to the memoirs on sadness, while triumph and therapy are embodied in confessional memoirs, the prototype for which is considered Augustine's *Confessions.*

The evolution of the "body memoir" – life writing that revolves around corporeal conditions – represents a significant subgenre within the memoir boom of the last century. In

the 1980s and 1990s, writing about HIV/AIDS exceeded any previous writing about illness. Scientific developments in the twentieth century made medicine not only more advanced but also more depersonalised, and this led to the patient taking on a more active role in questioning the medical institution, and by 1980, the century saw the emergence of what Lisa Diedrich has called the "politicised patient" (26). Thomas Couser attributes the rise of the auto/somatography to the emergence of the civil rights movement in the twentieth century, where the rise of narratives such as women's cancer narratives may be seen as "their claiming autonomy as patients in determining their own treatment (and as citizens more generally)" (2009, 4)[3]. Ann Jurecic attributes the reasons for the rise of illness narratives to a variety of changes in literacy, culture, media and politics, including

> medical professionalization; the rise of modern health care; the emergence of the women's movement and the gay rights movement; the etiology of the AIDS virus; the inability of master narratives to give meaning to suffering in the modern era; and technological advances that promote self-publication and the global distribution of information. (2012, 10)

Much scholarly writing has been produced about the development of the illness memoir, beginning with Arthur Kleinman (1988), Anne Hunsaker Hawkins (1993), Arthur Frank (1995) and Thomas Couser (1997). Scholarly writing in recent times, however, has shifted focus to the rapid expansion of the genre to include various kinds of narratives. This expansion is seen both in terms of the kinds of illnesses written about and the narrative modes of expression. While a few conditions were initially written about only by caregivers, first-hand accounts of illnesses such as autism (now with its own genre called *autie-biography*), anorexia, chronic fatigue syndrome, etc., have brought even hitherto marginalized illnesses to

[3] Audre Lorde's *Cancer Journals* (1980) is considered the most popular personal account of cancer; Lisa Diedrich calls the book a prototype of the "patient's counternarrative to medical discourse" and traces the politicization of the patient through prominent names like Sontag, Lorde and Sedgwick (*Treatments* 2007)

the narrative fore, responding to newer scientific developments. These include texts such as Alice Wexler's *Mapping Fate*, which document the decoding of the individual genome structure, the resultant discovery of BRCA or other genes that then lead into previvor memoirs by people who carry the gene of a disease and are likely to be afflicted, eventually. Digital media has enabled forms of writing such as the blog and the online diary, or video narratives on YouTube. Several of the first-hand narratives are written while the individual is in what Sontag terms the "kingdom of the sick", and the narrative itself serves as a boat on which the ill traverse between the two kingdoms.

Life writing is evolving as a genre, and now incorporates and makes use of various forms of the visual and the digital medium. Practices such as the collaborative auto/biography, autoethnography, and personal genomics as life writing are emerging forms in the discipline. In his essay on the future of life writing (2017), Thomas Couser predicted the rise of the refugee memoir, the proliferation of electronic writing, and illness interactive video game memoir; and that "less and less life writing will involve what we used to mean by writing" (379). In *Illness as Many Narratives* (2016), Stella Bolaki challenges the dominance of the literary mode of illness writing by including scholarly examinations of photography, artist's books, performance art, film, theatre, animation and online narratives. The memoir, as a means for the ill person to tell and retell one's illness to the self and others, is gaining momentum with flourishing genres like the graphic medical narrative. Over the past decade, a new breed of comics examining the patient's experience with illness or the caregiver's account of illness has evolved, which Ian Williams, the British graphic novelist has called 'Graphic Medicine'. These auto/biographical narratives explore themes such as the doctor-patient relationship, institutional negligence, the commercialization of medicine etc. One could trace their history down from Justin Green's *Binky Brown Meets the Holy Virgin Mary* (1972), a graphic tale about Binky Brown's compulsive neurosis, through Harvey Pekar and

Joyce Brabner's *Our Cancer Year* (1994), considered the first cancer graphic narrative, to the plethora of graphic texts on various illnesses found today. These graphic texts provide a new dimension to the somatography, with their unique use of non-linear narrative techniques, ability to articulate temporal flexibility and incorporation of multimodal elements.

Journals like *Biography* and *a/b Auto/Biography* engage in scholarly discussions of these newer narrative forms, besides dwelling on the conventional memoir and what it means in contemporary times. Journals such as *Literature and Medicine*, *Medical Humanities*, *Body and Society* further the scholarly engagement with these genres and firmly situate them in the field of the medical humanities.

3. Texts

My primary texts consist of conventional print memoirs, print graphic memoirs, and weblogs written in the 21st century. The two print memoirs I study are Paul Kalanithi's *When Breath Becomes Air* (2016, hereafter *WBBA*), Susan Gubar's *Memoir of a Debulked Woman* (2012), and Nina Riggs's *The Bright Hour: A Memoir of Living and Dying*. Paul Kalanithi's *WBBA* (2016) describes his journey battling metastatic lung cancer. The hugely popular memoir by the young neurosurgeon, published posthumously, begins with Kalanithi's diagnosis during his final year of residency, and through its course describes his journey as a medical student, an avid lover of poetry and someone fascinated by ideas of mortality, until his death at the age of 37. Divided into two parts, the book addresses the different roles of doctor and patient that Kalanithi inhabits in each. In Part I, Kalanithi reflects on his experiences of becoming a doctor, "illustrating how medical ethics plays out in, and is coloured by, the clinical encounter" and displaying "remarkable gravitas and moral earnestness" (Miller 583). Outlining various 'rites of passage' that the doctor-in-the-making undergoes as part of their medical education, including, importantly, the encounter with the cadaver and the reading of personhood into the medical record, the first part serves as a

Doctor Bildungsroman. In Part II, Kalanithi deals with the devastating news of his diagnosis, confronting his imminent death through textuality and forming an example of an "autothanatography" – a narrative of the dying self in which "Thanatos" (death) replaces "bios" (life).

Susan Gubar's *Memoir of a Debulked Woman* (2012, hereafter *DW*) was the first of a series of cancer narratives written by the feminist scholar popularly known for her work *Madwoman in the Attic*. The memoir was followed by her blog *Living With Cancer* (2016 – present) and the book *Reading and Writing Cancer* (2016). Diagnosed with ovarian cancer at the age of 65, *Debulked Woman* is part personal memoir, part scholarly examination of the history and cultural reception of ovarian cancer. Replete with facts, detailed notes and references to medical and critical literature on cancer (the memoir finishes with a seven-page 'Works Cited' section), Gubar's memoir mostly stands out for her unflinching examination of the physicality of ovarian cancer, a fact that she is both apologetic for but does not shy away from, situating her lived experience of cancer as one that foregrounds physicality rather than the absence of a sexual body part. Despite this detailed understanding and explication of the cancer's cultural history, Gubar's memoir embodies the uncertainty that marks the lived experience of a cancer patient, as Rita Charon (2012) states:

> But these knowings are hollow. The knowings confer, indeed, a form of certainty. Yet knowing of what you will die does not fill the beaker of knowledge needed toward the end of life. Knowing even, in some detail, how one might die does not near the urgent questions that include, "Then what?" The opposite of doubt here is not certainty. It is instead dread. (XIV)

In speaking candidly of the grotesque nature of ovarian cancer and its treatment, but also embracing the uncertainty of living on after the "mother of all surgeries"- debulking,

Gubar gives voice to "what has often been exiled to the realm of the unmentionable" (Schultz 75), extending the scope for discourse about cancer in women.

In *The Bright Hour* (2017, hereafter *TBH*), Nina Riggs chronicles her journey with breast cancer, diagnosed at the age of 38. The memoir stands out because of its treatment of parenting as a cancer patient and its poetic prose style. Riggs concedes to her family history of cancer, attempting to leave behind some part of herself for her kids and her husband while seeking inspiration from the words of Montaigne and Dillard. *The Bright Hour* is a parent's memoir that chooses to foreground familial dynamics and the domestic sphere that affect and are affected by the person with cancer.

The graphic narratives I have studied are Brian Fies's *Mom's Cancer* (2011, hereafter *MC*), Stan Mack's *Janet & Me: An Illustrated Story of Love and Loss* (2004), Marisa Acocella Marchetto's *Cancer Vixen: A True Story* (2014, hereafter *CV*), Miriam Engelberg's *Cancer Made Me a Shallower Person* (2006, hereafter *CMMSP*) and David Small's *Stitches: A Memoir* (2010). *Cancer Vixen: A True Story* is the illness narrative of Marisa Acocella Marchetto, a comics artist from New York whose everyday, fashionista life is turned upside down when she is faced with a world of expensive treatments and hospital visits. The novel traces her journey from the diagnosis of breast cancer to its treatment, digressing into her past as a comics reporter who covered 9/11, to her present as a new bride recording her experiences in comics for magazines. Published the same year as *Cancer Vixen*, technology-trainer and cartoonist Miriam Engelberg's graphic memoir *Cancer Made Me a Shallower Person* was released first as a webcomic and eventually the comic strips were published as a memoir. The memoir is episodic, and each episode is a humorous take on Engelberg's trials with breast cancer, which eventually led to her death in 2006. David Small's *Stitches: A Memoir* (2010) is an autopathographic that traces the writer's troubled childhood in and out of hospitals and his tryst with throat cancer. The American writer and illustrator, who has

also written other books for children, incorporates important themes such as truth and agency, and children's medical rights in this coming-of-age graphic narrative.

Janet and Me (2004, hereafter *JM*) by Stan Mack, has been called the cartoonist's "homage to his lover Janet Bode who died of disseminated breast cancer, a touching and engaging account of their experiences in 'Cancerland'" (https://www.graphicmedicine.org/comic-reviews/janet-and-me-an-illustrated-story-of-love-and-loss/). The illustrated narrative is an account of the tribulations the couple face with myriad issues that cancer throws into their lives, ranging from insurance to the hunt for specialists. The book was written and published after Janet's death and contains reproductions of the comics that Stan drew about her illness while she was still alive. Brian Fies's *Mom's Cancer* similarly is not a patient narrative but a caregiver account about the cartoonist's mother who suffered from lung cancer. Launched as a webcomic in 2004, the memoir was published in print in 2006. The first webcomic to receive an Eisner Award, *Mom's Cancer* traces the writer's caregiving journey with his sisters.

The next group of texts examined in the thesis are digital narratives of cancer. Nancy Miller's webcomics project "My Multifocal Life" (2012-20) is a part of the hybrid blog by the feminist literary critic and memoirist known for pioneering the form of personal criticism, a mode that encourages autobiographical acts within a work of criticism. An embodiment of this form, Miller's blog comprises both the academic and the personal, containing her academic CV, her personal diary and other projects such as the "Feminist Friendship Archive", a "Paris Memoir" and the focus of this dissertation, her webcomics/collage project called "My Multifocal Life" that draws on her tryst with metastatic lung cancer. The seriality of her blog posts about cancer, the inclusion of images that are mostly self-portraits, and the accompanying text make the blog a cohesively fragmented and visual representation of a cancer patient for the reader.

In addition to her books on cancer, Susan Gubar also writes a blog called *Living With Cancer* (2012 - present) for the *New York Times*'s digital 'Well' column, an enterprise she undertook because she wanted to "write differently—not scholarly tomes but easily accessible and, if possible, widely circulated essays" (148). In the blog, Gubar is able to write from a variety of perspectives that includes personal experiences, institutional grievances and the healing power of art. The most important difference between the memoir and the blog is that by utilizing the mode, Gubar is able to evoke a sense of community that foregrounds her activist-self and accounts for several cancer experiences and not just her own.

Tom Corby's *bloodandbones* (2013-19), as the artist-author titles it, is a data documentary. Begun after he was diagnosed with multiple myeloma in 2012, Corby painstakingly records everyday illness data as it exists in the medical, financial, and affective spheres. Corby's project attempts to decode and recode data regimes, and investigates if and to what extent they can represent the lived experience of cancer. Using his categories to record, classify, and picture data, Corby turns the body's medical mapping on its head by introducing his own lexicon. Corby's project is not confined to the web but is truly transmedial and performative, traveling to museums and being exhibited in shows.

Tackling the same subject – data – but adopting the stance of a data rights activist is Dave deBronkart's blog, "ePatient Dave: Democratising Healthcare". Dave deBronkart pioneered the participatory patient movement when, after being diagnosed with kidney cancer, he turned to an internet support group to share his medical records and converse about treatment options that similarly diagnosed patients were aware of. Dave's popular movement, "Gimme my damn data!" situated him firmly as a data rights activist. The project will analyse a few of Dave's blogposts as being indicative of the technological shift in the self-health movement besides reading his website for narrative style and as a transmedial illness storyworld.

I also examine Brandon Stanton's photoblog series, "Pediatric Cancer", stories gathered from the Memorial Sloan Kettering Cancer Centre and shared over two weeks in May 2016 on Facebook, and archived on the *Humans of New York* website. *Humans of New York* is a popular photoblog page on Facebook with over 17 million followers, an exemplar of a 'networked narrative': digital stories that use and work via the technological affordances of the medium, in this case likes, comments and shares. Started by Brandon Stanton as an everyday digital journal of photographs from around New York City with engaging captions, it soon catapulted into socially relevant and focused photo series partnering with human rights groups from around the world. These have included a series about American veterans from the Iraq and Afghanistan wars (*Invisible Wounds*), interviews with the refugees of Syria (*Syrian Refugees)*, stories across five different prisons in Northeast America (*Inmate Stories*), and the stories gathered from the cancer ward at the Memorial Sloan Centre (*Pediatric Cancer)*. The last of these forms a part of my study, and I examine the series not only for the formal elements of the photographs and the response these evoke from the spectator (in this case, both myself, and respondents on Facebook), but also and as importantly, how the storytelling is used to form a collectivizing narrative community for crowdfunding cancer treatment.

Through these texts, I study the illness narrative in various media: the conventional print memoir, the comics medium, digital narratives and photography. Besides, several of these texts are intermedial, that is they contain within a single text various other media: such as Nancy Miller's blog that contains text, comics, collage etc. I also study different forms of life writing about illness: the personal memoir, the caregiving narrative, health activism narrative, the online diary and the data record.

These 'texts' thus require a way of reading that considers how the various modes and media utilized construct these illness 'storyworlds'.

4. Methodology

The dissertation explores how various media offer opportunities to present the discourse around disease differently. By studying emerging forms of representation of disease, such as the social-media enabled Biosocialities (for eg. crowdfunding on the internet), Autobiologies, and the self-fashioning that is aided by technology, the dissertation will show how illness narratives across different modes and media reflect or subvert the cultural contexts that shape our understanding of illness.

4.1 Premises and Research Questions

My project employs the methodologies tested and theorized by a diverse set of thinkers in the Health Humanities, social historians and anthropologists of medicine and the body, and literary critics mentioned in the preceding sections. The 'ailing body's' interaction with the world can no longer be seen solely in terms of impeachment of the body by external forces, as Laura Otis suggested in her study of the nineteenth century, or in terms of one that is affected by its own workings (like that with the immune system, as studied by Donna Haraway and others). The dissertation will study illness, or in Haraway's preferred term, its 'articulation,' demonstrating how the illness narrative – a tally of accounts by the sick person or the caregiver, or the medical discourse in the form of the medical report or even the DNA (which Couser calls 'nonverbal life writing' (2001)) –collectively juxtaposes personal, political and theoretical stands to form an assemblage. This assemblage not only finds modes of expression that combine genres like the multimodal website, or the graphic novel but is also a combination of narrative strategies (like collaborative memoir writing), always existing in the plural.

The rhetoric of health is most easily available to wider publics in English, the popular language of communication among medical practitioners, in medical institutions of learning and between medical institutions and the layperson, and used in the most influential

international medical journals, conferences and on popular websites. The selection of English texts for my study is also because of, and therefore limited by, my work on these from within a department of English, and hence my access to methods more suited to the study of texts in the language[4]. The rapid proliferation of patient stories in response to institutional narratives is an indicator of the need for counter-narratives and community engagement. This is also why recent times have seen the preference of the term '*health* humanities', a more encompassing term especially for community engagement, over the '*medical* humanities'.

Since the focus of the thesis has been to study these narratives against recent developments in storytelling and science communication, and inter and transmediality, the selection of texts has been confined to popular twenty first century narratives that reflect these formal and thematic developments. However, the influence of earlier and important critical/illness narratives such as Audre Lorde's *Cancer Journals* (1980), Sontag's *Illness as Metaphor* (1978) or Jackie Stacey's *Teratologies* (1997) is palpable both in the primary texts and in the thesis, though they have not been analysed as primary material.

The foundational premise takes the form of a set of questions: in what ways does language capture the experience/ response of the ill person to the illness, and what role does language play in reading these responses? As scholarship produced from within a department of English, how can literary ways of seeing be used to engage with narratives that are not conventionally literary and that are not just verbal or visual but intermedial as well?

The dissertation offers the following responses to the questions. The multimodal illness narrative, containing text and image, and designed with the affordances of the internet or graphic medium in mind, utilizes language in relation to the network of options available

[4] This does not discount the presence of scholarship in other languages in the health humanities or even scholarship in English about narratives in other languages. An example of the latter is the recent *PathoGraphics* (2020), edited by Susan Squier and Irmela Marei Kruger-Furhoff, a collaborative scholarly enterprise between the University of Pennsylvania and the Free University of Berlin which explores both English and German comics using inter- and cross-medial methodologies, and that is published entirely in English.

to the medium. The narratives utilise various media both for communication and community engagement. The method of close reading, a cornerstone for practitioners of Narrative Medicine for its ability to help "thicken" the story, enables the reader to read not just the literary text, but also beyond it – to study the medium, the genre, the reader's engagement, the image etc. The thesis has thus employed close reading to study similarities in written, drawn and digitally presented stories of illnesses without losing sight of their media-specific or genre-specific qualities, or their social-semiotic features.

In Sontag's ground-breaking work on illness, where she posits cancer as a disease one is embarrassed by and cannot speak about, she underscores cancer as an illness that 'is unimaginable to aestheticize' (40), even as she asserts that an "erotics of art" and not plain hermeneutics is what is required in another equally influential work, "Against Interpretation". Sontag had probably not foreseen that illness could be aestheticized in forms that broke disciplinary barriers (eg. BioArt[5]), but even in simpler ways, like Nancy Miller's blog, 'My Metastatic Life' where she uses diverse multimodal forms such as collage and/or comics to articulate her illness experience. As Miller has said in an interview,

> And I know it may sound odd, but in some ways, terrifying as it is, cancer has become a cliché of our culture. I had the sense that anything I wrote would already have been written by someone else, that my own language would not express the sense of shock that I felt. . . I guess I wanted to express something I couldn't always put into words. (2013)

Miller consequently begins to look for newer ways to form a cancer narrative of her own.

4.2 Cancer and Life Writing: A Literature Review

[5] A creative practice where art is created using scientific methods, blurring the lines between art and biology and challenging scientific thinking. An example of the conjunction of BioArt and Medicine would be the recent work of Stelarc (http://stelarc.org/?catID=20242), who engineered a prosthetic ear into his arm to look at the body as "an extended operational system".
Inevitably, the practice has come under ethical criticism since it involves modification of the living organism.

A group of essays and monographs serve as starting points of scholarship around cancer and life-writing for this dissertation.

In her monograph, *Teratologies: A Cultural Study of Cancer* (1997), Jackie Stacey systematically looks at the role of metaphors, heroes, the self and the body in cancer culture through a feminist analysis of personal narratives. The monograph is an exemplar of the academic-personal essay, with Stacey scrutinizing her own cancer journey through her narratives and photographs to provide critical inroads into the theorizing of the cancerous self as a deviant other. Of specific relevance to the project is her theorization of the monstrous self through the ideas of purity and dirt and abjection by Mary Douglas and Julia Kristeva. The interspersing of personal, political and theoretical strands in this book of academic-personal criticism make it a useful template for studying other such texts in the project such as the life writing by Gubar and Miller.

Barbara Ehrenreich's essay "Welcome to Cancerland" (2001) provides a valuable insight into the need for counternarratives to the "mindless triumphalism of survivorhood" (53) that has pink-washed contemporary cancer culture, terming the wave of misplaced optimism "brightsiding". The essay is an incisive commentary of the overuse of "survivor" terminology, marking a point in millennial cancer narratives that give equal attention to non-survivors as well, refraining from universalizing the cancer narrative to that of triumphalism. Ehrenreich is quick to point out that the diagnostic technology that is so celebrated may not actually be helping in the detection of cancer, similarly the pharmaceutical companies engaged in the celebration of the "pink movement" are also the ones engaged in manufacturing the poisons of chemotherapy. This non-triumphalist outlook is seen reflected in several of the memoirs being studied in the project.

In providing a comprehensive account of thematic concerns available to a researcher of cancer narratives, Mary DeShazer has made a significant impact on the project. In

Fractured Borders (2005), DeShazer lays the ground for an understanding of the evolution of cancer literature, primarily in America, focusing on experience, representation, difference and audience. While several of the early chapters in the volume focus on fictional representations of cancer across the genres of poetry, drama and novel, in the final chapter, DeShazer studies personal narratives of cancer that foreground multiculturalism, sexual orientation and the ecological investigation of cancer and their intersection with life writing.

In *Mammographies* (2013), Mary DeShazer carries forward her work on non-fictional accounts of cancer by focusing on the malady of the century in America: breast cancer. She groups her study into analyses of what could be called the 'canonical' breast cancer narratives: those by Audre Lorde and Susan Sontag, before embarking on a discursive study of different genres including the photonarrative, fiction, graphic memoir (including *Cancer Made Me A Shallower Person*), and the autothanatography, or writing about dying. DeShazer examines how these premillennial and postmillennial cancer narratives offer critiques of the breast cancer culture of the time. Her study also uniquely examines the photographic traces of lives cut short by cancer: photographs of abandoned shoes and an empty apartment all form objects of analysis.

A group of special issues published by journals have helped in producing some important theorizing in cancer studies:

Published as the first focused group of essays on cancer, a special issue of the journal *Literature and Medicine* on *"*Cancer Stories" (2009) remains an excellent resource for exploring various tangents within the study of cancer narratives. The essays help locate cancer, with its medical, bioethical and autobiographical strands, from authoritative clinical and narrative modes to "the embodied perspective of the sufferer" (Schultz 371). The question of *why* people need to narrate their illness continues to be the thematic concern. Arthur Frank for instance takes up cancer life writing by Audre Lorde as an endeavour of

"truth telling"; Mary DeShazer looks into the authenticity of commemoration in her essay about two different texts of mourning written about Sontag by her son David Rieff and the photographer Annie Liebovitz; Jane Schultz on the other hand talks about the psychological and material work of being hairless that women with cancer do, engaging with its everydayness.

Similarly, a special issue of *Configurations* on *Graphic Medicine* (2014) takes into account the "disruptive urgency" of the graphic memoir in redefining the meaning of life writing. Among other essays on health and embodiment in the graphic narrative, two essays on cancer narratives stand out for the ways in which they inform this dissertation. Emily Waples's "Avatars, Illness and Authority: Embodied Experience in Breast Cancer Autopathographics" (2014), through an analysis of *CV* and *CMMSP* looks at the word "graphic" for both its connotations of the visual and the 'excess' for which these pictorial representations of the disease are critiqued, before arguing that it is these affordances of the graphic medium that enable cancer patients to register the disruption of temporality that the terminal disease causes. Nancy Miller's "Picturing the Trauma of Cancer" (2014) examines the harbinger of disruption: the moment of diagnosis and studies them across graphic memoirs for their representation of and deviance from cliches in cancer narrative-types. Both of these articles inform my attempt to uncover universalized narrative strategies to pictorially represent the cancer journey.

Elisabeth El-Rafaie's *Autobiographical Comics: Life Writing in Pictures* (2012), while not solely about cancer narratives, makes important insights about the conventions of representing illnesses in comics. For example, she delves into detail about the society's perception of youthful bodies in opposition to those that are diseased and ageing through an analysis of *CV*. Her analysis of *CMMSP* details its embodiment of "explicit authentication" (144), exploring questions of performance and genuineness that life-writing criticism often

grapples with. Her section on imagined audiences ("Patterns of Affiliation" 187) and the role of the internet in shaping classic narratives of cancer like Brian Fies's *MC* has also influenced my study of the formation of transmedial communities to some extent. El-Rafaie's classification of the conventions she studies: in terms of pictorial conventions, performativity and readership have served as inspiration and foundational starting points for sections throughout the thesis.

4.3 Theoretical Frameworks

Having set out the premises, assumptions and research questions, and a brief literature review of scholarship around cancer writing that has shaped this dissertation, I shall now outline in some detail the methodology employed.

The dissertation analyses cancer narratives using theoretical frames from across disciplines. The narratives are analysed using concepts that i) define the form or genre, ii) are drawn from socio-historical-cultural studies of the body and iii) are explorations of newer embodied identities emerging from newer modes of representation of the body.

Cutting across various media, the study takes as one of its main areas of attention, narrative form. Thomas Couser's work on the memoir, specifically the illness memoir (1997, 2001, 2004, 2009, 2012, 2017, 2018), will be used to explore the concepts of voice, agency and ethics of representing illness. Couser explores contemporary variants of the conventional memoir form to foreground the role of voice, agency and the ethics of writing, while introducing newer forms of the memoir such as the collaborative and public memoir. His ideas of ethics and vulnerability as seen via narrative will form much of the framework required to study the life writing in the project. Similarly, Hillary Chute's ideas of the "hand," "memory" etc. will be used to study the form that embodiment takes in the graphic narrative (2010). The work of critics like Nancy Pedri on the incorporation of visual media in comics

(2015, 2018, 2019) and Martha Stoddard Holmes on embodiment in cancer narratives (2013) will be used to explore the multimodal form of the cancer comic.

The narrative representation of the 'extremities' of illness forms an important part of the thesis. The victim of a traumatic event, here cancer, and the author of the traumatic testimony are at loggerheads with these identities. "How does the memoirist represent realistically this space of death? How can a language that must remain ordinary portray the heterogeneity of the extreme without neutralizing it?" (Rothberg 96), are questions that will be explored through the work of Michael Bury, Michael Rothberg, Arthur Frank and Shlomith Rimmon-Kennan. Such representations disrupt everyday space and time, producing epistemologies of importance to both the cancer patient and the reader, and in Rothberg's formulation, transforming readers so that they are forced to acknowledge their relationship to post traumatic culture (103). These frameworks describe well the extreme condition of living with a fatal illness as represented in heterotopic textual spaces.

In situating the ill person as occupying the borderlands between the human and posthuman through interaction with techno-medicine, frameworks of Posthumanism and Monster Theory, in the contexts of illness, will be utilized and the positing of the ill person as an 'other' will serve as a focus. For instance, the cultural construction of the ill person as a 'monster' will draw from Jeffrey Jerome Cohen's 'Monster Theory', where his major argument is that the monster can be best defined "as an embodiment of difference, a breaker of category, and a resistant Other known only through process and movement" (x). Cohen's basic definition of the monster will be employed in tandem with Julia Kristeva's theory of abjection and Mary Douglas's conception of purity to make them relevant to cancer. The hypothesis that the terminally ill engaging with technomedicine occupy the borders of human consciousness and posthuman subjectivity will be explored. The dissertation concentrates on how the lived body remains the most important site to study both individual subjectivity and

interaction and connectedness with the world. This is a posthumanist stance: Manuela Rossini, Cary Wolfe, Katherine Hayles, Stacy Alaimo, Donna Haraway and Karen Barad all talk about the human's embeddedness and dependence based on the biological circumscription of the body.[6]

While Chris Shilling's theories of embodied identity have formed the basis in studying identity (and Shilling himself draws from Giddens, Turner and other sociologists), this will be taken forward by studying newer identities that are formed by positing the cancer patient as one in a network of the ill, using Rabinow's concept of Biosociality as it exists in a digitally networked world. The 'Body Work' and 'Body Pedagogics' that Shilling proposes are used in tandem with the self-fashioning that occurs when illness is placed in the public sphere. For instance, while Joseph Dumit talks of "objective self fashioning" (2016) and Anna Harris et al, propose 'autobiologies', which are "the study of, and story about, one's own organism" (62), my research has attempted to study how these concepts can be adapted to different modes of representation such as the graphic novel or the mediated website.

Given the different dimensions this dissertation hopes to explore, its theoretical framework, understandably, draws upon many theorists and critical approaches. In what follows, I have organized the framework and key theorists around the themes and modes the thesis examines.

The Gaze: Medical and Human

Foucault's *The Birth of the Clinic* (1989), which introduces the concept of the medical gaze, will remain fundamental here for his thesis that medical discourse makes visible the invisible and externalizes the internal. His major argument is that the body is wholly constructed by discourse, and is built around vision: the gaze describes observation that depends on medical expertise. Where Foucault's gaze was limited to the two dimensional,

[6] Manuela Rossini provides an overview in her essay "Bodies" (2017, 153-169)

advances in technology have shifted the power of the gaze to the machine, as embodied in Van Dijck's *The Transparent Body: A Cultural Analysis of Medical Imaging* (2005). In his cultural analysis of medical imaging's cultural history, he asserts that "the transparent body is a cultural construct mediated by medical instruments, media technologies, artistic conventions, and social norms" (3). Through his analysis of various imaging technologies, like the CT scan, the X-ray, Endoscopy, and the MRI, Dijck highlights how the use of these technologies presents people with ambiguous information, haunting dilemmas and uncomfortable choices.

Narrative competence can widen the clinical gaze to include personal and social elements vital to the tasks of healing. This is the definition of Narrative Medicine, an important concept humanizing Foucault's gaze and forming the core thesis of Rita Charon's book *Narrative Medicine: Honoring the Stories of Illness* (2006). Charon's taxonomies that will be of relevance to the project include: the four types of divides between patients and health care professionals: the relation to mortality, the contexts of illness, beliefs about disease causality, and the emotions of shame, blame and fear; besides the five narrative features of medicine: temporality, singularity, causality/contingency, intersubjectivity and ethicality.

The Body and Society: From Metaphor to Social Constructivism

Written after she was diagnosed with cancer, Susan Sontag in her treatise on illness *lllness as Metaphor* (1977) famously describes illness as an 'onerous citizenship' in the 'nightside of life' (3). Sontag shows that illness and metaphor cannot be viewed separately but that only its de-metaphorization can help understand illnesses for what they are (an opinion that Nancy Scheper-Hughes and Margaret Lock would argue against in an essay in 1986). Sontag's metaphors make cancer at once an invasive force, a psychological condition and a symbol of otherness.

Following in Sontag's tradition of terming the imaginary built around illness "stereotypes of national character" (3), Laura Otis traces "culture's demand for borders" through an examination of seven writers/ scientists/ physician authors belonging to the nineteenth century: Virchow, Koch, Mitchell, Cajal, Conan Doyle, Schnitzler and Mann, who use metaphors to confront these borders, in *Membranes: Metaphors of Invasion in Nineteenth Century Literature, Politics and Science* (1999). Otis studies art and scientific advancements in order to show the shared use of metaphor and language with a focus on the boundaries that separate the self from the not-self.

Shifting from the metaphorical tradition to the theoretical realm of "body studies", Chris Shilling in "The Socially Constructed Body" (1991), traces the "absent presence" of the body in sociology. Shilling also offers three ways in which the body builds self-identity: corporeal absence, corporeal presence, and the body as a mask of identity.

Illness and/as Narrative Disruption

The basis for a study of illness-as-disruption remains Michael Bury's adaptation of Anthony Giddens's concept of "critical situation" for illness in his 1982 essay "Chronic illness as biographical disruption". In "The Story of 'I': Illness and Narrative Identity" (2002), Rimmon-Kenan, writing as a literary narrative theorist, examines the narrative reconstruction of the lifestory as a result of the disruption by illness. Kennan suggests that narrative reconstruction occurs either as an attempt to bridge this divide, via recourse to master narratives that exist in culture, or by emphasizing the disruption through a fragmentary narrative.

As a specific contribution to the study of narrative and the ill body, Arthur Frank's *The Wounded Storyteller: Body, Illness, and Ethics* (1995) remains a fundamental critical text as it defines a typology of the ill body, expanding on Frank's previous classification of the ill body in his analytical memoir (1991). In *The Wounded Storyteller,* Frank provides a

theoretical framework for the different ways in which the sick body interacts with others, and how the narrative differs, describing four kinds of narratives: the restitution narrative, the quest narrative, the chaos narrative and the testimony. Ill bodies have an elective affinity towards a particular kind of narrative during different phases of their illness.

The Ill body and Techno-Medicine

The body and the machine form an assemblage and illness cannot be seen as distinct from this. Using the ANT (Actor Network Theory) as their basis, Annemarie Mol and John Law in "Embodied Action, Enacted Bodies: The Example of Hypoglycaemia" (2004) argue that the body we have (conceptualized as an object, after Foucault) and the body we are (the subjective perception) can both be distinguished from the body-we-do (the enactment of the ill body). The interaction of the patient's body with the clinical environment, various spaces, medication and regiments of self-care forms the basis of Mol and Law's thesis, thereby sharing features with the Actor Network Theory. Writing about the embodiment in technology, Eugene Thacker in his study of Biomedia (2004), makes biology a medium, "an instance in which biological components and processes are informatically recontextualized for purposes that may be either biological or nonbiological" (6). The body in biomedia is understood as both the biological body and a body that is compiled through methods like visualization, modeling, data extraction etc, both technically enhanced and biological. The reconstruction of the cancerous body by technology is the focus of Diane Prince Herndl in "Virtual Cancer: BRCA and Posthuman Narratives of Deleterious Mutation" (2016). Herndl proposes that, "the simulation, the representation, the language of the pathology report produces the reality of being a card-carrying member of the cancer community" (6). She attempts to place previvor narratives within definitions of posthumanism and proposes that 'thingification' (after Karen Barad) is an apt way to understand the illness narrative.

While adapting Jeffrey Jerome Cohen's definition of the monster cited above, the study also employs Jackie Stacey's interpretation of cancer as monstrous. Basing her study on the theories of abjection by Julia Kristeva (and purity and dirt by Mary Douglas), Jackie Stacey in *Teratologies* (1997) defines the cancerous body as abject, also positing her deviant sexuality as being considered monstrous by society.

Illness, Affect and the Public Sphere

Displacing suffering from the personal to the public realm, Paul Rabinow in "Artificiality and Enlightenment: From Sociobiology to Biosociality" (1996) defines the concept of biosociality as a means of group affiliation that leads to definitions of the self, and "a circulation network of identity terms and restriction loci through which a truly new type of autoproduction will emerge" (99). Rabinow's response to Foucault's Biopower was centred on genomic identities and research, but may also be widened in its scope to include networks that find as their common thread the formation of biosocial identities through sharing biological and pathological conditions.

The project draws from the work of Rosemary Garland-Thomson, and her conception of the disabled as 'freaks'. For instance, in "The Politics of Staring" (2002) the argument that Garland-Thomson presents is that disability is a culturally fabricated narrative of the body. She describes a typology of public staring enabled by the media, and lists four visual rhetorics of disability: 1) the wondrous, which capitalizes on physical differences, 2) the sentimental, which diminishes the sufferer or the victim into an object of sympathy, 3) the exotic, which present the disabled as alien, distant and sensationalized, often also sexualized and 4) the realistic, where a relationship of contiguity is established between the viewer and the viewed. The representation of the multiple-ill self in a highly mediatized and networked environment also forms a focus of the study, taking off from Sidonie Smith's conception of the "identity assemblage" that consists of distributed autobiographical agencies (2019).

4.4 Chapter Plan

In this Introduction (Chapter 1), I have outlined the contexts, texts, research premises and questions, and methodologies that have enabled and informed this dissertation. The chapter traced a short history of the 'body' memoir, a genre that established itself firmly in the memoir boom that began in the late twentieth century and has continued into the twenty-first century. The chapter has explored various definitions of the field of the Medical and Health Humanities and Narrative Medicine before engaging in a brief exploration of the genres the thesis studies, such as Graphic Medicine, the memoir, digital illness narratives, etc. I have thematically and theoretically contextualised this study of representations of cancer. The chapter has also laid out the hypothesis and scope of my thesis.

In Chapter 2, "The Everyday and the Extreme", I study the aesthetics of representing the (im)balance between the extreme and the everyday across time and space in cancer narratives and argue that trauma is narrated by the ill as an account of "broken boundaries." The chapter demonstrates that *the narrators foreground the construction of the ill body in both material and abstract ways, and see/represent the self as abject, monstrous and emerging from the site of the illness. I deduce that the narrative reconstruction of everyday spaces and actions to incorporate extremity helps the writer regain agency and a sense of identity.*

The concepts of the "foreigner" in the context of the biological and social signages of cancer are studied. The chapter identifies the game metaphor as a motif to describe this liminal space between the extreme and the everyday. I argue that extremity manifests in bodily and domestic spaces, and in objects of mourning such as photographs and letters, rendering them uncanny. I then focus on the shifting temporalities experienced by the ill person and their use of fabula time and narrative time in the memoirs to indicate "cancer time".

The texts studied in the chapter include Paul Kalanithi's *When Breath Becomes Air* (2016), Susan Gubar's *Memoir of a Debulked Woman* (2012), Brian Fies's *Mom's Cancer* (2011), Stan Mack's *Janet & Me: An Illustrated Story of Love and Loss* (2004), Marisa Acocella Marchetto's *Cancer Vixen: A True Story* (2014), and David Small's *Stitches: A Memoir* (2010).

Chapter 3, titled "'Technologized Terrain': Medical Visions and Patient Re-visions" studies the patient's response to medical imaging, the body's mediation through new media and photography, and the reproduction of these images in the memoirs. *The chapter demonstrates that the graphic narrative organizes an informatization of the body by incorporating and writing (drawing) over scientific images. It proposes that the remediation involved in revising medical images and making them subjective is ekphrastic in nature.*

Biomedical technology such as diagnostics situates the body in a technoscientific field through the mathematization of the body. Narratives that use such biomedia impart existential authenticity to the patient. The chapter goes on to show how the patient uses techniques like focalization to picture science, leading to a "layering of perspective" that turns the gaze back on medicine, supplementing the loss of subjectivity by affective renderings of lived experience. The incorporation of portraiture in the cancer narrative engenders/necessitates the ill person's participation in the cultural iconography of the ill and a resistance to it while encouraging a mode of staring at the deviant body. Photographs incorporated as part of illness narratives show that the narrator's position is that of a witness to the experience of disease and is an affirmation of belonging to a scientific culture. The texts studied in this chapter are Paul Kalanithi's *When Breath Becomes Air* (2016), Fies's *Mom's Cancer* (2011), Stan Mack's *Janet & Me: An Illustrated Story of Love and Loss* (2004), Marisa Acocella Marchetto's *Cancer Vixen: A True Story* (2014), Miriam Engelberg's *Cancer Made Me a Shallower Person* (2006) and David Small's *Stitches: A Memoir* (2010).

In Chapter 4, “The Public-ation of Illness and Transmedial Communities,” I deal with questions of community formation engendered by the multimodal affordances of digital media, and both the biosocial implications and the semiotic features of the narratives are studied. *The chapter demonstrates that collaborative and transmedial storytelling involving both human and nonhuman actants can be used in collectivising projects that can create empathetic communities and generate therapeutic capital, forming therapeutic citizenships.*

The chapter traces different kinds of ‘therapeutic citizenships’: ethnographic on the one hand, as seen in the ‘Humans of New York’ series, rights-citizenships, such as ePatient Dave’s blog, or everyday online journals such as Nancy Miller’s *My Multifocal Life* and Tom Corby’s *bloodandbones* project. I also examine how the use of an interface to shape the autobiographical self, renders these narratives as both text and artefact. The narratives keenly acknowledge the presence of distributed agencies, especially that of the nonhuman, to foreground ‘the force of things’ in the posthumanist space of the narrative.

The concluding chapter is divided into two sections. The first section, called “The Covidian Pathography: Cancer, Coronavirus and Comorbidity” contextualises two cancer narratives in the present moment, that is, the Covidian age. The Covid-19 narratives of Nancy Miller and Susan Gubar, whose cancer narratives were already considered in the body of the thesis, are briefly examined as they describe their lives as bodies-at-risk in the Covid years of 2020-2021. In the second section, the chapter traces the major arguments made in the thesis, lists its limits and discusses the scope for further work.

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Chapter 2

The Everyday and the Extreme

Synopsis

1. Cancerland
    - 1.1 Body Spaces
        - 1.1.1 Terms in Context: The Abject and the Uncanny
        - 1.1.2 Texts
    - 1.2 House of the ill
        - 1.2.1 The lived body in space
        - 1.2.2 Objects of mourning
        - 1.2.3 Photographs and Mourning
    - 1.3 Corporeal Space as Play
2. Cancer Temporalities
    - 3.1 The Moment of Diagnosis
    - 3..2 Cancer Time
3. The Cancer Memoir as Posthumanist Life Writing

Nancy Miller and Jason Tougaw begin *Extremities: Trauma, Testimony and Community* (2002) by listing various definitions of "extremities": "a condition of extreme urgency or necessity", "an instance or act of extravagant behavior", "to be in extremity: at the point of death" (1). Cancer pushes the ill person to these extremities: identity enters a flux as the lived body navigates extreme spaces and times, exhibits extreme behaviours and seeks extreme forms of treatment in the face of death. While several of the essays in Miller and Tougaw's volume are about living in the wake of war and genocide, it is their notion of trauma as an account of "broken boundaries" (7) that I will draw on in this chapter. Those living with illness bear witness to what has "broken through the subject's protective shield" and their renderings of these boundaries will form the object of my study.

This chapter studies the aesthetics of representing the (im)balance between the extreme and the everyday across the texts selected for the study. The broad theoretical

framework will be that of 'traumatic realism' as proposed by Michael Rothberg. In his essay, "Between the Extreme and the Everyday: Ruth Kluger's Traumatic Realism" (1999), where he reads the Holocaust survivor's memoir *weiter leiben* (meaning 'living on'), Rothberg asks, "How does the memoirist represent realistically the space of death. . . ? How can a language that must remain ordinary portray the heterogeneity of the extreme without neutralizing it?" (96). Drawing from Frederic Jameson's ideas of realist discourse, Rothberg delineates the barbed wire, an image of a "shared/divided space" that Kluger uses throughout her memoir, as an example of a metonymic figure that brings the extreme and the everyday together while keeping them disjoint in the memoir.

The depiction of everyday activities rendered uncanny, the presence of a homely object in an unhomely landscape, the ambiguous nature of the extreme in both occupying and evading language – it is in this shared/divided space between extremity and normalcy that Rothberg locates trauma. While Rothberg includes both "the encounter with death" and "the ongoing experience of having survived it" (99) in his description of trauma, in narratives of illness, the trauma derives from the ongoing experience of surviving while waiting for the encounter with death. This chapter will employ the methods Rothberg identifies in *weiter leiben* to study the representation of cancer in select memoirs.

1. Cancerland

1.1 Body Spaces

Multiple definitions of the body exist; while on one hand it is defined as a corporeal, fleshy object– a purely biological entity, on the other it is a discursive, social construction. The rise of the 'social body' is attributed to several factors. The sociologist Chris Shilling counts the resurgence of feminism in the 1960s, the growth of political radicalism, the 'ageing' of societies, the rise of consumer culture, and advancements in science and technology as contributors to the increased visibility of the body in society (2016, 8-10). For

Laura Otis, the 'natural' body and the social body have permeable boundaries that help establish connections with the world (1999, 2). The body plays a significant role in a person's conception, experience and imagination of space, and it is here that disciplinary boundaries between geography and biology begin to crumble as one leaks into the other. How a particular space treats the ill body, and the interaction of the material body with space are both of importance to the spatial construction of disease.

With its organs, veins, tissues, blood, and generally splayed anatomy, the body 'houses' entities imperative to human functioning. I use the term 'houses' also because the body is a microbiome, an ecosystem with trillions of organisms including bacteria, fungi and viruses living in communities of their own. When a person gets uncomfortable in their own skin – or when one is deemed to be so – when the *heimlich* turns into the *unheimlich*, and when the person is made acutely aware of this lurking and then conspicuous difference, the body turns into the body politic. The spatial 'contingency' of the body, that both the performance of the body and its 'reading' shift across space and time, is foregrounded with the emergence of this body politic.

Michel Foucault in *The Birth of the Clinic* studied medicine in the 18th century and organized the spatiality of the ill body into three modalities: primary, secondary and tertiary spatialization. While primary spatialization discounts the presence of the individual, choosing to concentrate on situating the disease in a nosology or classification, secondary spatialization asks the question, "how can a disease, defined by its place in a family, be characterized by its seat in an organism?" (10). The question is essentially about the medical gaze, where medicine draws from different forms of knowledge to engage in a detective-like investigation culminating in a diagnosis of the disease. Foucault's third categorization situates the disease and diseased bodies in an ecology and holds a new institutional consciousness accountable for the disappearance of the 'medicine of species'. Foucault here is developing his theory of

biopolitics by foregrounding "a collectively controlled structure, or . . . one that is integrated into the social space in its entirety" (16). This section focusses on the convergence and dialectic set up between the social space and the corporeal space of the cancer patient in the narrative, and how this represents the dialectic between the everyday and the extreme.

Drawing from various descriptions of the porosity of the body's margins that render the body uncanny and/or abject, in this section, I argue that the experience of illness makes the cancer patients in the memoirs aware of their bodies *as both biologically and culturally uncanny and abject: biologically, as fragmented, consisting of separate entities that during illness render the body unfamiliar, and culturally when social constructions of the ill body render it uncanny and abject*.

1.1.1 Terms in context:

i. Uncanny

Reading women's autobiographies, Sidonie Smith points out that the body helps ground the autobiographical subject in a "finite, definite, unified surround – a private surround temptingly stable and impermeable", and the experience of finding one a stranger in one's own body, the experience of homelessness "derives from the relationship of specific bodies to the cultural meanings assigned to bodies in the body politic" (128). Nicholas Royle draws attention to how the uncanny can be found within one's body: it may be "construed as a body within oneself, even the experience of oneself *as* a foreign body, the very estrangement of silence and solitude" (2). Jonathan Sawday says that "the sexually undifferentiated body-interior is a region of eerie unfamiliarity made doubly eerie (and thus uncanny) by the knowledge that this unfamiliar geography is also part of ourselves" (160). This awareness is necessitated only by the awareness of *extremity*. It is the simple idea of the 'absent body' that comes into play here: as long as the body is healthy, one does not notice it much, but with the onset of the disease, there is an intense awareness of the corporeality of

the body and its various intricacies. Sawday ponders about the construction of the body-as-home in his book on dissection in Renaissance culture, *The Emblazoned Body*:

> A cycle of reflection surrounds the body: to imagine it (familiarly) as a home, it has to be constructed as such, but, in order to embark on the construction, it has to be deconstructed in the first instance and imagined as a scattering of parts. In modern scientific discourse, we are familiar with the language of construction and deconstruction. We speak, for example, of amino acids as the 'building blocks' of nature, out of which, through the mechanism of evolution, complex amalgams are formed which will eventually be identified as 'bodies' themselves constructed out of myriads of cells. Thus, the body (whether animal or human) is both unified and fragmented. (160)

The *construction*[7] of the body that Sawday refers to as homely and its recognition, similarly, as unhomely, are tropes that the writers of the memoirs take particular efforts to foreground. Jean-Luc Nancy combines these different notions of the uncanny in the familiar in *L'Intrus*, his essay on receiving a heart transplant. For Nancy, not only is the incoming heart, though welcome and necessary, a foreigner, but so is his own heart, by calling attention to itself in its sick state: "My heart was becoming my own foreigner – a stranger precisely because it was inside. Yet this strangeness could only come from outside for having first emerged inside" (4). Nancy becomes *aware* that life 'proper' is not confined to one organ but is transcorporeal.

ii. The Abject

The cultural construction of the body as an *other* operates with respect to borders and imagined spaces. These uncanny spaces, where both foreigners intrude and *othered* matter

[7] The use of "construction" is interesting here and holds true for both connotations of the word: material, as in "to frame, build, erect" the body and abstract, as "immaterial objects, creation of the mind" ("construction, n." *OED Online*)

resides, become home to the abject. The abject is neither subject nor object, according to Kristeva, and explored further by Grosz, quoted below, but that which makes us feel outside of ourselves[8]:

> The abject is the impossible object, still part of the subject: an object the subject strives to expel but which is ineliminable. In ingesting objects into itself, or expelling objects from itself, the subject can never be distinct from these objects. The ingested/expelled objects are neither part of the body, nor separate from it. (Grosz, 198)

Kristeva extends the definition of the abject to suffering itself. When the subject emerges from a place of suffering, as the subject of the illness narrative does, the narrative "can no longer be narrated but cries out or is described with maximal stylistic intensity (language of violence, or obscenity, or of a rhetoric that relates the text to poetry)" (141). This theme of suffering-horror is a clear representation of abjection. Narrative exteriorizes suffering even as suffering is close to ineffable.

The theoretical construction that helps us look at the biological signage that makes the abject body monstrous has been drawn out by Jackie Stacey. Basing her study on the theories of abjectness by Kristeva and purity and dirt by Mary Douglas, Stacey argues that cultural perceptions of her deviant sexuality and ovarian cancer leads to her conception of the body politic as monstrous. She calls both cancer and lesbianism cultural categories that generate "anxieties about the certainty of the boundaries between subject and object, between normal or abnormal or deviant, between inside and outside, between sameness and difference and

[8] This is essentially the etymological meaning of the word ecstatic: several "body" scholars draw attention to the fact that the body is naturally ecstatic, the Greek *ek stasis* meaning to 'stand outside', also meaning "astonishment" or "amazement". Judith Butler in *Precarious Life* (2004) explains how while ecstasy is conventionally read as being transported outside oneself by passion, it could equally mean being besides oneself with grief or rage (24). Drew Leder in *The Distressed Body* (2016) similarly teases out an analogy between ecstasy – to stand outside – and "distress", where we are "stretched apart" from our customary lives (1). Jackie Stacey finally draws attention to the abject as something that blurs the subject-object binary and makes us feel "beside ourselves" (76).

between life and death" (77), qualities she associates with the fear of the abject. She focuses on fear, revolting bodies and the monstrous maternal: cancer and pregnancy are both described by Kristeva as abject; the relationship Stacey draws to cancer and reproduction is that it is the life-giving process of cell division that perverted, leads to cancer.

1.1.2 Texts

Cancer reduces the person to the body as the "ground zero" of extremity: the person exists *as* the body. In tracing the narrative strategies that the memoirist uses to represent the strange midland occupied between extremity and reality, Rothberg points to the use of symbols that represent both differentiation and comparison, and are metonyms tied to the space's 'material conditions'. In *CV*, the 'hand,' embodied both figurally and literally, represents the space displaced from the traumatic event that the cancer victim occupies. The 'hand' occurs as a plot device to indicate the crossing of spaces (as indicated above): Marisa can only look on in helplessness as the nurses, unable to find spare veins, have to inject the hand she uses to draw (147. See Figure 1). At the same time, Marisa, being the illustrator of the narrative, is *embodied* in the drawings. The hand is thus a metonym of Marisa's artist self and a symbol that captures the oscillation between the extreme and the everyday. While the hand bore the signs of the illness, the same hand retrospectively draws the illness: the hand is past the traumatic event that occurred in the narrative, but it still lingers in the retelling of the tale. The hand thus stands for the everyday: since it is "the organ which (along with the brain) differentiates the human as a tool-making animal from the rest of creation" (Sawday 151), and being the point of contact for the infusions, a site of the extreme.

Figure 1 The hand as a metonymic device in *Cancer Vixen* (147)

The clearest recognition of the cancerous body in pain as being abject and in a state of utmost decay has already been made by Audre Lorde in her *Cancer Journals.* "Pain fills me like a puspocket", she writes one day, "and every touch threatens to breach the taut membrane that keeps it from flowing through and poisoning my whole existence" ("Introduction"). For Lorde, the despair that cancer brings with the awareness of the body transforming into something old, decaying, abominable only debilitates the person/persona more, and by itself is cancerous. In Gubar's *DB*, the tumour is the invisible enemy, one that is part of her (the subject) but at the same time an object to be expelled:

> Cancer is paranoia's dream come true: there is something in there that I cannot see or feel or imagine, trying to murder me. What was inside me, requiring gutting, that I could neither see nor feel but might attempt to imagine? (57)

Gubar's rendering of cancer mimics its malignant nature; but also how cancer is unnaturally growing and spreading:

> It starts to bring to my mind not a crab or a fetus, not an assassin or a beast or an emperor, but mucky seaweed clinging and clogging and swelling as it lodged in and over my internal organs, creeping rhizomes sending out circuitous tubers and gnarled nodes and octopus shoots, venomous suckers and blades of kelp slicking surfaces with the olive-green slime of slippery moss. Impossible to know the cancer cells' stealthy forays, disorienting to picture the masses of growth they seem to have laid down, unbeknownst to me, at the center of my being. (75)

The grotesque description of how cancer spreads quickly through her body parts ends with the phrase "at the centre of my being," an affirmation that cancer has not just occupied the interior physical spaces of Gubar's body, but also her state of being. Gubar can no longer find a clear distinction between her *self* and her cancerous body.

In David Small's *Stitches*, the comic form is used to show how his illness renders him voiceless, but more importantly and in the context of the self emerging from pain, how the subject now resides in the site of his illness – his mouth. This is shown to the reader in two different instances: one, when Small talks about the "sensation of shrinking down and living inside [his] own mouth . . . a hot, moist cavern, in which everything [he] thought, every word that came into [his] brain, was thunderously shouted back at [him]" (217). The accompanying graphic shows Small sitting on his tongue, hunched over, with his hands on his ears, surrounded by his teeth and the vocal cavity (see Figure 2). The blatant irony presented here is the loudness of Small's thoughts reverberating inside his silent mouth. In another instance, when Small runs away from his school and is sent back home, his parents confront him and ask him what he has to say about his behaviour. Small's preferred response is depicted in a splash page that shows his face, angry, with his mouth open, and this image recursively appears inside his mouth thrice (234).

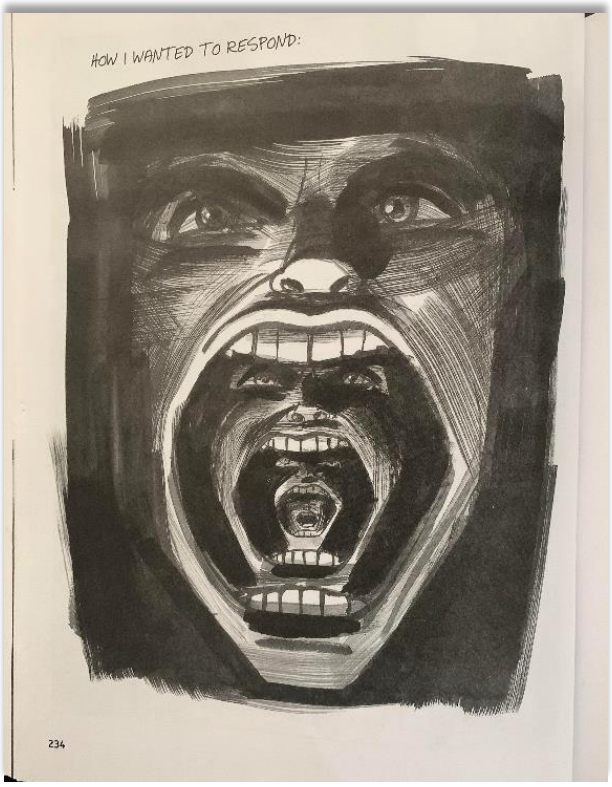

Figure 2 The dysappearing body in *Stitches* (234)

The visual effect, called the Droste effect, clearly shows that the boy inhabits the world in his mouth. Drew Leder calls this phenomenon 'dys-appearance', that is, the reappearance of the body as the focus of the illness experience. The focus shifts from the body as a whole entity enabling us to engage in normal activities to the individual entities of the body that make us uncomfortable during an illness – the part that causes the body to cease functioning as it should. The word 'dys'appearing here is derived from dysfunctional, meaning "any abnormality or impairment of function" ("dysfunctional, n," *OED Online*). The dysappearing body "alienates us, throwing us back onto the limited world of our bodies" (Shilling 2005, 218). Small turns helpless as he turns inwards into a world of corporeal pain.

While Jackie Stacey is quick to point out that the growth within is *not* an intruder since it is a growth that begins with and simulates cell division that is natural to the body, she discounts the presence of the foreigner that inadvertently enters the body as part of the cancer treatment: these foreigners could be as varied as external *devices* like the prosthetic breast

after mastectomy, a "chemo port" that becomes part of the body (implants), or a morphine painkiller that becomes the patient's constant companion. If the abject is defined via the porosity of the boundary through a corporeal orifice, then devices on the margin that *create* orifices are indicators of the abject too.

Gubar's narrative traces the slow dehumanization of the ill person that medical procedures set into motion. The horrors evoked by the impeachment of corporeal borders also shine light on the cultural marginalization of women. She traces the progress of a cultural and medical outlook towards the woman's body in distress: from the 19th century conception of gynaecological cancer as an outcome of the libido in overdrive, through the 20th, where ovarian cancer was a product of repressed desires to the 21st, where the routine ease with which a hysterectomy is suggested for ovarian cancer shows "the propensity of mostly male doctors to regard women's reproductive organs as diseased or abnormal" (50). Sandra Gilbert[9] gives us an apt description of the abjection that patients fear, "abjection linked to a process of medical reification that transforms a person not just into an object, not just into an object of indifference, but even into an object of indifferent laughter and scorn" (196). The reduction of the person to the body is amplified by the responses medical procedures evoke from medical personnel as well. Contempt and indifference are violent and abject in being responses that trivialize the impeachment of corporeal boundaries. "Think of debulking as evisceration or vivisection or disembowelling, but performed on a live human being", says Gubar when she begins describing what physicians call the 'Mother of All Surgeries', the removal of the bulk of the tumour, a procedure called debulking. Gubar not only finds herself marginalised as a woman, but also being refashioned corporeally when she is fit with a draining tube:

[9] Gilbert's memoir *Wrongful Death* (1997) recounts her husband's death following an operation he underwent for prostate cancer. From her own experience and those of others, she frames the phrase "writing wrong" for narrative acts that attempt to discover and expose the wrongs that medical practices commit and pass as "adverse events".

> Am I to go home with a tube longer than the length of my leg coming out of the tush, a plight I have never read about in any of the accounts of cancer I have consulted? . . . I am a cyborg, though I'd rather be a goddess—with one organic and one inorganic hole for excretions—and it's no picnic being tethered. Indeed, in a grotesque fashion I'm on Seneca's leash. (112)

Matthew Mewhorter writes similarly of the dehumanizing nature of his colorectal cancer in his blog, *Cancer Owl*. In a comic rendering of him lying sprawled on a gurney, back exposed to a bunch of doctors gawking at him, he says, "I quickly learned what makes Rectal cancer different from other cancers. . . ENDLESS eyeballs staring at your ass. Privacy is over" ("My cancer story"). Both narratives by Gubar and Mewhorter, and Stacey's earlier theorization, besides echoing various illness narratives about the adverse effects of medical procedures, also talk of being cast into the mould of the "other" due to cultural notions of defilement and purity. Mewhorter has an ileostomy: a surgical procedure that creates an opening in the intestine so that any waste can be collected in a bag that the patient wears around the stomach. "Most days I felt like it wasn't that bad," he writes, "But many days I felt like Frankenstein's MONSTER . . . some days the bag could feel like an udder hanging off my gut" ("My cancer story").

They both see themselves as monstrous: the choice of the words cyborg and monster evokes Jeffrey Jerome Cohen's postulates that the monster is constructed within the matrix of social, cultural and literary-historical relations and is a "harbinger of category crisis" (5-6). In recognising and narrating their *selves* as the abject, the cancer patients also draw attention to the fact that the medical/dehumanizing gaze that medical procedures subject them to compounds the abjectness already caused by the nature of their cancer. "No need to consult Julia Kristeva on the psychic power of my horror, but the truth of Freud's insight "dirt is

matter in the wrong place"—comes home to me. I am perpetually dirty, defecating incessantly from my belly" says Gubar, eruditely subjecting her body to the academic's gaze.

Every narrative of cancer under study describes a physical and psychic change in the self and body in their description of chemotherapy, a process where these changes become most perceptible to the patient. Chemotherapy is an example of a process in which nonhuman bodily matter, the abject and affect converge, leading to the emergence of the posthuman – one that is not only marked by the presence of technological prostheses, but also the emergence of a self that is markedly recognized as *other* by the patient.

Acocella's awareness of the body as fragmented, and both strange and welcoming/rejecting the strange is apparent in her imaginative rendering of the cells in the body. She *draws* close attention to the function of the immune system of the body during chemotherapy. While the entry of the drugs during chemo is necessary, her body must first be deemed okay for the procedure through a battery of tests. Her immune system, if affected at all, would render the treatment infeasible. Marchetto draws these white blood cells as soldiers waving a flag of peace during chemo, at rest, lying low so as to not harm themselves. Chemo makes Marchetto aware of her internal topography: over three panels that zoom in from a tube to the insides of her body, she describes the reaction she has to the chemo: "it feels like a tidal wave of crushed ice is crashing through my veins and the freezing liquid is flooding every outlet in my system . . . brrr!" (152). This intense defamiliarization of the body renders the body uncanny.

In *JM,* Janet's awareness of her body before and after sickness is drastically different. Before being diagnosed, Janet's friend points to how she speaks with "the body arrogance of the very healthy" (17), conceding the point about the "invisible" body and the healthy we have made before. After her mastectomy, Mack recognizes her body as the *unheimlich*: the body itself becomes a new landscape, and Mack wonders about this one night on their bed

after the mastectomy, “It disturbed me at first. What was once smooth and soft was now puckered and unrecognizable. . .I came to see that part of her as being special, deserving tender attention” (25). But once she starts on various treatments after diagnosis, Janet tries her best to incorporate these anomalies into everyday life: “And she had her first blood transfusion. It gave her renewed energy, and she spoke at a conference of young-adult librarians in Florida with someone else’s blood zipping through her veins” (64). This here is an example of Janet’s recognition of the body’s unhomeliness, but also her welcoming attitude towards it. The intruder is a foreigner, but welcome – because life-saving? – in this case (as in the case of Jean-Luc Nancy).

In chemotherapy, intrinsic binaries like human/posthuman and mind/body are questioned. Arthur Frank has already compared chemotherapy to torture. Keeping in mind the sharp ethical difference between torture and chemotherapy, Frank postulates how chemo converts everything the patient once thought was a strength into a weakness. While Eric Cassell’s postulates on suffering are based on his contention that the Cartesian dualism is elided and the suffering is of the person as a whole, in chemotherapy and other treatments that produce acute and chronic pain, it can be seen that the Cartesian dualism does exist, since the mind’s belief that one is being treated is in opposition to the body’s message that it is the treatment that produces the intolerable pain. Gubar compares the mental state of depressives to those undergoing chemotherapy, and says that the hours spent aimlessly depressed as the chemicals dull the senses are when “linearity, actions, and therefore narrative break down” (140). Kalanithi similarly speaks of the chemo pain as leaving behind a consciousness in flux: “I was in pain, floating through varying levels of consciousness” and “sentences would become slippery, voices would dampen and muffle and darkness would descend in the midst of doctors’ speeches as I wobbled in and out of coherence” (190, 191).

The 'new' subjectivity of the ill, who concede to the uncanniness of their bodies and its fragmentariness, becomes distributed. The body as bounded and autonomous is replaced by a body that is an assemblage of medicine, treatments, foreign objects like prosthetics, the immune system and the disease itself. The ill are always aware that the wellness of the body is dependent upon external factors: Marchetto, towards the end of the memoir says wishfully, "if there are any sleeping cancer cells, I hope they remain dormant" (208), recognizing the constant presence of the foreigner in her. Post-treatment, the cancer patient discovers a new self, one that is multiple and armed with knowledge of the body.

1.2 House of the ill

The *domestic,* from the Latin *domus,* meaning house, can describe something as "belonging to the home, house or household" or as "intimate, familiar" ("domestic, adj. and n." *OED Online*), that is, the description could be material or affective. Sandra Gilbert in *Death's Door* says,

> The hospital offers mostly stripped-down anonymous—in effect defamiliarized—versions of [the comforts of home]; mechanized beds that are and aren't like "real" beds; rolling tray "tables" that are and aren't ordinary tables; cubicle curtains that function as "walls" but aren't really walls; "gowns" that don't fasten in the usual ways; lights that never go out; "aprons" made of lead; hallways that don't seem to lead anywhere usable or familiar; "tables" on which people are placed like objects; examination "rooms" that turn out really to be machines; and so forth. (qtd in Gubar, 120)

In this section, I argue that the domestic space, like the body, becomes defamiliarized for the cancer patient. The defamiliarization is represented in the memoirs by the invasion of symbolic, melancholy objects and material 'foreign' objects into private and intimate spaces, and conversely the invasion of intimate objects into 'foreign' spaces. I argue that these

everyday objects, existing in and after the duration of the extreme cancer event, become significations of the disease.

1.2.1 The lived body in space

With respect to illness and disability, Kay Toombs invokes Merleau-Ponty's phenomenology when she talks of spatiality reconfiguring itself to form extensions of the human body itself. She says,

> Physical space is thus for my body an oriented space. Points in space do not represent merely objective positions but rather they mark the varying range of my aims and gestures. For example, the narrow passageway through which I must pass represents a "restrictive potentiality" for my body, requiring a modification of my actions. I must perhaps turn sideways in order to make my way through it (Merleau-Ponty, 1962: 143). Surrounding space is experienced as functional space – that environment within which I carry out my various projects. From my center outwards the world around me arranges itself in terms of near and far goals. (11)

This reformulation of the world is reflected in illness narratives. As Paul Kalanithi was dying, writes his wife Lucy Kalanithi in the epilogue to *WBBA*, he sat in his armchair bouncing their daughter Cady on his lap. Cady "grinned widely, oblivious to the tubing that delivered oxygen to his nose" (204). The oxygen tube becomes an extension of Kalanithi's self, not only to him but also those around him. Nina Riggs (*TBH*) has a mastectomy drain clipped on to her all the time, and at one point recounts the sound of her oxygen compressor at home "kicking on kicking off", a new addition anticipating her worsened condition after chemo, a future prosthesis. When Janet (*JM*) loses control over her bladder, Mack begins lining his apartment with objects that could help her. Urinals and bedpans soon give way to full sized commodes, and similarly a cane soon gives way to a walker and then a wheelchair.

Objects that are not out of place in a hospital begin to permeate the home, making even the homely unfamiliar. For instance, Mack looks at the steps that were "invisible" to them before Janet fell ill, and how with the wheelchair, they "loomed like Everest" (85). The house here mimes the body. The body usually remains invisible to people, since "the perceptual organ remains an absence or nullity in the midst of the perceived" (Leder qtd in Shilling 217). Only when the healthy body begins to improperly function does it "reappear with a vengeance" (217) – this is reflected in the defamiliarizing of familiar spaces like the steps. For Janet, the objects she relies on become prosthetic devices, and as Kay Toombs has argued, objects shift functions to become extensions of the body.

Marchetto comments about the clothes she is given in the clinical spaces in which she is tested as well: she points to every hospital gown she is given, and being fashion-obsessed, rates them according to style, length and colour, treating them as costumes. Interestingly, a synonym for costumes is 'habit', which also forms the root for *habitus*, meaning embodied disposition ("habit, n." *OED Online*). What Marchetto is actually doing is describing the *habitus* of the clinical space, its space through the interaction of the body with it, describing apart from the hospital gowns she dons, the doctor's dispositions (eg. a doctor's turned back is a bad sign, 4), the positioning of furniture (the presence of a table makes it convenient for her to draw while on chemo, 145) and the disciplining or lack of it that takes place within the clinic (one gives her headphones to relax, at one point her drawing hand is tied down because of the IV tubes, 147). This shows an interesting permeation of the boundaries between the clinical world and the world Marchetto occupies where Marchetto's world seeps into the clinic.

When the memoirist makes it a point to purposely make space for the everyday even in extreme situations, it is an assertion of one's (narrative) agency. The extreme is made banal to regain agency and recapture a sense of identity. In her reading of the cancer

autographic, Martha Stoddard Holmes comments on how in *Cancer Vixen*, "Marchetto both explicitly and implicitly asks us to read cancer, sex, and glamour as potentially intertwined discourses, both surprising us and making the book tremendously accessible to audiences who would otherwise be unlikely to pick up a serious-looking book about cancer" (159). I adopt Pramod K Nayar's sense of "cancer agency" here: he calls cancer agency "the attempt to regain a sense of the self by incorporating the extreme into [one's] traditional agential modes" (170). Marchetto's cancer agency enables her to use the signifier of her disease to make a statement about her 'self': both fashion and drawing define her identity, and by drawing her version of the cancer cells, and asserting her fashion sense even on the worst days, she is able to regain agency. This is the case with David Small and Janet Bode as well: drawing and activism are important aspects of who they are, and while by drawing, Small grows a voice, Bode uses her cancer to encourage children in crisis to push harder to succeed. An example of her using the cancer as a signifier is when she takes off her cap, while addressing a group of juvenile offenders, wearing her cancer like a sign: "You and I both have demons inside of us. We have a choice: we can overcome them or let them kill us. I can be a victim, but I choose to fight it and move on. You can do the same" (32).

A comparison of two panels from *CV* and *MC* in their descriptions of the chemotherapy bay is pertinent here. Both graphic narratives attempt to present everyday activities and the extreme event of cancer as being both, concurrent and mutually inclusive events in their depictions. Marchetto's mom describes the lobby outside the chemo bay as "Purgatory" while Marchetto calls it a state of "limbo", both terms used to describe the suspension of time while waiting for what both feel is clearly worse. She describes the chemo chair as a "La-Z-Boy", an upholstered furniture brand, and goes ahead to describe the TV and phone, and a "tray that functions as a desk where [she] immediately set[s] up shop" (145). The panel thus shows an interesting permeation of boundaries, where everyday parlance is

used to describe objects of extremity. The extreme is integrated and adapted to the everyday, which is seen when Marchetto places her sketchbook, pens and recorder on the chemo tray (see Figure 3). The panel contains only the image of the chair, which Marchetto and her mother have already deemed a source of pain, but the human presence is embodied in Marchetto's inclusion of everyday objects. Marchetto means for this description to be a statement since she makes it the largest panel in the page and does not enclose it in a frame.

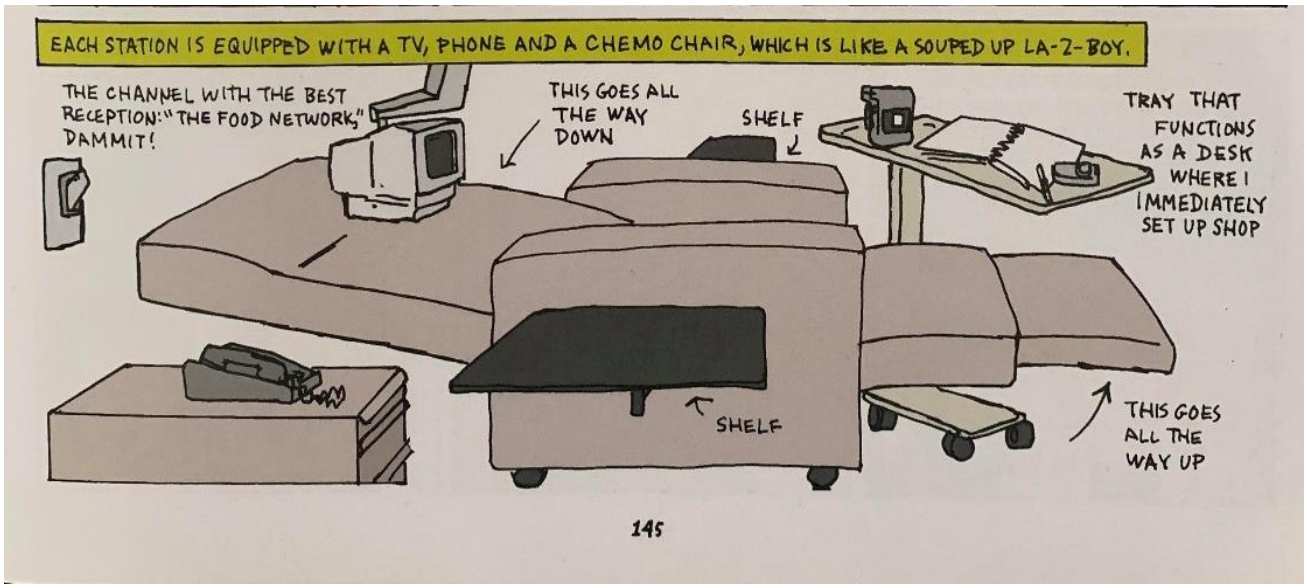

Figure 3 The permeation of the everyday into the extreme in *Cancer Vixen* (145)

The integration of regular, everyday activities into the extremities of illness is both a method to regain narrative agency, and a way to emphasize continuity despite disruption. In her essay on narrative identity and illness, Shlomith Rimmon-Kenan says that the western society's method of ensuring continuity despite the disruption of regular life by the disease "conceal[s] disruption under a semblance of continuity/ victory" (14). The memoirists subvert this notion by integration of the extremities into regular life, and by avoiding erasure/concealment.

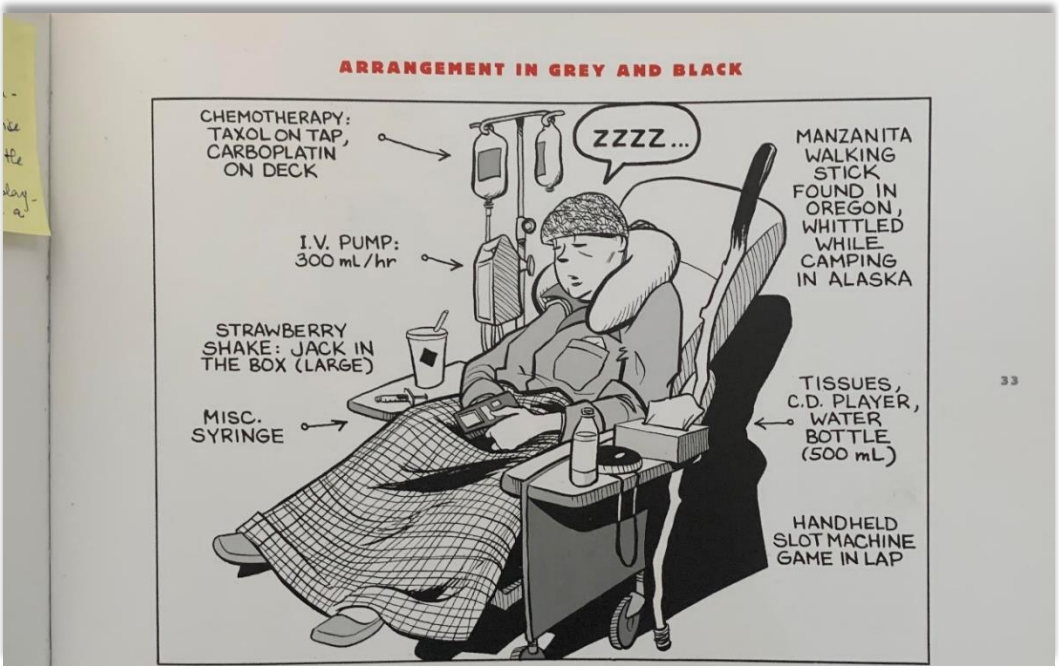

Figure 4 The sick body as an assemblage in *Mom's Cancer* (33)

Fies makes his description of the chemo bay a splash page, and titles it "An arrangement in black and white" (33. See Figure 4): Mom's chemo chair has her dozing off on it, the chemo bags, an IV pump accompanied by a strawberry shake, a walking stick from Alaska, a CD player and a handheld slot machine game on Mom's lap. The sick body is put on display here: an "arrangement" is defined in the *OED* as "a structure or combination of things arranged in a particular way or for any purpose", a piece of art or a production for display, but in music, an arrangement can also mean "the adaptation of a composition for voices or instruments for which it was not originally written" ("arrangement, n." *OED Online*). The chemo chair with Mom and the objects that she uses is first used to signify that the sick body is an assemblage; an assortment of human and non-human actants constitute the sickness. Simultaneously, the title also puts the sick body on display for us, showing a miscellany in order.

The vital materialism of the non-human entities of the cancer assemblage – biological, like the tumour, the deviant cells; biotechnological, such as the implants, catheters and tubes; and institutional, such as the hospital corridors, the various insurance forms, the *disposition*

of the hospital itself – all possess a certain agency of their own which induces in the subject of cancer certain actions or feelings. This is an *affective* agency. The young Small in *Stitches* says, "No one can love a hospital, but those bland, functional spaces and fixtures were a part of my life. There, I felt safe" (160). Small grows acclimatized to the medication and the injections, and begins to think of the nurses and doctors as his protectors. Once the book he is reading (*Lolita*) is placed in the bedside drawer in the hospital, he sleeps in peace – while the presence of his mother (someone he always connects with home) there acts like an intrusion, the hospital and its inhabitants, including the nurses, have a contrary effect and become *domestic*.

It is imperative to note that the conception of the hospital in the memoirs being studied is that of the uncanny – where the uncanny stands for the unknown, the unhomely, and also as Freud defines it, the repressed or the secretive. The hospital is "purgatory" according to Marchetto (145), it is a place where Small as a child encounters the foetus (39) – which is the uncovered, a secret, possibly a symbol of Small's troubled childhood) and the place where Kalanithi discovers that medicine "trespasses into sacred spheres" in the anatomy lab (49). When the familiar seeps into these foreign spaces, doubling occurs. This return of the familiar is of two kinds: in the first, it occurs unconsciously or accidentally, when it again acts as a signifier of the uncanny. While on a vacation in New York, on the banks of the Hudson River, Kalanithi recalls a scene from the past, where as a twenty-year-old, he would be surrounded by trees and birds, nose buried in a book on death – he was in a similar situation now, he ruminates, but "instead of a book on death separating me from the life around me, it was my own body, dying" (14). Kalanithi is admitted to the same hospital where he had worked all these years, and checked into the same room where he has treated patients before. The uncanny doubling marks Kalanithi's confrontation with his vulnerability

as a doctor, mortality and the image of the 'physiological-spiritual' man he had chased through his graduation.

The doubling occurs for Nina Riggs when she visits her parents' house when their old dog is being put down. The whole situation uncannily reminds the whole family of their mother's death; even the scrubs that the vet wears and her haircut are similar to that of their mother's hospice nurse. When she says "Rest in Peace", she does not know who she is speaking to, the dog or her mother. The traumatic doubling is accidental, but makes Riggs realize that to rest in peace is not just what she wants for the dead, but also for herself. Riggs seems to be surrounded by uncanny signs of impending death: the Halloween after her cancer returns, her son decides to wear the costume of the Grim Reaper instead of his usual fox costume, and as Riggs reasons this out with him, it appears as if she is confronting her own situation: "One minute you are a happy little woodland critter, and the next you are death incarnate" (278). Sander Gilman says that art is a projection of one's fear of loss of control, of disease: "the fixed structures of art provide us with a sort of carnival during which we fantasize about our potential loss of control, perhaps even revel in the fear it generates within us, but we always believe that this fear exists separate from us" (2). This is especially true of Kalanithi or Small, who have always pursued art to understand or escape their fears of mortality. The confrontation with these fears is their becoming the Other, the boundaries between art and reality collapsing.

1.2.2 Objects of Mourning

The manner in which objects are placed within the domestic space defines the functions of particular spaces, but the inverse is also true. Objects come to be defined according to where they are placed in the house. Much like physiognomy studies the character of humans through the appearance of faces, the aesthetics of domestic space could

also be used to study traces of the people who own them, as Walter Benjamin has shown in "Paris: Capital of the Nineteenth Century" (1969):

> The interior is not just the universe but also the etui of the private individual. To dwell means to leave traces. In the interior, these are accentuated. Coverlets and antimacassars, cases and containers are devised in abundance; in these, the traces of the most ordinary objects of use are imprinted. In just the same way, the traces of the inhabitant are imprinted in the interior. Enter the detective story, which pursues these traces. (169)

These traces transform into memory stains when the body – the first space the human occupies and where narrative is born, according to Julia Kristeva's semiotic *chora*, thereby the first real *domus* – is no longer comfortable in the *domus*, and when the objects double as reminders of what was, and what is not. I use Nancy Miller's term here from her essay "Memory Stains: Annie Erneaux's *Shame*" (2014) where while exploring the affect of shame through memory, she says that one often returns to the scene of trauma in the course of memory work, "looking for clues to the mystery of how we became who we are" (199). As for the last sentence I quote from Benjamin, the memoirs being studied *are* akin to detective stories (especially those written by caregivers), where the memoirist attempts to bear witness to the becoming of the ill person through the journalistic (and scientific) task of observation, selection, enquiry and narrativizing to uncover their memories by returning to the objects that embody them. Margaret Gibson, in describing the importance of intimate spaces and their objects in defining the identity of people, quotes Hallam and Hockey (2001):

> . . . body, self and space have been increasingly linked with one another in acts of memory that privilege and attempt to sustain the unique character as well as the social status of the individual. Not only have individuals been associated with the spaces of their intimate lives, but also the embodied experience of

> objects and spatial locations are seen to encode value, beliefs and memories. (2004, 79)

While Gibson theorizes 'melancholy objects' as objects in space used to memorialize the dead by the bereaved, I argue that these objects are also those that the dying and their family cling on to, to retain their sense of identity. As Kalanithi spends his last days at the ICU, he wonders with his wife: "was there some way to re-create home here?" and his answer comes to him in the form of his daughter's name. "Cady", he says, reminding us that the domestic space is invoked in the bonds of familiarity one forms there, and taking on greater importance given that Cady was born through assisted reproduction in *cancer time*, a "compressed, urgent and unreceding" decision in the face of Kalanithi's debilitating condition, making the child a result of, and a survivor of Kalanithi's cancer.

Nina Riggs talks about her friend Ginny leaving behind letters for her children and shopping for future clothes for them, that would help her in "parenting. . . from the grave" (260). The letters and objects are the cancer patient's attempt at leaving behind, for posterity, the part of their identity they hold close – that of being a parent, but the performative agency of *parenting* that Ginny encloses in the letter, along with the physical mark of the *hand* that the letters carry, evoke the sense of embodiment and make them serve as objects of mourning. On her mother's death anniversary, Riggs describes her own encounters with objects and places that embody her mother for her. She says, "sometimes, being in the same place helps, because it summons the intangibles of smells and the way the light looks" (267). Sitting on her mother's bed, she feels her sitting on its edge and recalls her predicting her death a few years ago. The presence of her mother through the old house she visits and the bed she sits on makes it a "visceral anniversary".

1.2.3 Photographs and mourning

After his diagnosis of metastatic lung cancer is confirmed, Kalanithi broods over a photo of his wife and him from medical school. “It was so sad”, he writes, “those two, planning a life together, unaware, never suspecting their own fragility.” (126). Besides recognizing the vulnerability of human life and invoking the phrase *memento mori* through his words, Kalanithi also distances himself from his old self. In using the third person to refer to himself in the photo, Kalanithi is already defamiliarizing himself from the happy scene. Freud’s uncanny returns, the photo ironically serving as a reminder of a past, dead self, in the light of the newer, cancer-ridden dying self. Roland Barthes is relevant here: in talking of the *punctum*, Barthes requires no analysis, merely the help of memory, for the punctum in a photograph is only “a detail” with metonymic qualities and the “power of expansion”, that can fill in a whole photograph (Barthes 42-43). Kalanithi looks at the photograph, but we must remember that this act is only a memory when he is writing his memoir, and the punctum that acts on Kalanithi is the temporality of their laughter – a sense of transience that can only be evoked by his changed subjectivity of time and death.

The photograph is an important material resource available to the writer of the illness memoir since it is an indicator of the biographical disruption that has occurred as a result of the illness and sets into motion the process of mourning for this previous self. This participation in a history that the self can no longer be a part of or revoke occurs on two levels through the photograph: one, that the photograph playing a double role is evocative of a memory and is also evidence of the non-presence of its characters in the space and time of the present; and two, that the subsequent identification of this fact and its projection and juxtaposition with a narrative of the present makes it an ‘object of mourning’. The graphic narrative lends itself most readily to this simultaneous proffering of different temporalities: space in a graphic narrative stands as an icon of time (McCloud 27) and can “choreograph

and shape time" (Spiegelman, qtd. in Chute 2008, 454), and thus in every panel, space is time, making the graphic narrative an apt medium for witnessing (and making readers 'bear witness', for we are reading but also looking at the same time). The insertion of a photograph adds another layer, and complicates, this already *excess* visual medium – excess because of its capacity to include several perspectives, temporalities and spaces within the confines of a panel – causing both the narrating self, as we have seen, and the reader, to engage with history. Hillary Chute also recognizes that this characteristic of comics to integrate pauses, absences and closures in its narrative sequence is similar to the process of memory (4). While the photograph becomes an object of mourning for a lost part of the narrator's identity, for the reader it is archival evidence.

A sequence of panels in Brian Fies's graphic narrative that culminates in the coalescing of temporalities, with the implied use of a photograph, puts what has been said above about time, memory and the photograph to use (see Figure 5). In the sequence, Mom reacts to the news of her diagnosis, explaining to her kids the will she has asked the attorney to draw up, while Fies's narration interprets for the reader the biomedical implications of the diagnosis. Taken as a sequence, the narrator's voice and the character's voice show the difference between epistemology and nescience, or the lack of knowledge. The final panel brings together the past: a figure of Mom as a model, dressed in a swimsuit with a beachball in tow in the foreground; the present: a silhouette of Mom handing over her will to the kids, sitting since the cancer has now affected her leg; and the future: the presence of a will denoting Mom's uncertain life. The panel is one of several visual metaphors Fies uses in the book – here, that Mom is only a shadow of her past, as the silhouetting indicates. The image of Mom as a model *before*, as the footnote informs, Fies was born, indicates that the drawing is from a photo, or a recollection of a photo. Fies corroborates this in his blog:

When I drew the picture of Mom modeling a swimsuit, I was relying on memories of photos I'd seen very briefly a long time before. Turns out my memory wasn't very good. Here are the actual pics of my Mom the model:

. . .

I could've sworn there was a beach ball.

What the heck, here are a couple more:

. . .

Beautiful! Classic Mid-Century Modern.

In case my asterisked footnote in the comic was too subtle, Mom worked as a model when she was 18 to 19. I was born shortly before she turned 20.

("Mom's Cancer Notes: Page 11")

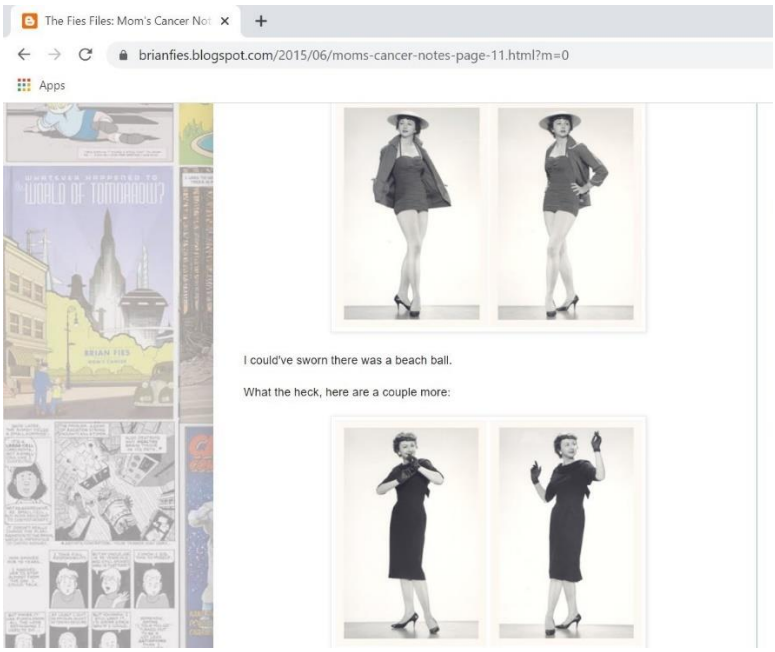

Figure 5 Time, Memory and Photographs: A screenshot from the "notes" for *Mom's Cancer*

The original pictures do not have a beach ball, and have different poses from what Fies draws in the comic, but reading Fies's notes in his blog as a paratext shows that the photograph for Fies is less about what Mom was, than about what Mom was *not*, in the

present. The addition of the ball and the mental image of a beach sport evoked by the picture, juxtaposed with a dark, hunched Mom appears to be Fies's manner of highlighting Mom's loss of mobility. *JM* also uses drawings of photographs from the healthy-past to contrast with Mack's narrative of the ill-present to stand in as objects of mourning and melancholia. A drawing of Janet's photo with arms thrown in the air in Machu Pichu is followed immediately by a drawing of a hand holding up a diagnosis report confirming the return of her cancer, after three years (55, 56). The happy and the extreme are both presented archivally, one documented via photography, one scientific documentation. The contrast, like the panel juxtaposing temporal sequences in *MC*, is used to foreground the melancholic present over a happy past. It is important also to note that both the images contain the subjective trace of the writer since they are both drawn – the presence of the writer's *hand* embodied in them both, a method that is followed both in *CV*, in the drawn photographs of the doctors (138, 139 and elsewhere) and *Stitches*, in the drawn representation of medical images (53, 54).

1.3 Corporeal Space as Play

"Space is play as well when human beings are forced to *imagine* space where none exists" (Chandran 73, original emphasis). In the case of illness, the spaces exist, but they are either invisible to the human eye, or cultural spaces that are visible but render one's identity mutable and ambiguous, continuously in a state of flux. In this section, I argue that this space of ambiguity is represented through the game metaphor in illness memoirs. How does an ordinary everyday activity like the game, meant for pleasure, fun or competition, cohere with a situation of extremity like cancer? The space of flux is concretized as an illness experience through the game that serves as a spatio-temporal microcosm of different experiences in the 'kingdom of the ill'.

Cancer traverses bodily and cultural spaces that one cannot see – except in medical images that render the invisible, visible – and encounters cells, changes them, destroys them,

and reproduces. The reimagination of cancer using gaming metaphors in the memoirs being studied leads to the conception of space as play. The disease in the body is mobile in its growth and malignancy, and in corporeal space, morphs and metastases. Like the popular *Game of Life*, where the board simulates the player's life through biological processes (birth, birthing), social and institutional processes (education, marriage), and abstract encounters (like Chance), the subject of these metaphors is the cancerous body – the tumour and the body that houses it – and its journey through its encounters with biological and cultural signage.

The traditional autobiography itself begins with genealogy, a story of origins. However, the *Game of Life* begins simply with "Birth" in block letters – that is where it chooses to begin narrating the player's story. If the beginning of a story is thus where the narration begins, what about beginnings unknown, unimaginable and unchartered? It is no surprise then that most game metaphors in our representations choose to focus on the genesis of the cancer, though the memoirs themselves begin at a point much after the cancer was born. But by genesis, we must ask, are we speaking about the origin of the cancer, or its beginnings? For Foucault clearly outlines for us that the beginning of the disease is the manifestation of its symptoms, the beginning of the cancer narration is the *appearance* of it – which cannot have started with its origins, since the division of cancer cells is invisible to us until it appears in the form of a corporeal abnormality. Thereby we arrive at Edward Said's popular formulation of the *beginning* as the "intentional production of meaning" (5). The memoirs begin at this point, rendering the cancer subjective by choosing its manifestation in the body as the beginning of the narrative, leaving the invisible story of its origin, its etiology, to the imagination of play.

The etiology of the cancers in the memoirs under study, except in *MC*, is unknown. In *CV*, Marchetto uses the play metaphor to explore both the possible etiology of the disease and

the treatment. Marchetto makes sure to *draw in* both cultural and environmental factors while talking of possible causes. In a centerfold- splash panel, "The Cancer Guessing Game" (34-35) simulates a board game, each small frame talking of a possible cause, covering lifestyle habits: eating chicken, smoking, alcohol, obesity, the coating on takeout containers; environmental causes: pesticides, proximity to a nuclear reactor; the genetic factor; and the impact of biomedicine itself: using contraceptive pills, antibiotics and hormone replacement therapy. Each step forward in this game is presented as a possible cause, is followed by research data that ambiguously disproves a clear link between cancer and the stated cause, and contains statements by corporates who deny any link between cancer and their product. Interestingly, there are no doctors in the mix: no doctor throughout the narrative ever offers Marchetto an etiology of her disease. In fact, when she asks her doctor if the asbestos she inhaled during the 9/11 could be a possible cause of the cancer, the doctor responds, "Do you really want to drive yourself crazy playing that game?" (32).

How does playing this board game differ from playing conventional board games? A game's object is to win it, but there is no end point to *this* game – and aptly, no starting point either. Thus the word START in block letters is embedded in the phrase "When did it START is another mystery" and the game does not end but shuffles back and forth based on ambiguous information the player comes across. Reading the game metaphor in illness narratives, Nancy Pedri says that they are "*creative metaphors* that pose a challenge to established schemes and conventional perceptions" (235). The perceptions being challenged here are not only those of the conventional game, but also those of the illness experience: even while universalizing the experience by using a game metaphor that requires a common understanding of its basic workings, the game metaphor means that the experience is unique to each person, and though the langue is understood, the parole is different. Pedri's reading of these game metaphors is through Roger Caillois's typology of play, and I adapt his

classification of the *chance* or the *alea* type of play and argue that the games in the memoirs studied depict this ambiguous state of destiny. Alea, for Caillois, consists of "games that are based on a decision independent of the player, an outcome over which he has no control, and in which winning is the result of fate rather than triumphing over an adversary. More properly, destiny is the sole artisan of victory, and where there is rivalry, what is meant is that the winner has been more favored [sic] by fortune than the loser" (17). Marchetto only needs a lighter chemo and hence doesn't lose hair (170); Engelberg's breast tumour turned out malignant while someone she met found out that her tumour was benign ("Luck"); after three years of being cancer free, Janet's cancer returns (56). These are all outcomes of fortune. One can see how the uncertain etiology, the lack of agency in treatment options or the outcome of these processes result from chance.

These games of destiny are imperative in establishing a lack of agency on the part of the cancerous body, emphasizing what Caillois calls *ludus*, with "arbitrary, imperative and purposely tedious conventions" (13). Here, the process of treatment is likened to a game in which the player is not the ill body but the institution, and the ill bodies are but pieces that are moved. In *CMSP*, Engelberg imagines being in a race where she is rolled down a hill by doctors to get her body wrapped around a bandage. While one of the doctors guesses his patient might win, the other says "too early to tell" ("Ace Bandage"). The panel appears to be a meta comment on the nature of cancer, with its high probability of remission. In *JM*, Mack tries to look at the treatment as an optimistic game, imagining the chemo medication to be Pacmen gobbling up the clustered dots of cancer. Mack describes how this imagined game within the body sets the body in a social space on an "emotional and physical roller coaster" (62). The metaphors here set up a multilayered game, where the game inside the body sets into motion a game on the social level.

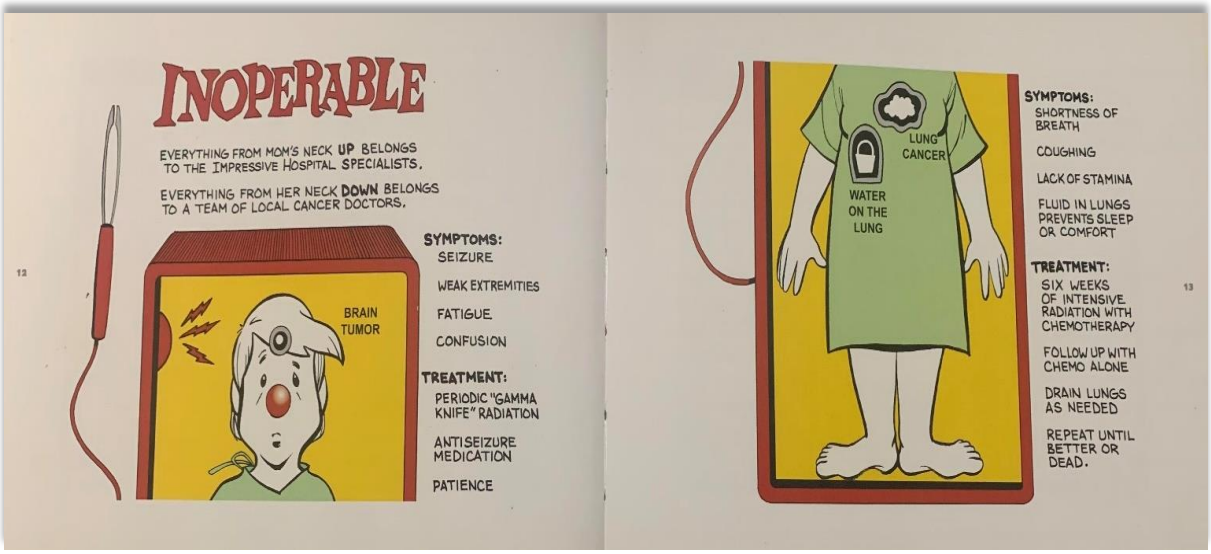

Figure 6 The Game as a metaphor for objectification in *Mom's Cancer* (13)

Similarly, several game metaphors mark the objectification of the body in *MC*. The family stumbles through game elements such as "dumb luck" and "random chance" to arrive at an appointment for a diagnosis – which as we know is not really an end, but another beginning. In his most symbolic game metaphor, Fies divides Mom's body into two – both formally, into two pages, and metaphorically into two parts of a game called "Inoperable," saying "Everything from Mom's neck up belongs to the Impressive Hospital specialists. Everything from her neck down belongs to a team of local cancer doctors" (12-13. See Figure 6). Fies draws the body as a cartographic object that can be mapped, but can also be divided: a body that can be played with. What is remarkable is that Fies simultaneously foregrounds the objectification of the body and its humanness. Qualities like "patience" and perseverance: "Repeat until better or dead" are thrown into the mix of treatment options.

In yet another sequence, Mom walks on a tightrope and as she moves, more numbers of elements are added to each successive panel: the pole she uses to balance has a vulture on one side and an elephant on the other, she walks over a tank of water with a crocodile on it, and soon the rope's end is on fire (60-61). Fies uses this incrementation to stand in for the effects of chemo to make Mom the subject of a complicated comedy routine at a circus, the

motif being of a game with no end but one in which the difficulty level keeps rising. At one point, Fies describes the doctor's face as he describes the complex radiation procedure that Mom has to be put through, "The doc in charge is almost giddy. . . it's a video game to him" (22). The *ludus* of the game is in operation here, chemotherapy appearing as the contrived, complex and arbitrary part of the game.

Stitches gives play a different dimension. To Small, whose father is a doctor, the hospital becomes a familiar place. He treats the different floors and objects in the hospital as games and as a playing ground, wheeling himself around on wheelchairs, traveling up and down the elevators and using the linoleum floors as his skating rink. This part of his childhood makes Small feel at home in the hospital, a place where there is no cruelty and violence when compared to the oppressive atmosphere at his house. It is also through play that Small as a child encounters the *unheimlich*, a fetus in a glass jar in one of the rooms in the hospital (38) and play here turns into a rite of passage towards identifying with the self. Play through imagination becomes a recurring motif throughout the narrative, as the images that the lonely child draws come alive to play and dance around him. Small imitates Alice as he goes to the playground, hoping that he would be able to travel to the magic lands that she travels to, but when the other kids make fun of him for behaving "Queer" runs back to his sheets of paper, drawing a hole and (metaphorically) disappearing down it. The game for Small exists as a space-time separate from the real world, one where he can be himself. It is in this constructed world that Small begins to embrace himself as the "other". A particular drawing shows the child jumping down the rabbit hole, and as he does so, he transforms into a rabbit, happiest when he is not human but in the world of his imagination (63).

I argue that these acts of imagination, where the memoirists *playfully* imagine spaces, draw from the visual literacy of the writers to describe the cancer experience. This literacy is used as both "a coping mechanism", and "a communication tool" (Sadokierski 191).

In a flashback sequence about Fies's childhood, the origins of his interest in science, particularly that of outer space, are outlined: "I was born at the dawn of the space age", he says in a panel where he sits as a child, cross legged in front of a television set, watching a rocket take off. From then onwards, his hobbies, education and career revolve around science. This scientific literacy makes him see the cancer in terms of data, a *problem* to be *solved*, and the solution to which can be drawn from resources: "folders and binders with facts and theories" (24) that are part of his research literacy. The comparison of the tumour to a nebula is also his attempt to communicate to the reader the experience of cancer through images he is comfortable with. Right from the beginning, the influence of popular cultures of science in his description of Mom's cancer is apparent: half of her disappears while watching *The Time Machine*, a film about disappearing through time into a space-time detached from reality. The cartoon he is shown watching at the beginning – *The Powerpuff Girls* (creations of science), foreshadows the segment later ("Rx Kryptonite") where the family argues about caregiving duties, turning into superheroes who use their superpowers against each other. The panel showing mom "drowning" in medical terminology is a clash between Fies's ordered and calculated world of science that promises a solution and Mom's chaotic, unpredictable world.

David Small draws his descriptions of illness from the imaginary worlds he creates and inhabits. Small's fascination for Alice's world and drawing imaginary creatures makes him imagine the world of cancer similarly – play and his disease cohere as Small equates them to him receding into the world of his disease. A parallel is seen between the rabbit hole Small disappears into to escape from the rest of the world, and the dark, moist cavern of his mouth that he invites the reader to peep into (182, 216). David is confined to both his body and his imagination, but while the former confines him, the latter liberates him. His therapist appears to him as the White Rabbit, who with his watch, is also a symbol of how therapy

sessions are always bound by time [and money], much to the chagrin of the patient. For Small, play seems the easiest way to face traumatic truths – the Rabbit's speech is one such instance:

> A boy who has cancer. . . A boy whose parents and doctors did not tell him he had cancer. . .a boy who had to find out the truth on his own . . .is this crazy? No. It's sad. But not crazy. You've been living in a world full of nonsense, David. No one had been telling you the truth about anything. But I'm going to tell you the truth. Are you ready? Your mother does not love you (252-255).

The next few panels are quiet, as Small absorbs the truth, and for the next few pages, heavy rain metaphorically stands in for the barrage of emotions that the imagined rabbit has unleashed in Small. The imagined world becomes a space for Small to confront and embrace difficult truths.

In a related argument about the presence of play in Holocaust narratives for children, Daniel Feldman writes that play is "recruited . . . to diffuse tension by offering a ludic and therefore more pleasurable veneer to traumatic experience" (361). Small's memoir is from the perspective of a child – hence the treatment of the "childhood from hell" (as a review on the back cover says) requires that the lived experience be that of a child, for whom play, fable and allegory are apt ways of learning. This applies to Riggs's memoir, where for her children, play through imagination is both, a way of watering down the trauma, and of fighting back – when Riggs calls her latest chemo treatment Red Devil, she finds her son has dawn a comic strip called "Red Devil Vs the Cell Creep" (152), visualizing the cancer as a game that must be won.

This manner of *learning* about the disease through imaginative play drawn from one's visual literacy could be extended to adults as well. For instance, in *Cancer Vixen*, the doctor equates the cancer cells travelling to Marchetto's sentinel node to cars crossing the toll booths

to enter the tunnel from New Jersey into New York. In Marchetto's rendering of this metaphor she gives the cancer cell a bandana, making it look grumpy and like a gangster or a bandit in a car, asking the gang of cells, "Are we there yet?". The cells are thus envisioned as the enemy, much like the kids in Riggs's memoir do.

These spaces of play, or *imagined* spaces: the games in Fies, outer space in Marchetto, the rabbit hole and dream-spaces in Small, I argue, are not concrete, stable spaces but transient, and mark the contamination of boundaries between the everyday and the extreme.

In *Homo Ludens*, Huizinga says that the "arena, the card-table, the magic circle, the temple, the stage, the screen, the tennis court, the court of justice, are all in form and function, playgrounds, i.e. forbidden spots, isolated, hedged, round, hallowed, within which special rules obtain. All are temporary worlds within the ordinary world, dedicated to the performance of an act apart" (16). The insistence here is of a space isolated from the real world, a space where the conditions of the real world do not apply, a space with its own set of rules – these rules cannot be trespassed and are binding. If these rules are broken, the game no longer holds. Caillois builds on this in a chapter aptly titled "The Corruption of Games": "any contamination by ordinary life runs the risk of corrupting and destroying its very nature. . . If play consists in providing formal, ideal, limited, and escapist satisfaction for [. . .] powerful drives, what happens when every convention is rejected? When the universe of play is no longer tightly closed? When it is contaminated by the real world in which every act has inescapable consequences?" (42-44). By giving the play arena a consecrated spot, it is already deemed by Huizinga to be different from the everyday. In this analysis, we have examined play and its spaces through the everyday, while being cognizant of the intrusions into it by the extremities of illnesses. When both play and illness are bound by their own

rules, and they trespass each other's space, the contamination of the everyday by the extreme and vice versa occurs.

We have already seen how play, through the memoirs being studied, create spaces where the player struggles for agency, looks to destiny to decide the outcome of the 'game', uses the space to escape the realities of the world or contemplate them, and where the player is *played* due to the inequality of players in the arena. The experience of illness bends the rules of the magic circle, deviating from Huizinga's formulation.

I argue here that besides deviating from the norms of the magic circle, the imagined play spaces in these memoirs are also "supermodern". The word is drawn from the comic, *Desolation Jones* by Warren Ellis and JH Williams III. Jones explains: "Supermodernism. The fact that we don't build places, just to live in anymore. We build places to go through. To be in. To be transient." Karin Kukkonen equates this to Zygmunt Bauman's 'liquid society': "a world in which nothing is stable anymore, [there are] no social structures, no lasting work relationships and no permanent homes" (61). The comics-medium uses its affordances to help us realize the supermodern state of these imagined spaces.

In *Stitches*, the deviation is realized in a metaleptic turn when the rabbit from the diegetic storyworld steps out of the burrow into real life, leaving the play arena and seeping into reality. The introduction of the rabbit in the real world is more or less a jolting from sleep into reality for both Small and the reader. The rabbit breaks the rule of the playworld, leaving the arena and acting as Huizinga's "spoilsport", and what is shattered is Small's conception of reality as a world of truths one might escape from. In another imagined space within Small's storyworld, Small's recurring dream, he walks through a large house whose corridors and doors shrink in size every time he passes through one so that he has to crawl through the last one, always emerging into a large, dilapidated room. These dreams occur at two points in the memoir: one, after Small discovers he has cancer and feels that he is

reduced to his body, and one after he confronts his parents about his cancer but is not given the audience he deserves. This journey appears to be a metaphor for Small's illness experience, where every time he deduces something about his illness, he feels restricted to his body, his world getting smaller and smaller. The large, dilapidated house he enters at the end of his dreams is revealed in the last dream sequence to be the asylum his grandmother had been locked up in. As soon as it is revealed that the imagined space is an analogy to/of a real-time space, Small refuses to enter. The dream-building turns out to be a space in limbo, where real world measurements of space and time do not hold, a space where Small passes through only to realize he does not want to be there forever.

Marchetto's imagined outer world is dissimilar to Small's in that, while Small uses his world to escape truths, Marchetto uses hers to recoup from traumatic truths and confront the truths she encounters on her illness journey. Her imagined outer space appears after her diagnosis, when "the electrolux of the universe sucked [her] into a dark hole" (9), when she imagines the unaccounted cancer clusters whose lives were affected by environmental factors, when she experiences extreme pain (118), when she needs a moment to herself as she gets ready for chemo (143), when she discovers she cannot be a mother (150, 205). Marchetto populates this diegetic outer space world with projections of her internal state, desires, dreams and plans, elements that do not have concrete shapes in the real world – even the people she draws as having been a part of the cancer clusters are undocumented. Marchetto makes sure to tell us that this world is fictive (even if it is caused into existence by real events) by drawing her artist self into these panels. This play arena for Marchetto, where she can interact with people, with whom she wouldn't be able to interact in the real world – God, her dead mother, her unborn children – is never really an isolated world because Marissa the artist from the present, real world is always in them. To Marissa, this fictive, supermodern world is one where she is merely resting before continuing on her cancer journey again. It is

apparent that Marissa values her agential artist self, the everyday, above the extremities of illness.

Play as limbo, a transient state of affairs, is best seen in Fies's description of the waiting rooms at the hospital, where patients could attempt to solve a jigsaw puzzle. While at first, the puzzle seems like a trivial way to pass time while waiting, the fact that these puzzles are photographed and documented in scrapbooks makes them a witness to a certain moment in time the cancer patient is passing through – "They're touchstones of time invested. Reminders of where we've been. Models of incremental progress toward a goal" (67). The fact that these puzzles are kept in waiting rooms gives them an added symbolic meaning, since the room is a transition from the everyday world into a diagnosis, test, treatment – a world of extremity.

2. Cancer Temporalities

"I am an anachronism" – Audre Lorde (19.11.79, *Cancer Journals*)

While Susan Sontag's famous opening lines in *Illness as Metaphor* situate the ill in a space distinct from the everyday, a "kingdom of the sick", but also a temporally distinct place, in the "night side" of life. While the period of illness is marked by an extreme space-time, it also disrupts space and time as we know it. This distinction between other times and regular time leaves the ill body in limbo, what Audre Lorde calls an anachronism. How can this suspension between extreme and everyday times be told? The word 'tell' itself comes from the Dutch 'tellen' which means to count or to measure ("tell, *v*." *OED Online*). Time for the cancer patient is altered or realigned – the retelling of the cancer experience is to recalculate or remeasure this time. Time and space for a cancer victim are situated in the extreme: even within everyday life, the unreality of 'cancerland' which transports the patient to a surreal place where one remains frozen in time is traumatic and apparent in narratives of cancer.

Genette distinguishes between fabula time and text time (also called the pseudo-fabula or text time) as the opposition between the time of the actual story and the time of the narrative, based on three dimensions: order of succession, duration and frequency. Genette is quick to point out that the relevance of this distinction is less in comic strips, "which while making up sequences of images and thus requiring a successive or diachronic reading, also lend themselves to, and even invite, a kind of global and synchronic reading" (34). Genette is however not taking into consideration the longer graphic narrative, which accounts for the presence of nonlinear (i.e. non chronological) forms of narration. The memoirs under consideration constantly swerve between fabula time and narrative time to set up an experience for the reader of what cancer time would look like. In this section, I argue that the constant juxtaposition of various times narratively reflects the convergence of various kinds of time for the ill body. Apart from Genette, whose ideas I use to examine the formal representation of time, I will also employ Nancy Miller's ideas of "living in prognosis" and "cancer time" (2014), and show how these are represented in the memoirs.

The Moment of Diagnosis

The fabula in *Cancer Vixen* begins a week before May 13, the day Marisa goes to the doctor to get a lump on her breast checked. The narrator is very specific about times and dates and gives the reader minute updates. Hence after the check up on May 13, the reader is informed about what happens 5 minutes later, Marisa's conversation with her mother a few minutes following this, the phone ringing a very specific 57 times the next day and even a log of the number of calls she gets from different people the same day. The narrator attempts to build up some reliability in terms of temporality. However, consider the moment of diagnosis: once again, a specific "10.12 A.M. The exact second [she] found out" (8) is provided. The fabula here takes a break, and the narrator depicts being frozen in time by creating a space-time away from the conventions of real time and space to show the trauma of

diagnosis. This shift from the meticulous, punctual sequence of events to a sudden frozenness in time points at the distinction between the objective fabula time and the subjective narrative time.

The "psychic geography" (a phrase used by Susan Gubar to describe the space of pain she occupies after chemo) that the patient represents in the memoir is a combination of real and imagined spaces. In *Cancer Vixen*, the moment of diagnosis is depicted as being surreal, instantly transporting Marchetto to another universe where she is sucked into a black hole, where she is "frozen in time for an eternity in a vast experience of nothingness, surrounded by dark matter" (9). In the sequence of panels on the page, Marchetto is seen reduced from a person being sucked into the hole, to a spiculated mass that resembles the tumour, to a pair of eyes, to finally just the blackness. This reduction of her world to just the black hole is simultaneously a distancing of herself from the real world to an isolated world where she is alone, and the reduction of her world to that of the tumour. The 'black hole' has already been foreshadowed in the first page of the graphic narrative, where a photographic image of her X-ray shows her tumour, which she calls a "black hole". The tumour signifies the unmaking of her world into a black hole. The moment is also significant because of its recursive pattern: by representing an image of an image, and by drawing over it her experience, Marchetto attempts to reclaim autonomy from the medical discourse, turning the critical gaze (of the observer, and her own gaze) on medicine itself. Kalanithi also views the tumour in the scan as an out-of-the-world object. When he looks at the CT scan and finds that his cancer has returned, he describes the tumour thus: "It looked, oddly, like a full moon having almost cleared the horizon. Going back to the old images, I could make out the faintest trace of it, a ghostly harbinger now brought fully into the world" (174). Co-incidentally, *Mom's Cancer* also utilizes outer space imagery. In a panel titled "A Universe inside her Head", Fies compares the MRI scan of his mother's tumour to a Nebula, both dying entities. In all three

memoirs, the images are an embodied form of both corporeal excess and the surreal imagined.

Similar to Marisa, Mack recounts the day of diagnosis with clarity: a day that begins bright and sunny turns unnerving when the surgeon decides to deliver the diagnosis in a narrow corridor, hardly even stopping to talk to them. Small's discovery that he has cancer does not come from a doctor, but is accidental – he finds the news mentioned in one of his mother's letters, which says, "Dear Mama, David has been home two weeks now, of course the boy does not know he has cancer" (204). The next two pages, comprising of ten panels, all zoom in on Small's eyes as he reads the letter again. The moment is stretched out, the words repeated as a sentence, and then as words, the pause after every word conveying the frozenness of time. In comics, space is used to convey time, and McCloud notes how time can be held for the reader through the use of pause panels or irregular panel sizes (100). The moment that the artist chooses to freeze time at is of utmost importance in a medium like the graphic novel in which multiple temporalities can be presented all at once. By freezing a particular moment over space, the shock of the diagnostic moment is conveyed. The reader experiences a sudden jolt as one is denied access to the subjective state of the patient during the exact moment of diagnosis – the pause thus is a "pregnant moment", pregnant with fear in anticipation of the unknown.

Cancer Time

After the diagnostic moment, the subject no longer goes along with the fabula's precise progression of time. The subject is now a cancer patient and the disease ushers in a temporality of its own. "Cancer Time" is a combination of biological time, where cancer is growing rapidly, the cells multiplying, what appears like the slowing down of the brain during chemo, processes like ageing; clock time, which is the objective passing of actual fabula time; and social time, time spent in social etiquettes.

Marchetto establishes a visual grammar by situating her moment of diagnosis in outer space. She begins to depict all her moments of apprehensions and ambiguity, moments when she is lost in time, in this separate space-time signified by panels set in outer space. What Marchetto does using the metaphor of outer space, Fies does through the metaphor of the game. Time is confined materially to the space of a gameboard, but expanded indefinitely as these games are, as shown already, games of chance. Even within these metaphors, Fies takes care to present a difference between games used to represent cancer (games of *alea* or representing an ambiguous destiny) and others: while Mom's progress during chemotherapy is likened to an unending tight rope walk with dangers amplified at every point, his father's scrambled life is depicted as a maze. The latter is a game charted out from start to finish, indicating a complex route but an attainable end; in the former, the emphasis is on how the game only worsens as it progresses, with no end in sight.

Consider the panel where Marisa decides to get ready to tell her fiancé about her cancer. She says, "10.31 am. I got ready to tell my Fidanzato... and I sat.. and I sat.. and I sat.. in the shower" (11). The repetition of this narration leads to the formation of what Genette calls the speed of the "pseudo" narrative. In the narrative that begins as soon as the protagonist understands she has cancer, time moves at alarmingly different speeds, and this is conveyed formally by playing with the speed of narration. Marchetto devotes considerable attention to the diagnosis: her description of her reaction, pondering of the possible causes – which makes her delve into her experience of 9/11 as well – and conveying the news to friends and family takes her 78 pages of text time even as she acknowledges the brevity of the actual clock time: "Lapsed time of officially having cancer: 6 hours, 48 minutes" (74).

Mom's Cancer describes how her brain rapidly digresses and slows down her reaction times. In a sequence titled "One Night at a Condo", Mom begins speaking and then abruptly stops, and for the next 8 panels does not move a muscle. Fies leaves her pupils uncoloured in

these panels, leaving her with a glazed look. Fies explains in the next page how Mom had just had a seizure, and blanked out of consciousness for a while (70. See Figure 7). Mom has no memory of this incident. Time is thus also unconscious or semiconscious time for the cancer patient on heavy medication.

Figure 7 Cancer Time in *Mom's Cancer* (80)

Cancer establishes a temporality of its own. Time revolves around the disease for the cancer patient. “Diagnosis, staging, prognosis, protocol: the only future fixed chronology is that of treatment sessions”, writes Nancy Miller in “The Trauma of Diagnosis” (217). Time is suddenly decided not by clocks but appointments, and statistics. Miller calls this “living in prognosis”: “to live with your future coded in some kind of number, a statistic that either your oncologist will give you or you can scout out on the internet” (219). Cancer time also has much to do with waiting. As she waits to hear about being included in a clinical trial, Nina Riggs says, “The days pass – a couple of weeks. In cancer time, that feels like years, decades – like the remaining days of your life are soaring by on a busy interstate” (259). Waiting turns out to be an everyday activity for the cancer patient. Each day appears the same, but at the same time appears unpredictable. Kalanithi talks of the conflicting definitions of time itself; to him, time was less about the clock and more about a “state of being” (197). He asks himself, “Which is correct: I am a neurosurgeon, I was a neurosurgeon

or I had been a neurosurgeon and will be again?" (198). The convergence of times also disrupts one's biographical identity.

What is thus seen is a convergence of times: the time of the fabula that is specified now and then through calendar entries, wall clocks and the narration itself, and cancer time, a temporal dimension that is made possible through the depiction of subjective temporality. The narratives in most cases do not only contain depictions of two distinct temporalities (fabula time and narrative time) but are also asynchronous. For instance, at the beginning of the story, when the diagnosis has been announced, the reader expects that the narrative henceforth will be about the cancer. However, the narrator immediately launches into an analepsis, talking of her experiences of 9/11 which are traumatic as well. *MC* distinguishes its analepsis (a foray into Fies's grandfather's life) from the rest of the narrative through the use of sepia-hued pages. Rimmon-Kennan's concept of disruption can be applied here, where the life narrative is divided into two (the before and after) by a life changing moment and the representation of this division is asynchronously presented, leading to a break in the linearity of the narrative.

The disruption of the regularity of daily events that occurs in the face of death can also overwhelm the patient, leading to the making and remaking of identities. Michael Bury records a disruption in embodied behaviour, a person's self-concept and mobilization of resources (169). This unmaking of the meaningful world leads to a craving for what Giddens has called "ontological security," during times of crisis when "questions of time, space, continuity and identity" disrupt one's sense of self (36). It is suggested that the patient in the medical narrative attempts to overcome this disruption through an attempt at wilfully adopting the body pedagogics that were in place before the illness occurred and which indicated an uninterrupted life. Thus, when Paul Kalanithi returns to the surgical table after having taken a break of several weeks to undergo treatments, he finds that at first his body

remembers the role it played before the illness took over: “Everything felt familiar, muscle memory kicked in” (153). But the body cannot continue to play the old role with enjoyment for long: “the visceral pleasure I had found in operating was gone, replaced by an iron focus on overcoming the nausea, the pain, the fatigue . . . I was determined to restore my life to its prior trajectory” (156). The pedagogics for the role of a surgeon and the role of the ill are different, and the yearning for the healthy body cannot be materialised without the body adapting to the new role.

The representation of the ‘extremities’ of illness forms an important part of the ill, narrated, lived body. Such representations disrupt everyday space and time, producing epistemologies of importance to both the cancer patient and the reader, and in Rothberg’s formulation, transforming readers so that they are forced to acknowledge their relationship to post traumatic culture. These frameworks describe the extreme condition of living with a fatal illness as represented in heterotopic textual spaces.

3. The Cancer Memoir as Poshumanist Life Writing

Kari Weil asserts that the task of the posthumanist autobiography is to “take account of those who and that which have made us who we have been, and help us be open to the myriad ways we will continue to be affected, if not infected, by others and the world we are a part of” (93). If we accept Weil’s definition, the narratives we have studied are posthumanist in that they not only trace the evolution of the self through their illness, but take into account those nonhuman processes and elements that contribute to this making of a composite self.

Gubar’s, for instance, is not a conventional memoir. Examining in detail the historical, biological and subjective construction of ovarian cancer, she can both universalise and isolate her experience. Gubar’s memoir reads like a cultural and historical study of cancer, while also containing painful personal experiences backed by frightening statistics and data, and literary examples that she takes both solace and insights from. Her memoir

defies categorization just like the graphic narratives do, with the ambiguity playing around fact/fiction, word/image, science/ subjectivity. Similar to these are the blogs by Mewhorter and Nancy Miller: while these are very much accounts of their cancer journeys, they are also the stories of others, they are also cyborged versions of themselves narrating a differently cyborged self. The "I" that emerges from these memoirs thus develops along with a bodily and material history that shapes them, that is, the process of narrative identity formation is given due consideration. In *Kafka: Toward a Minor Literature,* Deleuze and Guattari call the assemblage a method that can be explained "only if one takes it apart to examine both the elements that make it up and the nature of linkages" (53). Most of the memoirs under consideration (some more formally so, like the graphic narratives) use assemblage as a method, rendering illness "a complex interplay among bodies, minds, diagnoses, treatments, and clinical, political and narrative discourses and practices" (Diedrich 98). The thesis will return to this self-conscious construction in Chapter 3.

Along with these different kinds of composite disciplinary discourses, comes the varied treatment of spaces and times. Time is no longer restricted to the calendar or the clock. In fact, these instruments are indicators of the material presence of time rather than an indication of temporality itself. The treatment of time instead is marked by an interest in the genealogy of the disease, the self's emergence, and the situatedness of the ill body in certain *times*. These are thus also non-human temporalities equally important to the cancer patient as has been stressed early on in the analysis: the beginning of the cancer, its growth and progress determines what "stage" the patient occupies. Marchetto and Fies set their cancer journeys against other times, like 9/11, and while wondering if the disaster could have impacted their bodies, imply that we live in a world where 'normal' temporalities must be replaced by ones that take into account *disastrous* times that have *affect*ed mankind in more ways than one.

These narratives pay clear homage to the nonhuman entities, spaces, times and technologies that shape the emergence of their "I", acknowledging that the presence of the other in them has been imperative in the formation of the subject and without whom they would not fully know themselves. In Braidotti and Hlavajova's *Posthuman Glossary* (2018), Goodley et al in "Posthuman Disability and Dishuman Studies" state that "disability epitomizes a posthuman enhancement of the self while, simultaneously, demanding recognition of the self in the humanist register" (342). The memoirists find themselves at these crossroads, demanding that the autonomy of the self be retained even as they acknowledge a coexistence with nonhuman entities.

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Chapter 3

‘Technologized Terrain’: Medical Visions and Patient Re-visions

Synopsis

1. The Informatization of the body
2. Layering of Perspective: The Ekphrastic Function of Biomedia
3. Affective Impressions: Scanxiety
4. Portraiture and Staring
5. Witnessing: The ethnographic role of photographs

In this chapter I study the technological and human gazes as they operate in the graphic narratives *CV*, *CMMSP*, *Stitches*, and *MC*; the print memoirs *WBBA* and *MDW*; and the digital narratives *Cancer Owl*, *Living with Cancer* and *HONY*.

The chapter will examine the technological gaze and the human’s subjective response to the gaze in the memoirs under study. By technological gaze, I do not just mean the gaze of medical imaging technology, though that is the first kind that springs to mind. I also mean the mediation of the body by platforms on New Media, the use of photography and the gaze mediated by the narrative itself. At the outset, I use the term “technologized terrain” to describe the body’s various interactions with technology, as Mary DeShazer does in her book on representations of breast cancer (2013). DeShazer uses the following frames in her study of photographic representations: “photography as a technology, photographs as a means of documenting the technologies of breast cancer treatment, the photographic representation of technological imaging in/as a diagnostic or medical protocol, and the ways in which ill and medicalized bodies are mediated by technology” (17). Several scholars have studied the medical gaze of ‘penetrative’ technologies like XRays, arguing that these extend the surveillant gaze into the ill body, especially the ill woman (eg. Lisa Cartwright 1995); that diagnostic imaging is not necessarily anti-technological but demonstrates the inextricability

of visual imaging and male desires (eg. Braidotti 1994, 68), and optical technologies are "techniques of illusion, deception, and voyeurism" (Van Dijck 2005,13). This chapter is interested in the narrative response of the ill to these images, and the remediation that is employed in these.

The visual representation of illness in pathographies is indicative of an 'unofficial iconography' of illness (Williams ch. 5). It is interesting that the three iconographic elements that Ian Williams delineates as being contributed by graphic medicine: the manifest, the concealed and the invisible[10], find themselves aligned with the apparent objective of diagnostic imaging, which is to make visible what the body conceals. I suggest here that since optical technology and diagnostic images are an unavoidable part of the illness journey, remediated digital images incorporated in cancer memoirs add a fourth category to the iconography, that of the technologized terrain. While the graphic memoirs under study make this iconography clear, the prose narratives examined also spend a considerable time dwelling on the patient's encounter with scans, and consequently the emotions, dilemmas and decisions that these scans set in motion.

These memoirs, by incorporating or describing digital images of the body, indicate a new mode of embodiment: the digital images represent the palimpsestuous body that is first written on by the objectifying medical gaze, and then *rewritten* in the memoir. These renderings show vision and perception, gaining both history and character. Through a study of representations of medical imaging in conventional print memoirs, digital narratives and graphic medicine, this section attempts to understand the ill person's ambivalence around, and response to technologically mediated images of themselves. The patient encounters these images, datasheets and generally "objective" truths about the body – made objective via the

[10] The "manifest" refers to visible signs of illness or scars of treatment; the "concealed" to the physically "hidden", but psychologically impacted; and the third "invisible", in which the conditions are only felt or produced psychologically (Williams ch. 5).

authority of science – and counters them through a subjective re-fashioning of the self. The intervention of the scientific image attests and contributes to the visual literacy of both patient and reader, situating us in a scientific culture accustomed to various ways of observation, besides contesting the idea of the photograph as merely an object of memory.

1. The Informatization of the body

Medical imaging has enabled the transformation of the invisible body into the visible. The mapping of the body, perhaps begun by De Vesalius's 1543 text *De Humanis Corpora Fabrica*, through to the 'art' of dissection during the Enlightenment and the Foucauldian spatiotemporal disciplining of the body, has followed different philosophical notions of the body, but if they have collectively contributed to one specific notion it is that the presence of technologies to map the body contribute to its informatization. The discovery of X-Rays offered a mapping of the body different from the anatomical gaze, in that X-Rays were specifically built around processes of decoding and filtering to help with specific diagnoses. This then led to the discovery of other imaging devices, such as CT scans, MRIs and PET scans. Diagnostic technology, as part of a larger ecology, including charts, databases and such records, takes part in the informatization of the body, "with the opened body on the operating table, and the various TV monitors and biomonitoring equipment surrounding that body as its main tensive site" (Thacker 1998).

The diagnostic technology can set in motion a series of remediations in various semiotic modes, such as scan reports that assign mathematical qualifiers to the ill body. In *Mom's Cancer*, for instance, the doctor tells Mom that her tumour is 24 millimetres in size, to which Mom responds, "How big is that?" (23). In the panel, Fies draws the doctor much higher than Mom such that he looks down at her when pronouncing these statistics, with Mom looking up with an expression of ignorance. Fies himself is an onlooker in this panel. A close up of Mom's profile in the next panel reveals her discomfort with information that she

cannot process. Later in the narrative, in a sequence called “Mom in Mathemagic Land” the family troops in to see the scans displaying the results of two months of chemotherapy and brain radiation (see Figure 8). The over-the-shoulders PoV of the scans shows us what the family is seeing, and we notice little difference in the before and after scans placed alongside each other. This kind of focalization keeps intact the moment of discovery for the reader. When the oncologist tells them that the tumour is fifty percent smaller, Fies has to resort to math to decode and to explain to himself and the reader, that to understand the physical reduction in size, length has to be converted into volume. He inscribes the panel with the dictum “Quod Erat Demonstratum” (54), i.e. that which was to be demonstrated. This sequence represents the failure on the part of the physician to simplify the information, but more importantly newer ways in which the patient or the family explains the images to themselves. Math turns out to be the interpretative or ekphrastic language that Fies uses to describe medical images to himself, and the drawn representations of these to the reader. In *CV*, the use of diagnostic scans is described in detail – this includes not just the scans themselves but the objects used for the scan as well. The doctor here does the mathematics himself to make the size of the tumour clear to Marchetto. After a sonogram test shows him the image of the tumour onscreen, he deduces that it is 1.3 cms in length, “the size of a large pearl” (4). While the scan, in this case, is as baffling as in Fies’s, the doctor decodes this information into terms intelligible to the patient. Marchetto also presents a life-sized drawing of her biopsy needle, labelling it “4” actual length” and “actual width”, along with a vial with her name on it and containing life-sized slivers of cancer. In *Cancer Vixen*, Marchetto continuously attempts to show the material conditions of illness and the embeddedness of the sick person in a network of actors which includes the nonhuman.

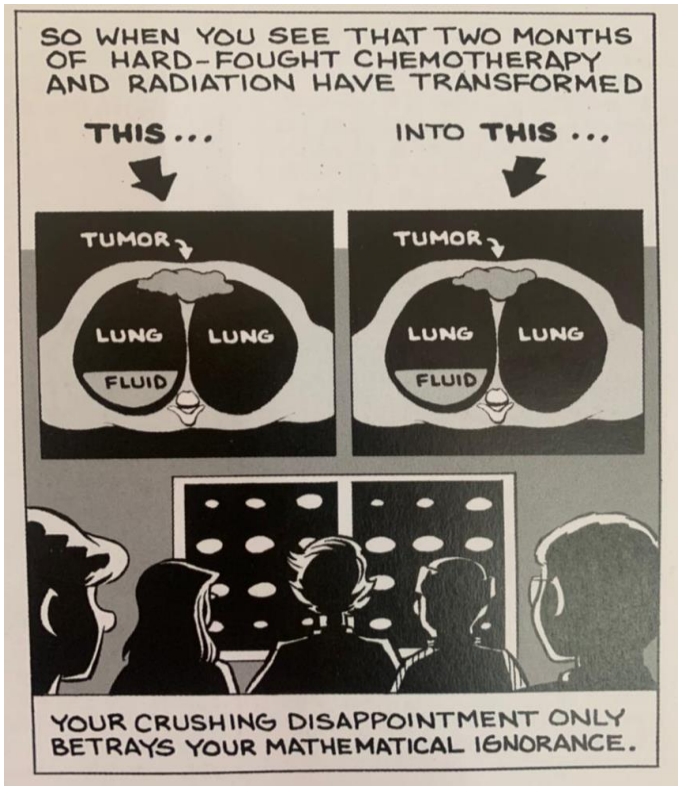

Figure 8 Ekphrastic Biomedia: the use of mathematics in *Mom's Cancer* (53)

As Kalanithi goes through his diagnostic CT scan image, the cartographic slicing of the body becomes more apparent: "I went through each sequence again: the lung window, the liver window, the bone window, scrolling from top to bottom, then left to right, then front to back, just as I had been trained to do, as if I might find something that would change the diagnosis" (4). The body *becomes* the data on the screen. When Kalanithi and his wife pore over EKGs, she decodes the waves to identify a fatal arrhythmia: "All at once it dawned upon her and she began to cry: wherever this 'practice EKG' had come from, the patient had not survived" (51). *WBBA* also dwells on the embodied nature of medical statistics like the Kaplan Meier curves. These statistics are generally used to study survival rates from collected lifetime data. While physicians are usually reluctant to divulge much information about these stats, since they are not definite indicators or a prognosis, for patients, these represent an "existential authenticity" but one that, according to Kalanithi, is no remedy to the impending

mortality of someone with cancer (135). He finds that his perception of statistics changes when he *becomes* one.

Stripped to the bone, these statistics *are* bodies, they are embodied data representations of those that are alive and surviving the disease by being part of such and such experimental drug trials over a period of time and those that could not survive. Biomedia, after Eugene Thacker, makes biology a medium, "an instance in which biological components and processes are informatically recontextualized for purposes that may be either biological or nonbiological" (6). The body in biomedia is understood as both the biological body and a body that is compiled through methods like visualization, modeling, data extraction etc; hence biomedia concerns the biological body as situated in a range of technoscientific fields (13). Biomedia aims at an intersection of genetic and computer codes that is achieved through a mathematization of the body facilitated by processes like decoding and encoding. Thacker includes representations of informatics and biology here when he says:

> Biomedia is neither a technological instrument, nor an essence of technology, but a situation in which a technical, informatic recontextualization of biological components and processes enables the body to demonstrate itself in demonstrations that may be biological or non-biological, medical or militaristic, cultural or economic. (79)

Encouraged by these parameters, we may now argue that the pathography, containing depictions of and responses to the codified body falls within the definition of biomedia. The body frames the data under the gaze of optical technology. When this demonstration is enframed again within the intermedial[11] nature of the graphic novel, attention is brought back

[11] The words intermedial, transmedial, multimodal and remediation have been employed throughout this dissertation. Intermediality is used here in the broad sense of the interaction and crossing of borders between different media, as opposed to transmedial, which is the continuation of a motif or narrative across media;

from the digital scan to its bodily source. Mark Hansen argues that when the body enframes data in new media, bodily affect transforms "the unframed, disembodied, and formless into concrete embodied information intrinsically imbued with (human) meaning" (13). Biomedia – the pathography in this case – not only accrues nonbiological or cultural meaning but also importantly, an affective and human meaning. While the narratives rely on information discourses to make cancer and its material conditions understood to the patient, by incorporating both the material conditions and the subjective response to these, the "objective" vision of science and bodily affect are simultaneously represented.

2. 'Layering of Perspective': The Ekphrastic Function of Biomedia

> "Another part of me flew like a big bird to the ceiling of whatever place I was in, observing my actions and providing a running commentary, complete with suggestions of factors forgotten, new possibilities of movement, and ribald remarks."
>
> Audre Lorde *(Cancer Journals* 30*)*

This section will argue that the picturing of science – by which I mean the visualization of scientific data and theories/arguments – by the patient leads to a 'layering of perspective' that turns the gaze back on medicine. I begin this section by talking about the *absence* in scientific images. While the scientific image is an accurate rendering of the internal state of various body parts or processes, it is bereft of affect. That is, the image presents a fact that is devoid of human actions or emotions. However, as soon as one encounters this 'fact', it no longer holds the status of being purely objective and is imbued with the meaning that the spectator attributes to it. One must remember that had this 'fact' not been digitally created but created by hand, an aura[12] would already have existed. The medium

multimodal, which is the presence of different modes (eg words and images) within the same media and remediation, which is the conversion of one medium into another (eg a printed novel into an audiobook).

[12] The aura here is an allusion to Walter Benjamin's term as he uses it in his famous "The Work of Art in the Age of Mechanical Reproduction", where he remarks that techniques like photography cannot capture the "fleeting aura" of pre-mechanical modes of creating art. Mechanical reproduction, according to Benjamin, transforms their ritual value into exhibition value.

shift that occurs here, of the biomedia encoding the body into computerized information across an array of types: scans, records, algorithms, waves etc., turns the biological and the affective into an image that without an interpreter and a spectator generates no meaning. Zac Zimmer treats ekphrasis, which he defines broadly as "the aesthetic act of rendering a representation in a different medium" (95), a way to counter this specific loss. Ekphrasis originally referred to the remediation of visual art by and in a verbal narrative. Zimmer extends this to the digital, and asks, "we do not lack for language to talk about *information lost during compression*, but how do we talk about the *stuff* lost during a medium shift?" (95). Let us specifically address the two parts to his question, and then look at the ekphrastic function that the narratives perform to engage with the loss.

A brief look at how diagnostic technology operates is valuable here; the ones used in the narratives include X-rays, CT scans and MRIs. The X-ray scan is produced when electrons come into contact with a tungsten receptor or target. These rays are directed at specific body parts that absorb them to different extents: for instance, bone absorbs more than tissue. The image on the scan thus shows the pictures of those parts that absorb more of the rays. Computer Tomography is an improved version of the X-ray mechanism: the apparatus is larger, round and the rotating apparatus is able to give us a cross-sectional "slice" of the body. The digital form of this data is reconstructed to produce a picture of the anatomy, using various shades of grey to represent different tissues. The X-rays and CTs are thus transcoding the biological medium into data. The information lost in the X-ray, which can only represent fewer grey scale variations, is bettered by the CT scan, which uses digitalized images to help visualize the body better. The information lost in the CT, which is that the images are still two dimensional, is bettered by Magnetic Resonance Imaging. The magnetic field of these machines causes the movement of hydrogen atoms within the body and measures the electric discharge from these, their speed and volume, and translates this information into an image

on the screen. The MRI is not just confined to bones: the *stuff* that X-rays and CTs lose is made up here since MRIs can detect tissue as well.

If Zimmer's extension of ekphrasis to include all kinds of transitioning between representations is taken into account to describe the narratives under study, then the specific loss that these digital images embody – of affect, information and *stuff* – could be given a more material account. The examples of biomediation provided above can now be seen in a different light. While the CT scan in *MC* shows a marginal reduction in the size of the tumour, the stuff lost in this transcoding – the difference in the volume of the tumour, its materiality, is brought back and addressed through the discourse of mathematics. Fies prefaces the scans with "So when you see that two months of hard-fought chemotherapy and radiation have transformed this. . . into this. . .". While scholars (eg. Chute 420, and Nayar 91) have read the depiction of extreme time in these sequences, we also see in them what the medium of comics is able to add through an ekphrastic rendering of scans is an affective history of the images. This affective history is both a case history, that is, an affective history of how things came to be, and a reckoning of the iconography of the clinic as represented in the history of medicine itself. This is reflected in the panel which mimics the creation of a Frankenstein-ian monster by a scientist (21). The words Fies chooses: "the doc in charge is almost *giddy* . . .it's a video game to him" (96, emphasis mine) only adds to the trope of the scientist about to experiment on the body. The next page shows Mom pinned down to the table in a plastic mesh mask, resembling a corpse (see Figure 9). These images are strikingly close to Enlightenment-era representations of the doctor as a God like figure, and the corpse as a deviant figure, but with contemporary equivalents of making visible the body's interiors. Jonathan Sawday describes the "didactic body" through the paintings of Rembrandt and Descartes, calling the corpse in those descriptions both the deviant person who deserved to be punished and the *vanitas* figure, that is, the figure that would remind the onlooker of human

mortality (152). In Fies's narrative, Mom, dressed in the shroud of a corpse and exposed to radiation that would do more harm to the living cells than good, resembles this (21-22). In *Cancer Vixen*, the size of the tumour is conveyed by the comparison to a pearl. In the very first page of the memoir, we are presented with an image of Marchetto's scan, with a green arrow with the words "Here is the tumour, it looks like a black hole" written over it. Similarly, the full-page picture of the M57 nebula in *Mom's Cancer* describes the similarities that Fies sees between the tumour and the nebula: "It's a bubble of gas blown into space by a dying star. Gas that will someday form a new star with new planets. . . a new chance for life. It's also almost identical to an MRI scan of a dying brain tumor. The intersecting beams of radiation worked. The tumor's hollow now, rotting from the inside out. It's funny how death giving way to life can look similar on such vastly different scales" (79). Fies resorts to the metaphor of a nebula here not just to describe the tumour in the MRI scan, but also to refer to the *process* of the death of the tumour, including in his descriptions the material conditions that made this possible.[13]

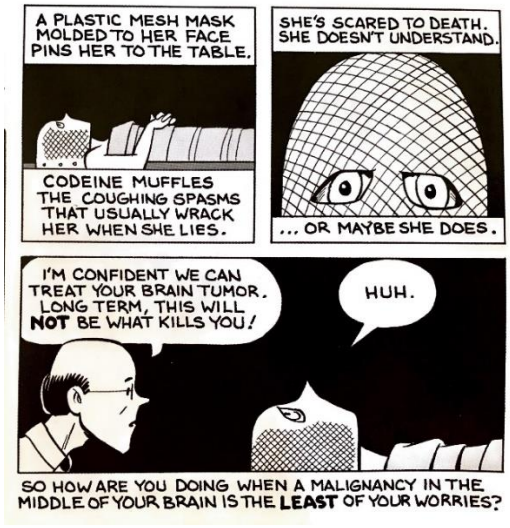

Figure 9 Iconography in *Mom's Cancer* (22)

[13] The comparison of medical and astronomical imaging is not a coincidence and has historical significance. Sarah Kember calls this a framing of the body according to the medieval concept of "microcosm/macrocosm in which the body and the cosmos were analogically mapped" (104).

In her analysis of Fies's narrative, Lisa Diedrich describes illness narratives as posthumanist, drawing attention to how "Fies becomes subject not only in relation to his mom but also in relation to his mom's cancer *and* in relation to the math on his mom's cancer." To her, the point/counter point of images and text captures the tension of the uncertainty of illness, and helps "'see' – and become in relation to – this double movement, between a biological event of cancer and an affective experience of cancer" (105). This layering of perspective, where the subjective experience of the patient is juxtaposed upon the medical fact or image, while turning one's gaze back on medicine also contributes to the making of the individual subject, which is an important goal of the memoir. The patients here mimic the language of medicine. The medical record itself signifies the making of a palimpsest: the body is written on. As the patient notices his/her body rewritten via medical discourse, a personal affect evolves. The patient begins to learn the jargon himself/herself so as to understand better. As Jennifer Willet has argued, every entry in the dossier becomes an entry into the body, and into the self: "The text is reabsorbed into the body by the constructed self of the patient" (290).

The "layering of perspective", a phrase borrowed from Nancy Pedri (2017), is achieved by employing the technique of focalization. *Stitches* provides several examples of this. Early in the memoir, Small recalls the countless X-ray tests he was given by his father. In three consecutive panels (22), Small shifts between the steely machine seen from Small's perspective as he lies on the gurney, to a close up of Small's perplexed face as it lies there and moves to a long shot of the boy and the machine together. The close up of Small's face is the panel that captures one's attention, the only one with any human emotion and in sharp contrast to the intimidating machine on top of him. The page facing this shows the result of the whole venture: an X-ray image of Small's head, the presence of the person obliterated by the X-ray, but re-emphasized in the memoir by the use of focalization to present an affective

history. *Stitches* continues to emphasize the human presence in the midst of the technological gaze through shifts in perspective. Small's description of the time his brother and he look with fascination at X-rays of little kids' stomachs is an example. The first panel focalizes on the expressions of the boys, the text reading, "My brother and I liked seeing the x-rays of little kids' stomachs, the stuff they had swallowed like keys and pop beads . . ." (28). The ellipses indicate a pause in time, as the next panel suddenly swings to the X-ray they are looking at. The next panel still focalizes on one object within the x-ray, a small cowboy figurine. The text above it reads ". . . And cracker-jack prizes," the ellipses indicating a continuation from the first panel. The difference in framing the three panels shows the layering of perspectives: the x-ray is devoid of a frame, showing its objective nature. The cowboy on the other hand is also without a frame, but the waves indicate that the focalizer here is Small, and the cowboy is uniquely what Small notices or imagines. Such panels act as reflector narratives that present the X-ray through the consciousness, and shake the alleged position of authority given to photography (or, in this case, photographic devices), since the photographs in them are capable of accommodating "a narrative intervention" (Pedri 7).

3. Affective Impressions: Scanxiety

In *Archive Fever,* Derrida questions the effect and affect of technological prostheses such as "microcomputing, electronization and computerization" on the psychic apparatus of the person. He asks,

> Is the psychic apparatus *better represented* or is it *affected differently* by all the technical mechanisms for archivization and for reproduction, for prostheses of so-called live memory, for simulacrums of living things which already are, and will increasingly be, more refined, complicated, powerful than the "mystic pad". . . (15)

He goes on to argue that this technological archive does affect mental space, naming the archive the "prosthetics of the inside" (19). This section will study the affective impact of the

ill person's interactions with the scan, which is a materialization of physical impressions, and the digital image in the narratives - the materialization of the recollection of the patient's encounter. The subjective experience of the uncanny encounter with one's interior on the screen, i.e. with your person turned inside out, can lead to both an affirmation of and a detachment from the self. Steven Kenny talks of the anatomical drawing as being a

> reflective reconstruction of the physical body, an external other. . . [that] can at first seem all too revealing, but it is a form that subsequently comforts, aiding the awareness of medical conditions that can ultimately help to prevent – and, it is hoped, aid the curing of ill health and disease. (157)

Scans function in a like manner.

The scans display one's interiors, but they also show us that our mortality resides in our bodily matter. This fearful encounter with scans that signifies one's mortality is termed "scanxiety" in representations and constitutes the affective dimension of diagnostic imaging[14]. In a webcomic titled "Everytime", Matthew Paul Mewhorter describes a visit to his doctor for a scan to check if he is still cancer free. Even as the doctor gives him positive news, he retches, and a creature emerges that chants "Cancer's back, cancer's back". Mewhorter describes the creature to his doctor as "scanxiety", the recurring dread of a cancer relapse with every scan (see Figure 10). Mewhorter's stance is that scans are a part of survivorship as much as of treatment and indicate the persistence of cancer as a lifelong situation.

[14] This negative affective feeling is not the same across illnesses; for instance, in his analysis of the emerging use of brain imaging technology in psychiatric illnesses such as Bipolar Disorder or Schizophrenia, Simon Cohn (2011) identifies a certain relief that patients experience in finding a material manner of expression of their illness in scans that indicate a concrete causation.

Figure 10 Scans signifying mortality: Scanxiety in *My Multifocal Life*

These patients are not only stating the fear that accompanies diagnostic procedures in cancer, but by giving the fear different forms and a specific name "scanxiety," affirming that the cancer patient has a mental image of the cancer that is distinct from the scientific image, and that is born out of the emotions experienced in clinical encounters. In her blog post on scanxiety, called "Tackling Cancer Anxiety", Susan Gubar coins yet another name for this constant fear: "Cancerchondria." She explains it thus:

> Like hypochondriacs, cancerchondriacs imagine every cough, twinge, bump or rash as a malignancy stealthily creeping back. Since cancer can recur with or without producing obvious symptoms, we may fritter away a remission of months in obsessive brooding. The dread of relapse hisses, snorts, whimpers, roars, drowning out all else. Checking our bodies for indications of disease, searching the internet for the causes of possible warning signs, we lay waste our powers. Healthy people can also suffer from cancerchondria, sometimes because a specific type of the disease is said to "run" in their family. (November 15, 2018)

The fear of cancer remission, an example of which is scanxiety, serves also as an indicator of temporality for the patient. Nancy Miller uses the term to describe her "scan-to-scan" existence. In a collage titled "Scanxiety" (July 28, 2016), she juxtaposes her progression from one scan to the next, with calendar pages to describe how days are replaced by scans. Nearly a year later, in "Scanxiety 2", where she has found out about her remission, she repeats six times the original picture to create a collage, showing that her anxiety has catapulted in intensity to panic.

In his analysis of medical imaging's cultural history, Van Dijk looks at the cultural perception of the X-ray when it was invented. The *skiagraphs*, or the images of Roentgen's X-ray machines, were the first inventions that could produce a photograph of the interior of the body: "the shadows of bones on skiagraphs were strongly associated with mortality; death was imprinted in the living body and X rays made it visible to the naked eye" (Van Dijck 94). In Miller's collage, the images of the MRI scans closely resemble funeral caskets, contributing to this analogy of the medical image with death. The moment of diagnosis leads to an immediate imbalance in identity for Kalanithi, and he realises that his identity as a physician no longer matters. The scans display one's interiors, but they also immediately signify one's mortality. Gubar, who does not look at her scan directly, but only at the young doctor who reads it, says, "Based not on my account of symptoms but on an image from a scan I would never see, the diagnosis of the disease as well as the impending mortality I attributed to it stunned me" (15). Marchetto begins to visualize the grim reaper following her about after her very first sonogram with a breast specialist, even though she has not been diagnosed yet (5). For Small, X-rays are associated with both the fear of death and the 'miracle' of life. He recalls his father and the other radiologists poring over X-rays and likens them to "soldiers of science" for whom the "weapon" was the X-ray (27). Even as he acknowledges the penetrative power of X-rays – they could "see through clothes, skin and

even metal", he attributes a curative power to them. Ironically, Small also discovers that the X-ray as a weapon is painful, since his cancer is attributed to his constant exposure to them as a child.

Figure 11 The ecosystem of medical imaging in Engelberg's *Cancer Made Me A Shallower Person* (" A Potpourri of Scans")

Engelberg devotes a chapter in her memoir to the barrage of scans that a cancer patient encounters, aptly titled "A Potpourri of Scans" (see Figure 11). Engelberg's description is important as she situates the encounter with the scans in a particular clinical and affective environment. The conditions in which the diagnosis and testing take place, consisting of the rooms with their equipment, personnel, the atmosphere and the patient herself, comprise what Kirsten Ostherr calls "the ecosystem of medical imaging" (60). The body's encounter with the technology used in diagnostics, including the sonogram, the mammogram, the X-ray and MRI machines, shows the tensions and contrast between the steely and "sterile" mechanical devices used to test the illness, and the organic structure of the sick body. These instances are brought to the fore in both Engelberg and Marchetto's memoirs. In *CV,* Marchetto describes her breasts being "squeezed, squished, slammed and jammed" (85) by the mammogram machine, presenting graphic images to accompany the

words, clearly indicating the cold abstraction and objectification the diagnostic technology subjects the patient to. She follows this up with these words in bold letters, “Why don’t they put testicles in a vise?!” (85). In Engelberg’s memoir, the experience of the mammogram is similarly painful with wires inserted into the breasts.

The diagnostic technology acts as an agent of invasion and probes the private, indeed interior, spaces of the body, reflecting the historical and cultural tropes of invasion being both an impeachment of personal boundaries and modesty and the general tendency to distance oneself from the sick, and hence impure. Gubar in her memoir recounts how her affirmation of the self as the other, as impure, results from an othering set into motion by the technology and the physicians: “With sophisticated technology at their disposal, my physicians prefer ordering tests, rather than actually looking at the skin or touching the area around the dripping, swollen wound on my bottom. Who can blame them?” (201). However, the acute trauma she undergoes because of the nature of her illness makes the technology a welcome release for her to preserve whatever shred of modesty she can hold on to, it is “worse for her” to have them look at her, positioned embarrassingly over a table with the help of gynecological stirrups. After a few classes exploring cadaver-dissection, Kalanithi realizes that “[d]octors invade the body in every way possible. They see people at their most vulnerable, their most sacred, their most private. They escort them into the world, and then back out. Seeing the body as matter and mechanism is the flip side to easing the most profound human suffering” (49). The examination room here becomes a private space reflecting the classical idea of a bounded, individual self whose disease isolated her from society but at the same time became a site for further examination of the disease.

The scans in the incidents specified above are used to indicate a predisposition to disease. However, so used are the patients to the scans being the harbinger of bad news that the scan becomes a sign that stands in for the reality of cancer. The scans are similar thus to

Baudrillard's simulacrum or hyper real: the sign of the disease *is* the disease. Scans become, by acquiring the signage of death, death itself. Engelberg's equation of the scans to an infomercial shows not just how the scans are materially an indicator of the cancer, but also how they condition the patient to a progression of bad news. The rhetoric Engelberg uses to express this is wry, sardonic humour: "Call now and this CT scan will be yours! It features possible spots in the liver and lungs! But wait- there's more! Call in the next half hour and we'll add just discovered bone mets!" ("Infomercial"). By equating the progression of scans to infomercials, Engelberg is foregrounding the excess of information that the cancer victim is exposed to in the form of medical imaging. The space of fear of the recurrence of cancer that the patient inhabits after the first treatment also puts them in the ambiguous position of having to decide whether constant self-surveillance is required at all. In "Nude Mice," Susan Gubar describes the conundrum of making a choice not to know:

> As with genetic testing, some want to know and others want not to know. For some, statistics and prognoses form a protective shell, but the weight of that carapace becomes an unbearable burden for others. Quite a few feel that knowledge furnishes if not power then at least control, whereas quite a few contend that all-consuming research allows disease to contaminate every moment of waking consciousness to dread. (December 4, 2013)

In *MC,* similarly, Mom chooses not to know the probability of her life ahead, the prognosis. "But Mom trusts fate more than odds", narrates Fies, "She doesn't want to know. She needs to **not** know. It lingers, unasked and unanswered . . .maybe for the best" (32). The imperative that she does not need to know arises because the surplus of information inflicted upon Mom is more than she can understand and assimilate, pushing Fies to wonder aloud if she was being stupid, but portraying her metaphorically drowning in medical jargon (10).

The encounter with imaging dwells long after the actual moment of encounter. In "Living into the Imagined Body: How the Diagnostic Image Confronts the Lived Body", Devan Stahl, who writes about the impact of imaging technology after her own experience with Multiple Sclerosis says, "we are no longer concerned about our health just when we feel diseased, but seemingly at every moment" (56). The fear persists in the patient, and "even after the initial symptoms have gone, the battery of testing causes the patient to continue to objectify the body" (57). Ian Hacking terms the action of the imaging device "intervening". He says, "Every look into the body is also a transformation – 'Seeing is intervening' – because it affects our conceptualization and representation of the body" (qtd. in Van Dijck 8). Imaging representations display images of the body with both its phenomena and the symptoms, and by doing so, use the symptoms to distinguish between an 'idealized' body and a pathologised body, urging actions that try and fit the ideal map of the body drawn by them. The confrontation with a diagnostic scan leads to an immediate ontological shift for the patient. However, the initial, overwhelming feeling of confronting one's mortality soon leads to a dependence on the scans for assurance, and to decide the medical steps that need to be taken. With consecutive scans determining the ill subject's next course of action, the patient grows accustomed to them, and an acceptance and expectancy builds around the scans as being imperative to plan one's life. The patient begins, as Angela Lefler suggests in her essay on masculinity and visual imaging, "to embrace the medical designation of the body as anomalous, worthy of observation" (386). It is based on this recognition that the patient begins to fashion her or his life around biomedical imaging.

In tracing the subjective effects of PET scans in "A Digital Image of the Category of the Person", Joseph Dumit coins the phrase 'objective self-fashioning', defining it as a process in which "we take facts about ourselves – about our bodies, minds, capacities, traits, states, limitations, propensities etc. – that we have read, heard, or otherwise encountered in

the world, and incorporate them into our lives" (367). He delineates two ways in which self-fashioning occurs with biotechnology: where one understands oneself as subject to the technical, scientific discourses and the other, how the discourses choose one as their object of study (368). Here, during diagnostics and testing, the encounter with the imaging representation or the medical record provides the first concrete facts about one's disease, leading to an immediate effect on the patient's fashioning of the self, according to it. A self-fashioning takes place in the patient.

In Gubar's description of her cancer recurrence, she considers joining an experimental trial after speaking to her doctor, who is optimistic about a new chemo drug. However, the trial works by randomly allocating 50% of the new drug, and the others undergo chemo without the new drug. Gubar becomes but a number in a randomized computer algorithm and unluckily, does not fall into the demographic that receives the new drug. The scans and statistics, while instilling hope in the patient, also define the patient's course of action in the future. Dumit's self-fashioning works here in the manner that Gubar fashions herself into an object of study for the medical discourse in order that she may be subject to the new drug. Gubar's self-fashioning is also informed by both academic and personal accounts of ovarian cancer that she has read about, and her emotional response to her diagnosis. The memoir is littered with intertexts from scholarly medical and sociological studies so much so that Gubar begins fashioning her own identity after them: she calls her body, with its cancer cells, the betrayer Judas, after she reads about the same analogy in Stacey's *Teratologies*.

There is a different kind of self-fashioning that takes place in the cancer narratives under study, with respect to the identity they *choose* to represent. According to Dumit's definition of self-fashioning, the patient's concept of the self is drawn from various sources. Engelberg's interactions with her doctors and support group, and Gubar's with the research she does on ovarian cancer play a role in fashioning their cancer narratives. Both Engelberg

and Gubar are faced with discourses that fall into the mould of a commonly construed cancer metanarrative: where the diagnosis *ought* to serve as a moment of epiphany for the patient, to confront life "courageously" and look for the silver lining –Barbara Ehrenreich's bright-siding (2009). After diagnosis, Engelberg meets with a friend, a breast cancer survivor, who tells her, "Whatever happens, this is a wake-up call for you about how you're living your life" ("Waiting"). However, Engelberg chooses instead to focus on herself as someone 'shallow' when she says, "But maybe nobility and courage aren't the only approaches to life with an illness; maybe the path of shallowness deserves more attention!" Similarly, Gubar acknowledges the life stories of courage and hope she hears on CD recordings by terminal cancer patients, and says, "the courageous resolve of women dedicated to their own survival moved me to tears. I honor and admire them for their bravery – without sharing their optimism" (30). While Engelberg is against the 'nobility' that popularly marks a cancer narrative, Gubar is against the unflinching hope that the patient ought to possess. They are both thus, consciously fashioning their selves to differ from what is expected, and making this visible to the reader, making their work counternarratives.

4. Portraiture and Staring

This section argues that the incorporation of portraiture in the cancer narrative engenders the ill person to participate in the cultural iconography of the ill and resist it, while encouraging a particular mode of staring at the (supposedly) deviant body. Engelberg begins her graphic narrative with an account of the staring that a cancer patient must encounter. The opening panel shows Engelberg coming out to her friends about her cancer, while her friends think, "Don't look at her chest". The next panel shows another friend diagnosed with cancer faced with a question from a coworker – "So which breast was it?" The voyeuristic tendency that medical imaging technology subjects the patient to is often shared by the people the patient encounters. Consider Mewhorter's comics about his colorectal cancer. In "My Cancer

Story", a series of sketches that Mewhorter makes in his journal over a period of two months, he draws himself as an owl on a gurney, lying on his front, an exposed bottom being examined by a group of other animals: "I quickly learned what makes rectal cancer different than other cancers . . . . . ENDLESS eyeballs staring at your ass. Privacy is over" ("My Cancer Story"). A "visible" disease like cancer – visible mostly because of the ramifications of treatment, with the accompanying hairfall, mastectomy, or as in Mewhorter's case, an ostomy bag to carry around– usually makes the patient a spectacle.

Portraiture finds itself situated in the history of medicine's visual culture. Sander Gilman, in tracing the history of the representation of madness, discusses how as the eighteenth century ended, several forms of insanity could be identified by the appearance of the person inflicted, that is, via physiognomy, and how photography fostered this method (1984, 39-47). Photography was considered an accurate representation of physiognomy, a catalogue of psychopathologies and a direct revelation of the pathology to the patient.

Before moving on to the direct use of photographic portraits, let us also, following Gilman's tracing of the early use of drawn images of patients, look at how the graphic narratives under study use portraiture on their covers to depict the cancer patient. All four of the graphic narratives use portraits of the cancer patients on the covers, with varied expressions and framed in unique ways. *Stitches, CV* and *CMMSP* contain self-portraits, while on the cover of *MC,* Brian Fies draws a profile of his sick mother. Self-portraits tread softly on the line between fact and fiction, much like the medium of the graphic memoir itself. While a portrait drawn by another is determined by certain fixed features, like the colour of the eyes or kind of hair, self-portraits attempt to display the inner mutability of the person as well, a thread that Laura Cumming explores in her study of Rembrandt's self-portraits in *A Face to The World*: "We clearly do not consult self-portraits for documentary evidence. . . The pose could be an outright lie, for all we know, but the fiction always carries

its own truth – the truth of how the artist hoped to be seen and known, how he wished to represent (and see) himself" (7). The portraiture in the book covers both partakes in the visual iconography of the ill and resists it, while falling in with the narrative of the memoir.

MC's cover prominently announces the subject of the memoir. Divided into two panels to indicate the comic format of the memoir, the cover shows Mom's side, divided into two by the gutter. Mom is bald, bears a stitch at the side of her neck and looks broken as she stares out into the unknown. The fragmented body is a sign of the fragmentation that medicine subjects the ill body to, but by showing the fragmented body together, as two pieces that can form a whole, perhaps Fies is indicating that the purpose of the memoir itself is to humanize the dehumanized and fragmented patient. The memoir's cover page promises neither plot nor closure but presents the memoir as a case study of Mom's cancer. *Stitches* presents a more animated cover page, so to speak, showing Small as an angry child, displeasure writ large on his face, positioned with his back to the door such that he is keeping someone out or hiding, or both. The text announces the subject of the narrative as a young David Small and when read alongside the narrative, represents the crux of it: that of Small trying to hide away from his morose life. It should be noted that the cover image closely resembles Small's portrait on page 61, where he has just run away from the mean children in the playground who jeer at him imitating Alice. While *Stitches* is a cancer memoir, it is also the story of a disturbed childhood, and at several points shows Small being physically punished by his parents and by his grandmother. In addition to this, Small's perception of and response to this was that he deserved the punishments (for example 97, 105). In a striking dream sequence, his grandfather carries his frail little body to a funeral casket in the basement. His grandmother and a few other adults stand around him with angry expressions on their faces while his grandmother proclaims, "He needed to LEARN!" (105). Thereby, both the cover page in isolation and the narrative of the memoir fall into the iconography of

the patient that the Enlightenment contributes to, that of the deviant figure who had to be punished with illness and the metaphors specifically associated with the twentieth century cancer patient, who is defined as a "forlorn, self-hating, emotionally inert creature" (Sontag 53). However, when studied in isolation from the narrative, the cover portrait does not explain the unkind look on Small's face or the narrative of child abuse, which the memoir does. By expressing a seemingly different standpoint from the narrative, the cover page reveals the falsity of an iconography of the ill that considers the drawn/photographed image a complete narrative. Leigh Gilmore observes in her work on the visual depiction of pain that "[c]over images may stealthily import meanings about pain that the narrative resists, and thereby become incorporated into the knowledge the memoir produces. In this way, the visual and narrative elements fuse text and peritext into an assemblage" (105).

The covers of both *CV* and *CMMSP* act as foils to the memoirs as narratives that both adhere to and resist the iconography of the contemporary cancer patient (see Figure 12).

Figure 12 Self-Portraiture and Iconography in the Graphic Memoirs

The cover of Marchetto's memoir resembles a superhero comic, with Marchetto standing taller than New York city's skyscrapers. Hands on her hips, blonde hair flying and heels in place, Marchetto presents a chic portrait of herself, a caricature emphasizing her stylish self over the fast paced city (and over the disruption of illness, as the reader is to discover) with the words 'Cancer Vixen' brandished across her body. Adding to this, the cover is coloured a bright hue of pink, the universal colour used to designate breast cancer. The word 'vixen' is defined by the OED as "an ill-tempered quarrelsome woman; a shrew, a termagant" ("vixen, n. and adj." *OED Online*) – which while resisting the iconography of both the ninteenth and twentieth century cancer patient whose grief and anxiety caused cancer, or cancer as "a disease of insufficient passion, afflicting those who are sexually repressed, inhibited, unspontaneous, incapable of expressing anger" (Sontag 21),

unfortunately succumbs to brightsiding. While *CV* as a narrative offers much to think about the political and cultural implications of cancer in the twenty first century, and does *not* seek to normalize the current "barbarous" approaches to cancer's treatment" (Ehrenreich 49), the portraiture on its cover displays a slight disjuncture with these aspects of the narrative, locating it in a conventional phoenix narrative, one where the ill person emerges victorious from the disease, "flawed by an all-too-easy triumphalism" (Chute 416). Engelberg's memoir on the other hand presents an expressionless woman, thinking aloud the title of the book. The more generic the face, the more iconic it becomes and induces more relationality (McCloud 31-36). In this case, Engelberg resists all iconography associated with the cancerous or generally with the sick, making her stance clear that illness does not have to specifically elicit one particular reaction, actively resisting brightsiding[15].

Alan Sekula, in "The Body and the Archive" traces the rise of photographic portraiture and its stature in opposition to commissioned painting portraiture. He says,

> . . . photographic portraiture began to perform a role no painted portrait could have performed in the same thorough and rigorous fashion. This role derived, not from any honorific portrait tradition, but from the imperatives of medical and anatomical illustration. Thus photography came to establish and delimit the terrain of the *other*, to define both the generalized look – the typology – and the contingent instance of deviance and pathology. (7)

Sekula is talking of a movement in photography as an extension of the panopticon that made people both "look up" and "look down" upon the people in the portraits: the photographs captured for the first time not just the honorific but also the criminal and the deviant. Modern

[15] Engelberg's use of simplistic portraiture has also elicited some criticism in that it does not use the comics medium fully to convey the complexity of emotions and embodied dispositions. However, my stance is that the portraiture falls in line with Engelberg's 'sardonic' style in the memoir, and given that the book is intended to be shelved as "self-help" (back jacket), the simplistic portraiture engenders relationality.

photography in itself can exercise power through surveillance, without the exertion of violence or the use of arms:

> Just a gaze. An inspecting gaze, a gaze which each individual under its weight will end by interiorising to the point that he is his own overseer, each individual thus exercising this surveillance over, and against, himself. A superb formula: power exercised continuously and for what turns out to be minimal cost. (Foucault, 155)

Rosemary Garland-Thomson elaborates how photography continues to encourage the spectator to stare at the deviant body, an act that by the twentieth century had become impolite and impermissible (47). The gaze here functions to cast the subject of the photographic portrait as the "other".

Photojournalism projects like HONY attempt to humanize the subjects of the photos, where the photos function as testimonials. HONY 's archive of photo stories shot in the Memorial Sloan Kettering Cancer Centre's paediatric ward captures the different facets of a cancer hospital. There are stories about patients, families, doctors, nurses and researchers working in the children's ward. These are called "stories' because each post on the page contains a photo (sometimes more), usually a portrait, and an accompanying verbal narrative by the cancer patient, the family or their doctors. While the 'text' being used for analysis in this section of the chapter is the official HONY website, HONY is primarily a Facebook photoblog, where one or more stories are uploaded each day on the official HONY page, enabling millions of followers to respond. This collection of semiotic structures makes HONY a transmedial project, and this aspect will be studied with respect to community formation in the next chapter.

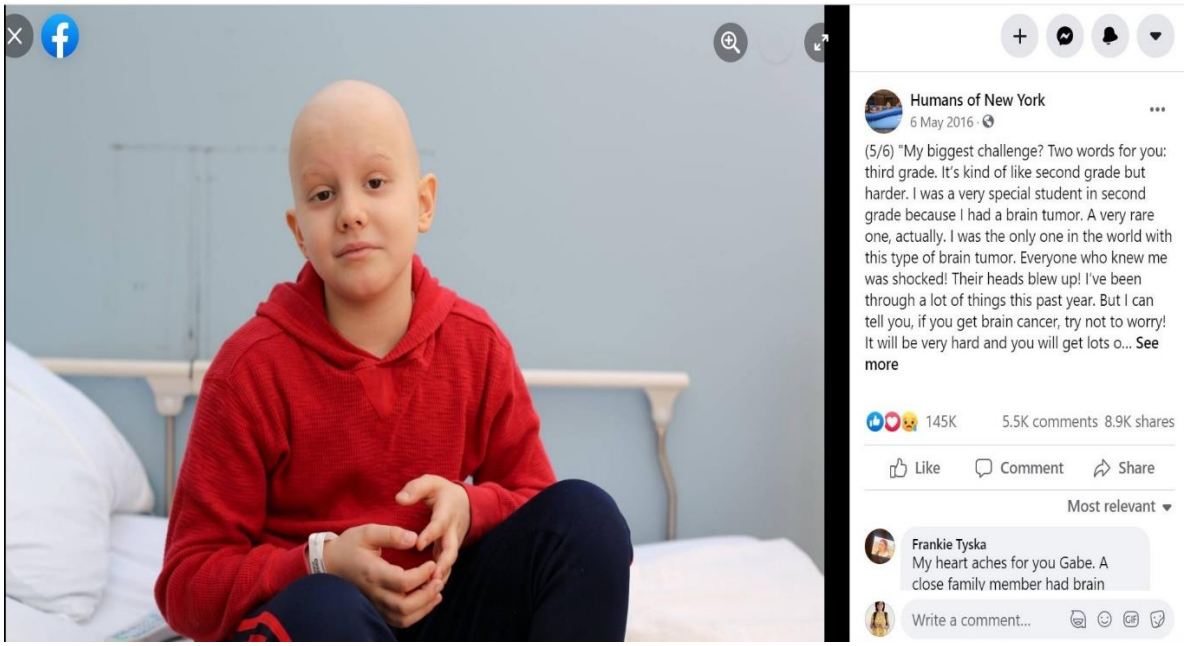

Figure 13 The rhetoric of sentiment and realism in HONY, a screenshot *(https://www.facebook.com/humansofnewyork/photos/a.102107073196735/1248765161864248)*

In the 'thumbnail' of the second story of the pediatric cancer series, a bald child with a red jumper sits cross-legged on a hospital bed, and the caption beneath the photo says "My biggest challenge? Two words for you: third grade. It's like second grade, but higher" ("Pediatric Cancer"). Once the reader clicks on the photo to read the full story, they are met with a myriad of images and narratives. There are five short narratives in the story, the first three belonging to the mother, and the second two to the son. The mother's narrative is experiential, speaking of a pre-cancerous state where the child was healthy, and suddenly one day is diagnosed with cancer in the brain. This accompanies a close-up shot of her hand holding up a phone displaying the picture of an apparently healthy child with a head full of hair, golf stick in hand, in what appears to be a lawn outside a house. The second photo is a portrait of the mother sitting on the hospital bed, hands clasped and with a very faint, sad smile, and the narration following this is of how she reveals the diagnosis to her husband with a short foray into their own difficult past. The third picture is of the boy looking sick and tired on a hospital bed (see Figure 13). The fourth picture jumps back to the mother's face, now crumpling up with tears. In the penultimate picture, the one used in the thumbnail, the

boy vividly talks about school, being sick, and anaesthesia. The final picture is that of the boy and his mother together, looking resolved to see the sickness through.

Seen by themselves, the photos offer a chronological and conventional narrative of cancer: a pre-cancerous happy time, the emotional turmoil following diagnosis, the physical degradation during the disease, and a resolved self that has come to terms with the shock and seeks to "battle" the disease. The verbal narrative gives us much more, situating the cancer not just in the patient, but in the family. It addresses the helplessness of the child and the family, the difficulty of explaining the cancer to the child, the child's bravery in the face of cancer and finally the necessity of strong emotional support from the family. The narrative elaborates the difficult choices that the parents have to make on behalf on the child: "The chemo is so painful for him. My family tried to talk me out of it. They told me that I'm killing my son with my own hands. But what can I do? There's nothing I can do. I want to give blood. I want to give bone marrow. But all I can do is watch" (*HONY* 2016).

Garland-Thomson traces four kinds of visual rhetoric in photographic representations of disability : the wondrous, which capitalizes on physical differences; the sentimental, which diminishes the sufferer or the victim into an object of sympathy; the exotic, which presents the disabled as alien, distant and sensationalized; and the realistic, where a relationship of contiguity is established between the viewer and the viewed (59-69). While the rhetoric of sentiment is clearly seen in HONY, the thumbnails attempt to minimize the difference between the viewer and the viewed by humanizing the characters and situating them in quotidian activities, like the child speaking of third grade at school being his toughest task in hand. Gratitude for the advances of science, posts showing the vulnerability of doctors and carers are shown in a similar sentimental light. At the same time, the posts also criticize the fallacies of the medical institution: that of embodied paranoia, multiple and opposing narratives, and lack of research. The same story serialized on Facebook gives some agency of

treatment to the community formed on the social networking site by adding a fundraising link at the end of each post: “Our donations will go toward the development of specialized treatments to give kids with rare tumours a chance at life. Thanks so much to everyone who’s donated so far. Even if it’s a small amount, please consider contributing” (facebook.com, May 2016). This aspect of community formation has been studied in some detail in the next chapter.

The rhetoric of sentiment and realism are both juxtaposed in different HONY posts, making both the ill and not-ill try to identify with the subjects of the photos even while acknowledging their differences. These impersonal (by way of being quite ordinary), but personal portraits (through the first-person narratives) in the public sphere attempt to challenge the notion of staring by familiarizing the public with the illness.

Instances of photographic portraiture embedded inside longer narratives also elicit a mode of staring. Earlier in *CMMSP*, Engelberg chooses to portray the biopsy procedure with her back to the reader, so that the reader cannot see her bared breasts. This depiction aligns with the view that the voyeuristic tendency of imaging technology that uses “techniques of illusion, deception and voyeurism” (Dijck 13) places the woman’s body under surveillance to record data. The only photographic record of Engelberg that her clinic preserves is one they take during her breast radiation, one with just Engelberg’s breasts on it, with only half her face visible such that it would be impossible to recognize her. In *CV* similarly, Marchetto makes a conscious effort to draw her bare breasts in the mammogram sequence. Both instances challenge the eroticized portrayal of female breasts with the medicalized breast. The breasts are desexualized by their ‘clinical’ portrayal.

While Garland-Thomson has argued that with the body actually absent, the photograph eliminates the “possibility for interaction or spontaneity between viewer and viewed” (48), the incorporation of photos in a larger narrative where the subject of the photo

has the agency to mediate this 'static' representation, either through a drawing or by it as such, asserts the materiality of the body. Thomas Couser considers this a requisite in the graphic somatography, in which, "for greatest effectiveness – and *affect*iveness – the body should be recognized as a particular human's – manifestly a thing of flesh, blood, and bone, a truly *corporeal* body" (original emphasis, 1). This move brings the medically and technologically erased body back into visibility.

5. **Witnessing: The Ethnographic Role of Photographs**

Nina Riggs's memoir has numerous descriptions of her taking 'selfies' in the most unlikely of places: in front of the waiting room after diagnosis, the photo with her husband documents "what two completely terrified people who are trying to act like they've got it all under control look like" (19); at the wig-shop, her friend takes photos of them laughing even as Riggs describes the uncanny feeling of being in "suspicious country" with the danger of cancer lurking around her (26). The photos here perform a double function: though they are evincing the lived cancerous body, they are also about keeping up appearances. Riggs clicks a picture in front of the crematorium with her mother inside: she calls it a "portrait of cancer patient with dead mother", and recalls how she smiles unconsciously for the picture, the gravity of the situation undermined by the action. The photos are a projection of a self trying to keep up with extremity.

Photography here performs the important ethnographic project of documenting the lived body of a cancer patient. While delineating the functions of a photograph, Barthes points to how it gives him access to "infra- knowledge," yielding "'details' which constitute the raw material of ethnological knowledge" (28). At least four of the books studied in this chapter concede that the memoirs are performing the act of witnessing the cancer experience and *documenting* it as a journalist might. As Rothberg has outlined in his essay on traumatic realism, the traumatic memoir "is not an attempt to reflect the traumatic event mimetically,

but to produce it as an object of knowledge, and to transform its readers so that they are forced to acknowledge their relationship to post-traumatic culture" (103). Both *MC* and *CV* are explicit about this role of a journalist that the writer takes on. Brian Fies refers to the time his comics appeared online as "a kind of underground journalism" and as he started creating the book, he "resolved to be a good reporter and tell it as squarely as [he] could" (Preface). Marchetto, also a reporter, makes reporting the natural form of narration throughout the memoir. The use of memory devices – the camera, the recording machines, drawing itself – are of paramount importance in *CV*.

While in the case of Kalanithi and Fies, the photographs perform, clearly, a melancholic function, photography takes on a more assertive function in *TBH* and *CV*. One of the only two 'real' photographs that Marchetto includes in the narrative, of her wedding day, shows empathetically the role of witnessing that the camera performs. The panel begins with the date of her wedding, and shows her "witnesses", her parents and the ring bearer, armed with cameras, and a callout that has bigger font than the other captions which asks the couple to smile. The cameras are pointed to the photograph of Marchetto and Silvano, the text around the photograph attesting to the presence of the absent witness, the photographer, Violetta Acocella. Another little caption reads, "We were 'wedding of the week' in the New York Post" (127). This is an assemblage of registers: Marchetto's drawing, the photograph, the snippet about being recorded in the *New York Times*, the absent witness embodied in the photograph and the juxtaposing of different fonts all play with the surface of the text, its material space. It seems like through this purposeful depiction of excess, Marchetto is asserting her right to be happy in this panel, foregrounding the everyday in the face of the extreme. In various parts of the memoir, this use of excess to depict both the everyday and the extreme returns, and this can be seen as Marchetto's ploy to assert narrative agency. Consider the photo of the family portrait that Fies reproduces in *Mom's Cancer.* That the

photo is drawn in is already an indicator of Fies's *hand*, but the descriptors of the people situate the family in the narrative of cancer as well. Fies labels them Dad, Mom, Kid Sis, Nurse Sis and Me, the same tags he uses in the narrative, thereby defamiliarizing them from the period the picture was taken in and putting them in the context of the cancer story.

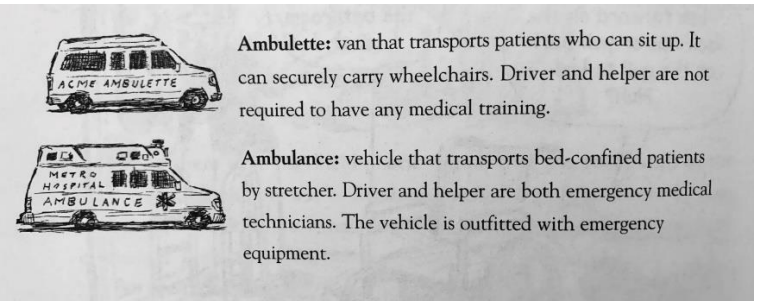

Figure 14 The use of different verbal/visual registers in *Janet and Me* (118)

Stan Mack uses three different verbal/visual registers in *JM*. In the author's note that precedes the narration, he specifies these as being the recollections of the witnesses speaking directly from the margins, the drawings that are "more cartoony" and the ones that are "more realistic" (ix). While Mack refers to these as registers of visual representation, they are also different voices: Janet's voice from her emails, letters and Mack's memory; the voice of the witnesses that Mack speaks to; and Mack's narrative voice itself. This interplay between voices and registers, text and archives adds to the materiality of the memoir (see Figure 14). In most cases the more cartoon-like drawings represent Janet's voice and the more realistic drawings represent intimate moments between Janet and Stan or grave situations they face together. Mack employs the more cartoon-like representation of Janet to show the stereotype of the sick body that overcomes its disability to look "inspirational and heroic to a normative audience" and the more realistic drawings to describe the more intimate moments where the stereotype of "pitiful, innocent victims who need help from the normative compassionate" (Richardson and Locke, qtd. in Quesenberry 6) plays out. Further, the transformation from drawing Janet as a universally known character (she is likened to Olive Oyl from the Popye cartoons) when depicting incidents and episodes from when she is healthy to representing her

using metaphors while dealing with the pain of her death, points to what Elaine Scarry says – that pain is anterior to language (1987). This assemblage gives narrative agency to the three different registers to shape the reader's perception of Janet's identity. Each of these registers thus engages the visual languages of identity markers. By employing different narrative voices that point towards a unified identity for Janet, thereby making her illness experience universal, the writer inspires in the reader narrative empathy.

The postmodern illness narrative shows both, the narrator's position as a witness to the experience of disease, and an affirmation of belonging to a scientific culture in which the rampant circulation of images is involved in meaning making. In tracing the literal and derived meanings of the word *testimonio*, John Beverly distinguishes between the *oral scientist*, a "recorder" or "social scientist" whose intention is of paramount importance in a participant narrative, and the testimonio, in which the intentionality of the narrator gains precedence. Beverly says that the narrator's *I* in a testimonio has the linguistic qualities of a shifter – "a linguistic function that can be assumed indiscriminately by anyone" (23). Thomas Couser presents the same vein of thought in his book on the disability memoir, calling it the "some body" memoir (2009, 3), pointing out to its added ability to qualify the stigmatized to display their lives for everyone to see, and thus to speak on behalf of a marginalized collective of vulnerable subjects. For Hillary Chute, who speaks specifically in relation to the graphic memoir, an 'idiom of witness' is a "manner of testifying that sets a visual language in motion with and against the verbal in order to embody individual and collective experience, to put contingent histories and selves into form" (3–4).

Examples of the singular voice standing for the collective are scattered through the cancer texts. In *CV*, Marchetto remembers other victims of cancers that owe their presence to the malfunctioning of social institutions and environmental hazards. In the full page panel, Marchetto sits on the surface of the earth, looking up at a host of victims on a cloud in space

explaining to her how their cancers might have been caused by “toxic garbage”, “jet fuel” containing benzene dumped into drinking water, “pesticides,” and “radioactive dust” forming cancer clusters. The panel is full-page, is not enclosed by a frame, and extends from edge to edge (see Figure 15). This is known as a bleed, and its temporality has been described by Scott McCloud thus: “time is no longer contained by the familiar lines of the closed panel, but instead haemorrhages and escapes into timeless space” (103). This thus adds to the concept of universality of suffering and shared vulnerability already indicated by the illustration of the world. That Marchetto is on her artist’s table, facing the cluster of victims, with her back to the reader, pen poised over a sheet of paper serves an interesting function: it places the reader at a shared vantage point with Marchetto, making us witnesses to the testimonies of the dead as well.

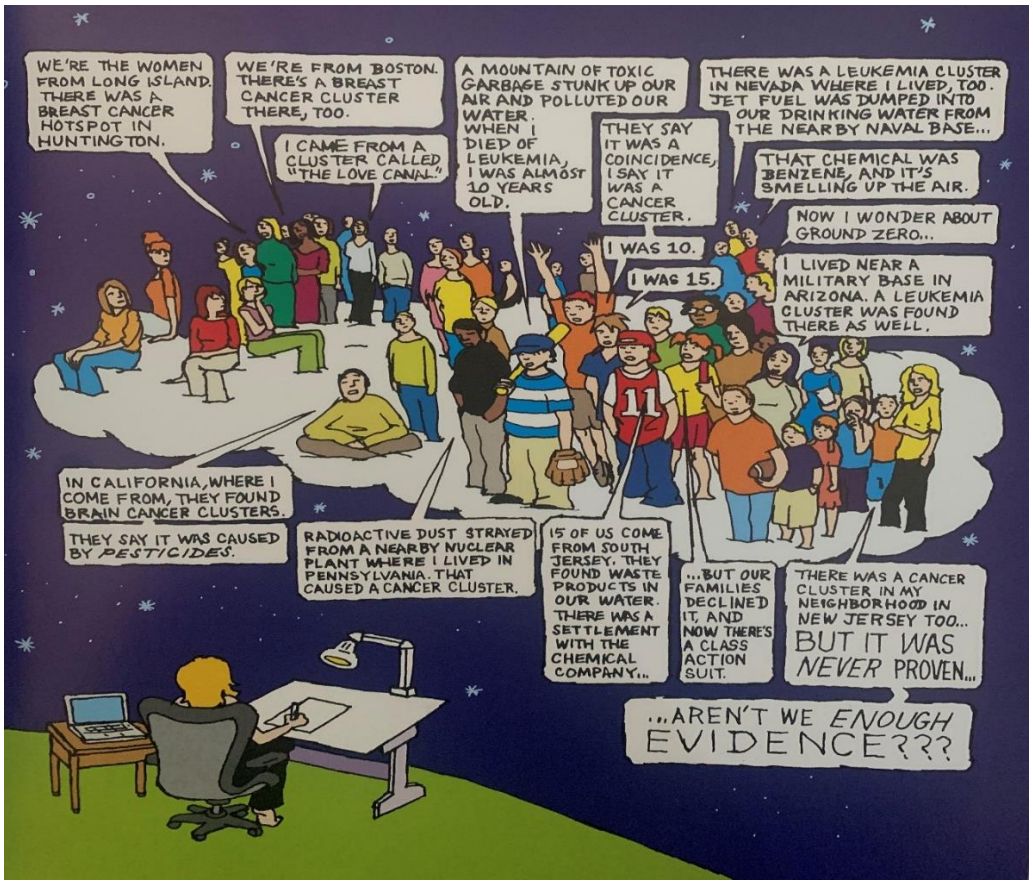

Figure 15 The memoir as testimony: Witnessing in *Cancer Vixen* (36)

The borders between these dead voices, anonymous but for their geographical locations, blur the line between dead bodies and the living. An interesting comment that these dead voices make is about how their deaths or the presence of the clusters were never proven or investigated. One of the victims says, "But our ritzy town kept it quiet. They didn't want their real estate prices to drop" (36). A cancer cluster is formed when a high number of cancer cases is found among people in a geographically defined area. In the examples given, the news of the invasion of corporeal borders by pathogens is restricted within state borders or never proven. The vanishing point here is marked by both cartographic states of exception and the concealment of truth. The cause for the invasion in the first place remains murky but is attributed to the state's negligence. Both Perera (2006) and Salgado (2013) register elisions in discourses of terror, where the precarious who are rendered invisible by the state are rendered visible in representations by writers. Suvendrini Perera's thoughts on bodies and borders are relevant here: ruminating on Mbembe's question about the conditions in necropolitics that enable the "right to kill, to allow to live or to expose to death [to be] exercised", Perera chooses to concentrate on the phrase *to expose to death*, bringing to light the percepticide of the government to acts of deliberate threat to human life occurring behind the closed doors of its borders (644-45). The representation of these anonymous bodies in the text makes them evidence of state negligence, and the readers, witnesses.

The illness narrative is both a recording of scientific and biosocial data and is a personal account of suffering. The doubling of the narrator as a presenter and observer of facts and a representative of a stigmatised group of the ill, an *other*, makes the illness narrative not just testify to the (lack of) deserved healthcare/ bioethical rights of the sick but also occupy a witness position to an evolving scientific culture.

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Chapter 4

The Public-ation of Illness and Transmedial Communities

1. Introduction

In this chapter, I focus on re/presentation and the community, departing from the preceding ones which focused primarily on the self. I examine how digital narratives[16] of illness form a bridge between representation and communication. I use Gunther Kress's distinction here: while representation is a meaning-making activity in a social space, communication is the creation of the social space (2009). The border that I situate the ill person in, in this chapter, is that between self-expression and community formation. I explore four digital texts and how their affordances[17] enable community formation: a section of Nancy Miller's weblog called "My Multifocal Life", Tom Corby's cancer data documentary *bloodandbones*, Brandon Stanton's photoblog series on paediatric cancer in the *HONY* Facebook page and website and Dave deBronkart's blog posts as ePatient Dave. I then look at the role of transmedia in creating illness storyworlds for the digital narratives and some of the

[16] The citational links provided to the digital narratives studied and consulted, including those of blogs and institutional websites, were found to be functional at the time of writing and submitting the thesis, but may change over a period of time.
[17] Here, properties of the technological medium that engender user interaction.

print memoirs (both textual and graphic) that were studied in the previous chapters. I hope to address the following questions through the course of the analysis: how does the transmedial construction and circulation of an illness story help build relations and identities through the formation of online and literary biosocialities? Considering that the ill person interacting through and with the computer has an almost symbiotic relationship with the system – the system generating parts of the narrative even – does the biosocial assemblage contain, in Katherine Hayles' words (2016), active "technological cognizers"?

There are a few affordances of weblogs that differentiate them from other forms of writing online. Those that will help construct the arguments of the chapter are being laid out. Culturally, blogs partake in a form of communicative capitalism, which Jodi Dean defines as a formation in which "contemporary communications media capture their users in intensive and extensive networks of enjoyment, production and surveillance" (4), and contain key features such as "the intensification of mediality in reflexive networks (communicating about communicating), the emergence of "whatever beings" (beings who belong but not to anything in particular), and the circulation of affect (as networks generate and amplify spectacular effects)" (29). As a technological application, the blog contains the following features: it is multimodal and contains hyperlinks and posts in reverse chronological order that establish connectivity as its major feature. The subjective nature of blogs makes them testimonies, and they serve as apt loci for activism and political activity. The serial nature of blogging lends itself to a narrative that emphasizes the everyday nature of a now-common illness like cancer, without resorting to a heroic narrative. Chronic illness and disability often create storytelling structures of their own, "undermin[ing] classical narrative structures and expectations, such as resolution (i.e., when the "problem" is solved) or closure (i.e., when the illness is

overcome)" (68, Wohlman and Harrison 2019).[18] The blogs chosen for discussion are ethnographic, personal diaries and topic-driven blogs. While the locus of these blogs remains the ill self, the writers also depart from their own stories of illness to discuss cancer as a disease or talk of 'worlds' they inhabit other than their illness. This plurality of subject matter and relational subject positions presents them as individuals whose lives are lived *with* their illnesses rather than *despite* their illness.

This analysis will consider both the biosocial implications of the narratives under study and their semiotic features, making it a social semiotic approach.

2. Biocitizenship(s)

Biosocial citizenship or biocitizenship is now a well discussed term (Petryna 2002; Rose and Novas 2005; Rose 2007). Petryna, describing the claims for rights by biologically affected groups in post-Chernobyl Ukraine, defines biological citizenship as "a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it" (6). Rose and Novas expand this definition to include global transformations and call biological citizenship "all those citizenship projects that have linked their conceptions of citizens to beliefs about the biological existence of human beings, as individuals, as families and lineages, as communities, as population and races, and as a species" (440). This description of biological citizenship differs from Petryna's in that it advocates a form of citizenship that is clearly different from national or social forms of citizenship, but is important because it links biological state to self-identity. While these descriptions are still connected to forms of citizenship that depend on advocacy or claims to rights, Paul Rabinow's biosociality (1996) is

[18] In fact, an otherwise illuminating text such as *CV* has received criticism that it is a "candy-coated narrative" with an "overarching romance narrative" (Chute 417). These triumphal narratives serve the danger of universalizing cancer stories and discounting the presence of cancer experiences that defy closure.

a broader conception of biocitizenship that links it to new practices of life that modify nature, drawing from Foucault's concept of biopower.

Centred on genomic identities, biosociality, a means of group affiliation that enables certain definitions of the self, is defined by Rabinow as "a circulation network of identity terms and restriction loci through which a truly new type of autoproduction will emerge" (99). The term could be used to include networks that find as their common thread the formation of biosocial identities through sharing biological and pathological conditions. Foucault's biopower operates between "the body" and "population" and Rabinow argues that with the birth of the new genetics, sociobiology will give way to a new understanding of social categories through biological information, leading to the formation of new individual and collective identities. Rabinow also expands this argument by stating that people will define their relationships with others based on their knowledge of everyone's bodily conditions. Thereby what Rabinow is driving at is a new network in which patients are not passive but active members, working together with doctors, institutions, and other patients to exchange stories of illnesses and create repositories of biomedical information.

3. Transmedia and Biosocial Communities

In this section, I explore the modalities and dynamics of biosocial groups that are formed out of the collaborative writing that readers/users in a transmedial storyworld are engaged in. The process of narrating and consuming lives situates them, in the words of Sidonie Smith, as secondary witnesses to "confront violence, advocate for the redress of injustice, and donate to rights organizations" (568). These actants can generate therapeutic capital as well. Collectivising projects such as HONY or advocacy narratives like ePatient Dave's are projects of self-health that bring together a community related to biological and social claims that assume a global form in these transmedial narratives. While some of these claims are quite specific, for instance, demands for access to health data and for technology

that facilitates this access, others attempt to universalise the whole of humanity (and not just the ill) into one political collective, like HONY's biosocial formation whose actants involve the healthy as well. These assemblages for ethical claims form a humanitarian apparatus that Vinh-Kim Nguyen (2004) calls therapeutic citizenship, which

> is a specialized and highly structured crystallization of broader, more diffuse transnational processes wherein a diversity of groups, often referred to as nongovernmental organizations (NGOs), involved in a plethora of activities ranging from advocacy to service delivery, coalesce across different settings around specific issues." (126)

Therapeutic citizenship works on a therapeutic economy that contains various actants in the form of practices, practitioners, and knowledge that the ill seek as therapy. The biosocialities formed become dependent on the ability to capitalize upon global networks, and as Nguyen points out, this is in turn dependent upon the capability to "tell a good story" (133).

3.1 "*These are war stories": HONY* and Therapeutic Capital

Plurality extends beyond subject matter to authorship in blogging. As Scott Rettberg (2014) reminds us, digital authors are often writing within applications and software that themselves have been written by another. Collaboration thus begins at the very inception of the writing process. Rettberg proposes three kinds of collaborations:

> (1) conscious participation, when collaborators are fully aware of the constraints and form of a project and the role of their contribution to it; (2) contributory participation, when contributors take conscious steps to make their text or media available to authors or to a system but do not know how it will fit into the overall project; and (3) unwitting participation, where texts are appropriated by the text machine or harvested from the network. (74)

This submission of the self (or rather, the presentation of the self) to the mechanics of software complicates the notion of the "human" subject. Thus, collaborative writing as it occurs especially on social networking sites like Facebook offers a means to explore the emergence of the posthuman subject embedded in a network of relations, and, as Laurie McNeill argues, "such networks are *designed* to become part of users' daily lives, and to shape their offline narratives and selves in Facebooked ways" (67). A continuum of power relations can be traced when collaborative writing is used as a mode of writing in the memoir or autobiography, and this can apply to such auto/biographical acts online as well. This continuum, as Thomas Couser traces, contains ethnographic writing on one end, where the power of the writer outranks that of the subject; and celebrity writing on the other, where the power of the subject outranks the writer ("Making, Taking and Faking Lives" 334). In the middle of this continuum are relational memoirs written by a close relative, such as *Maus,* and dualistic memoirs, written by partners with more or less equal contributions to the work. The Paediatric Cancer Series, HONY, narrated by Brandon Stanton occupies the ethnographic end of this spectrum of the memoir and draws from all three types of Rettberg's typology of collaborative digital writing. The dynamics of the life narratives mediated through HONY differ from those of a conventional memoir due to their transmedial circulation, institutional leanings and audience interaction.

While HONY's series on paediatric cancer does subscribe to a sentimental portrayal of ill people, it stays away from making gruesome or frightening spectacles out of them. The photo-narratives on the official HONY website were analysed based on the themes of humanizing and staring in "Technologized Terrain" (as discussed in chapter 3). This section is interested in their transmedial presence and the building of community. The presence of ill bodies elicits a mode of staring from the spectator, but the internet helps in creating a distance between the starer and the staree, and absolves the spectator of both a direct

relationship with the object and a responsibility towards them. This lack of dynamism is supplemented by the transmedial and participatory nature of HONY, which, spread across websites such as Facebook, Tumblr, Instagram and Twitter, and print, makes itself a platform for shared grief. While the photoblog is a display-site for the pictures, collaboration with participatory platforms such as Facebook taps into the interrogative potential of staring, a mode that can direct staring that is usually baroque towards goal-driven ends (Garland-Thomson 117). Not unlike several other photo essays by Stanton that attempt to crowdsource funds, this series on pediatric cancer stands out because of two reasons: its similarity to institutionally driven illness narratives and the formation of a vulnerable communicative community that arises as a result of the storytelling. The series unfolds over two weeks and 56 posts on Facebook, and as Stanton outlines in his first post:

> . . . obviously these are not going to be easy stories to read. These are war stories. The treatment of cancer can be nearly as violent as the condition itself, and even the doctors will frame their efforts in terms of warfare. But the fight against pediatric cancer is uniquely tragic because the battlefield is the body of a child. So these are definitely war stories . . . And most importantly, you'll meet the reason that everyone is fighting, and the greatest warriors of all—the kids. So yes, these are war stories . . . And as we learn these stories, we'll be raising money to play our own small part in the war. (5 May 2016)

Stanton's preamble covers two points: the goal of the activity, which is to "learn these stories" and raise funds, and a disclaimer sensitising the audience to the rhetoric of war and extreme language that would make up the content. The text follows the photo of a young, bald boy with his parents on a hospital bed with no descriptions about the photo itself (their 'story' is narrated in a series of five posts over the course of the day). The comments on this first post reveal that they are mini-narratives by caregivers about their own kids with cancer,

usually accompanied by their pictures. This is an example of the subjectification of the respondent that characterises weblogs (of which a social media network is but an extension). That is, the subject is constantly saying or doing something to captivate an imagined audience, turning the captivated into the subject instead (Dean 54). The gaze is thus reflexive, where the subject imagines being seen. The responses on a Facebook post, by virtue of their being permanent, serve as indicators of the respondent's identity, and may also be used as signposts that "teach or model 'appropriate' interactions for other members of the network" (McNeill 73). There are some who offer negative responses to Stanton's rhetoric:

> . . . it pains me to embrace the metaphor of "war" and the imposition of "violence" on our loved ones... when they are often desperately afraid and in need of reassurance that they are not so much under attack from an alien invader but that an integral part of them has lost its way and requires arrest, repair or removal. (Comment, 5 May 2016)

The rhetoric itself becomes a subject of discussion in a response to this comment: "In terms of metaphors, I really do think it depends on what helps the individual face their fear. Personally, the metaphor of a war was helpful to me. I can see that it may not be to others but it is important not to look down in any way on people who do find this a helpful way of viewing their experience. The war metaphor can be extremely empowering" (Comment, 5 May 2016). Much like the platform of Facebook itself, which contains carefully crafted fields for self-description – for instance, Facebook profiles ask one to fill in the music one likes and the movies one watches, prescribing these as qualifiers of presentability – Brandon is setting the qualifier for the community that will be formed around the Paediatric Cancer series as one that is filled with humanistic values. While the role of Stanton in other street photography on HONY is negligible, he clearly sets the tone for the formation of this storyworld (which includes the respondents). The comments are from people choosing to portray themselves

using this rhetoric (though as we shall see, there are some that present themselves differently as well). There are narratives by those who consider a popular forum like HONY the right platform to advertise their services: for example, an airline company that helps in carrying patients to the hospital links their Facebook profile in a comment, not just presenting their consumerist needs but also asserting themselves as part of the humanitarian enterprise of helping those with cancer. The networked "I" of these respondents is thus at all points defined by the organization or cause they choose to affiliate themselves with. The 56 stories in the series are narratives of patients and their families, teams of doctors and medical staff battling rare paediatric cancers, focusing on Neuroblastoma and DIPG (Diffuse intrinsic pontine glioma), rare kinds of brain cancer for which the Sloan Kettering centre discovered antibodies.

The power of such media for raising funds is overwhelming. By 20 May 2016, two weeks since Brandon Stanton starts posting the photo stories on the Facebook page, he manages to crowdsource a huge amount of money:

> Over the past two weeks, 90,000 of you donated nearly $3.4 million to help fight pediatric cancer. That is a staggering amount of money. Thank you. For those of you who might not have been in a place to contribute financially, thank you so much for engaging with this difficult material. The support and solidarity you showed these families was just as valuable as the money itself. You are the most caring community of people on the Internet. That's no exaggeration. It's proven by the tone of every comment section . . . Lastly, thank you so much to Dr. O'Reilly and the Department of Pediatrics at Memorial Sloan Kettering for making this series possible. . . (HONY, facebook.com, 19 May 2016)

These respondents serve as therapeutic capital and are as important (if not more) as the narrators of the photo essays. We see all possible therapeutic options thus laid out in the formation of this 'community': the healing team of doctors, the research that goes behind cures, and the crowdfunding that will enable this research. The audience or the spectators are visibly of two kinds, though undoubtedly there is also a third kind that is simply 'lurking': while one kind responds in material and quantitative terms measured in terms of the financial contribution made, the other "engage[s] with this difficult material", i.e. with the various somatic conditions of the children with cancer discussed over two weeks in the form of comments, likes or shares. The seemingly least visible actant is the mediator Brandon Stanton, the compiler/mediator of these testimonies. The project evokes a moral-aesthetic gaze from the audience: the sentimental photo-narratives evoke pity, urging one to contribute while standing out for their aesthetic quality. Traditional institutional narratives of illness, as found generally in brochures or advertisements put out by hospitals, tend to be *health* narratives rather than those of the body-in-illness, and concentrate more on successful journeys back to health. Though the contractual underpinnings of Stanton's collaboration with Memorial Sloan are unclear, an institutional will to present a restitution narrative is articulated through its tone, in the anticipatory storytelling pattern that takes advantage of the sympathetic gaze that illness can evoke. The doctor whose DIPG lab the money raised is donated to is rather candid about the interview Stanton conducts with him and says in an article published on Memorial Sloan's website: "He knows what his readers want to hear about: motivation, frustration, success, failure" (13 Sep 2016). Even as the stories are those of suffering incurable and rare cancers, they are restitutional because of the hope they present: the young boy, for instance, is interested in going from the second grade to the third, *despite* suffering through a terminal illness. The stories here thus model the kind of stories that patients ought to tell about their illnesses, and the restitution plot here involves suffering

whose remedy can be 'bought' (Frank 80) by the spectator's contribution. The therapeutic economy that exists in this form of therapeutic citizenship is not merely monetary but also, as Nguyen elaborates, a moral economy that relies on the network to uphold notions of living positively, taking responsibility and caring for others (131). The support system extends from treatment and research to moral support for caregivers and doctors. For instance, in one of the photo stories, the mom of a kid with a rare neuroblastoma says, referring to the other parents in the paediatric ward, "My only therapy is talking to the other moms here. We're all going through the same thing. So that helps" (HONY, facebook.com, 15 May 2016). Various modalities such as the use of confessional technology (Facebook/blogs), tactically used narratives, an organization that fosters online biosociality (Brandon Stanton or HONY), capital (crowdfunding), and therapy and research (Sloan Kettering Centre) make the presence of a therapeutic economy clear.

Rabinow, discussing the biosociality in the context of the Human Genome Project, describes one such group "whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on" (102). These groups often comprise a "group of medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and 'understand' their fate" (102). Rabinow's inclusion of *narratives* in this mix helps put the transmedial circulation of illness stories in context. While HONY uses an episodic and participatory narrative form on Facebook, its website resembles a carousel of carefully arranged and displayed stories.

Continuing the conversation even a year after the crowdfunding effort by HONY, the Memorial Sloan Kettering centre put up a Youtube video from its account on May 24, 2017. Gabe, the face of the series on the website is now suited up, has grown back his hair and says,

> So another advice to people who've been going through cancer. . . it'll be over before you know it. Like I said before, you just have to be strong, and believe in yourself, okay? I know it's going to be extremely painful when you get those needles. Trust me, I've been through it because I have my bald spot over here [points]. Still wish I had hair growing there, but yeah. So it'll be over before you know it if you be strong. (May 26, 2017, Memorial Sloan Kettering)

The video goes on to record testimonies from several of the people who featured in Stanton's series a year ago. By making the "you" in his narrative a cancer patient as well, the child is establishing an interpersonal relationship with the audience he is addressing, attempting to have us put ourselves in the shoes of the sick and empathise. In the opening pages of her memoir *But Enough About Me* (2002), Nancy Miller presents the reading of others' memoirs as akin to living various lives. "Sometimes my identifications with the stories *not* about me (not even remotely) came to feel like a rediscovery of my own life and memories, like a haunting" (xiii). This is a feature characteristic of memoirs, which causes readers to empathise with and remember the lives represented in them. Consider the testimony of an administrator from the Centre: "every one of our donors makes an impact", she says. "Whether they're funding the junior scientist, whether they're purchasing a piece of essential laboratory equipment, whether they're providing dollars so that we can have enough birthday parties and enough legos to keep up with our daily needs, they're making an impact." Spectators of such narratives are expected not to merely witness but to 'bear' witness, implicating the spectator in a form of 'response-ability.'[19]

[19] This empathetic association with the subject of testimonies varies across contexts. Sue Tait makes note (2008, 2011) of various subject positions set up for different media witnessing audiences, for example those witnessing body-horror websites – where the subject's pain is decontextualized and the spectatorship could be amoral, vulnerable, entitled or responsive. James Dawes posits the risks of over association, under association or anti association that empathizing with the subject can lead to, in the "distrustful account of sympathetic reading" he performs in his account of perpetrator testimonies in *Evil Men* (2014). In the case of the HONY

There is a distinction between the testimonies recorded on HONY's websites and the Institute's Youtube video. While the former were moving and heart-breaking, the 'update video' opens with chirpy music, showing most narrators from the series in a positive light: fighting cancer optimistically, engaging in ground-breaking research, reforming ties with family, the children going to school and taking classes, and mostly reinforcing a story of hope. The appeal for funding is thus built through a narrative of triumph laced with optimism: the point of departure for the video is HONY's campaign, where the cancer narratives helped a crowdfunding campaign, the campaign's success in the video in shown in terms of the better lives of those featured (though the exact progress in the treatment of their disease remains undisclosed), and these better lives are attributed to the *donors*, bringing back in cyclical fashion, the appeal for funding. The caption describing the video links the viewer to Sloan Kettering Centre's research page (https://giving.mskcc.org/impact), and then on to a report page describing their research every year.

HONY's Paediatric Cancer series extends the structure of a biosociality as defined by Rabinow – essentially a social group of the biologically vulnerable and suffering – mainly because a) being on social media opens it up to an audience that does not comprise only of the ill and b) the construction of the biosocial group is via narratives that are mediated. The 'bio-social' group formed here contains both the ill and the healthy and is termed so precisely because a group of narratives about the somatic conditions of people forms the reason for its construction. The reading public is united through affective modalities to constitute part of the biosociality that contains a large number of actants including the platform's affordances. The kind of biosociality invoked through collectivising projects such as HONY's crowdfunding also reflects certain aspects of Rose and Novas's description of biological

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photographs, there is no subjective evacuation of the patients represented and 'bearing witness' refers to a political participation in response.

citizenship that draws a line between those in the citizenship project and 'noncitizens'. The therapeutic community formed is based on exclusion in that the money raised is donated to a specific institution, and the deserving are those who suffer from rarer forms of cancers – prospective patients treated with prospective research aided by the money collected. While the comments are littered with shorter cancer narratives, these are not the beneficiaries of the money raised, though they are part of the narrative assemblage. This exclusionary network reveals a hierarchy of the disease, where the 'exotic' appeal of rarer cancers is capitalised on to raise funds for research.

While the series succeeds in raising money, the community of patients represented and the overwhelming tone of sentimentality raises a few disturbing questions. HONY's use of sentimentality has been critiqued several times on popular websites,[20] the main argument being that the weblog uses sentimentality to escape confronting social reality. For instance, we only get scant insights into the socio-cultural backgrounds of patients – such as in a story about a Jewish family where the father (wearing a black *kippah* in the photos) recounts appealing to synagogues for funds. Cancer and its treatment are presented as humanitarian tragedies. The staunch portrayal of universality elides important differences such as *who* speaks, and the absence of socio-economic processes leads to a non-addressal of health policies or health insurance, and no political consciousness. It follows that there are also anti-empathetic comments, for example, "Stop posting 'prayers' and 'thoughts' and 'wishing' for healing, and instead exercise your right to vote for local, state, and national government that invests in education, invests in science, invests in research, and then we can actually cure

[20] See
https://www.salon.com/2016/01/24/unfollow_humans_of_new_york_the_site_engages_sentimentally_with_real_political_matters_empathy_is_much_harder/
https://thepolitic.org/the-problem-with-humans-of-new-york/
http://www.warscapes.com/opinion/sentimentality-critique-humans-new-york
https://www.newyorker.com/books/page-turner/humans-of-new-york-and-the-cavalier-consumption-of-others

cancer" (May 15, 2016). Studies of other crowdfunding ventures begun by HONY's narratives show that these narratives help in humanizing the "other" and are examples of building virtual empathy via parasocial contact and encouraging prosocial action (Wang et al., 2017). The crowdfunding appeal might be read as an implicit indicator of the structural inadequacy in funding research on rare cancers, even as we argue that it might contribute to the hierarchy of the disease itself. The series strays away from politicising the patient and differs from health activism in that it focuses on building an economy of hope that relies on communicative capitalism.

In each of these media narratives, all contributing to the 'storyworld' of the paediatric patients at the Sloan Kettering Centre, the *mode* contributes to the affective relations formed. On Facebook, the textual narratives coupled with the photos instigate a mode of urgency that urges people to contribute. The urgent rhetoric of these narratives deems everybody reading the posts vulnerable. For example, the post announcing that the one-million mark had been achieved follows this statement by a paediatric oncologist at the hospital: "Twelve thousand kids per year get cancer in the United States. But the extraordinary thing isn't that cancer happens. The extraordinary thing is that cancer doesn't happen more often" (May 14, 2016). We read a reparative method in the building of a dynamic community here. First, patients and doctors recount painful past and present memories that lead to the formation of an affective archive of vulnerability. The last narrative by Dr O Reilly deems everybody a patient-in-waiting, making us all 'paranoid' readers. The building of the crowdfunding community thus becomes a therapeutic measure to this paranoid position that readers are led to adopt. A year later, on Youtube, the chirpy music foregrounds the positive impact of the donation; on the Research page, the bold statistics and human stories are used to emphasize the labour that the donor's generosity has expedited. The transmedial storyworld forms a community that is fuelled by narratives engaged in meaning making through the use of various social semiotic

modes. The networked biosociality works on what Novas and Rose call, "a political economy of hope" (2001). This hope centres on linking the different hopes of different actors: the use of hope by doctors as part of therapeutic procedures, the hope of scientists in generating enough capital for research, the hope of caregivers for a better life for the ill and for themselves, and the hope of the ill themselves.

3.2 *'Gimme My Damn Data!':* Data Ecologies and Community

The database is one form of narrative, though at first glance the causality and sequencing in what is termed a narrative deem it paradoxical to the unordered, raw entity that is data. However, all new media narratives are only interfaces to databases (Manovic 226). That is, considering that most websites are indexing sites – replete with hyperlinks and portals – and are working off underlying algorithms, they are databases as well, or contain databases. Moreover, the relationship between databases and narrative has been called symbiotic (Hayles 2007):

> Because database can construct relational juxtapositions but is helpless to interpret or explain them, it needs narrative to make its results meaningful. Narrative, for its part, needs database in the computationally intensive culture of the new millennium to enhance its cultural authority and test the generality of its insights. If narrative often dissolves into database, as Folsom suggests, database catalyzes and indeed demands narrative's reappearance as soon as meaning and interpretation are required. (1407)

The new media narrative as a cultural entity contains databases, which makes data a component of the narrative. Data management systems help the ill in reframing their illness around data. These digital data narratives enable the formation of therapeutic communities. I analyse two digital cancer narratives built of, and around illness data here. While the first, Tom Corby's bloodandbones.org is a data documentary that provides new means of self-

expression via the recording of everyday data, ePatient Dave's is a centre/site for activism for better patient control over data that is stored institutionally, including biomedical, insurance and research data. Corby's website contains narratives composed of data while ePatient Dave's blog contains narratives about data. These narratives indicate a movement where the patient's narrative develops a symbiotic relationship with database systems, the illness narrative written by both. Do these socio-technological systems, in Katherine Hayles's words, contain active technological cognizers? This section explores the failure/success of illness-conscious cognitive assemblages in writing an accurate illness narrative that can contribute to illness management.

Web 2.0 has led to the emergence of ePatients who seek to play an active role in managing their health themselves. This claim to self-management is not in many cases anti-medical. It is instead a complementary form of citizenship to medical knowledge, that opposes hierarchy and asserts the equal role of patients. Rose comes close to describing this in his 2007 expansion of an earlier description of biological citizenship:

> The forms of citizenship entailed here often involve quite specialized scientific and medical knowledge of one's condition: one might term this "informational biocitizenship." They involve the usual forms of activism such as campaigning for better treatment, ending stigma, gaining access to services, and the like: one might term this "rights biocitizenship." But they also involve new ways of making citizenship by incorporation into communities linked electronically by email lists and websites: one might term this "digital biocitizenship." (134)

Madeline Sorapure notes that the online diary is a database with "information entered in discrete, chronologically-coded units" (2003, 5). I argue that Tom Corby's data documentary is a means of pointing to the inadequacy of the medical lexicon for describing the cancer patient while framing new means of self-expression, and actively engaging in recording one's

own data through resources facilitated by the digital medium. Such an expression is an instance of biomediation, where the digitized body *becomes* the 'real' body, and the digitized body enables the patient to both shape and challenge the social construction of illness. Corby's bloodandbones.org project is a means to combine the personal, psychological, medical and financial data that he accumulates over his journey with myeloma. This representation of the self in fragments reflects an identity that is fragmented and disrupted by illness. The data Corby collects can be broadly categorized into medical, affective and financial data, and the collection and rendering of each of these has a specific method. Corby's purpose is not only to keep track of and structure his cancer – "a therapeutic conceit" as he calls it – but also to "contribute new languages and expressions of illness" ("About") that could be used by other patients.

While Corby documents a personal, everyday journey, he displays seemingly impersonal/unimportant pieces of illness data as well, making this journey very public. By making his data methods public, Corby's blog also serves as a gateway to resources that patients might find useful. Corby's affective data contains a mood indicator derived from WHO, a control index derived from Third National Scottish Survey of Public Attitudes to Mental Health, Mental Wellbeing and Mental Health Problems, a Physical Discomfort Index derived from the US Army Numeric Pain Rating Scale and two other indexes that he makes up himself: a stoicism index and a hat index. As Corby has said elsewhere (2008),

> what is normally seen as problematic in scientific IV—i.e. the ability of images produced to contain multi-level meanings—is productively turned to show that images grounded in objective data can be aligned with a more generalized and discursive function in the visual arts as a system that produces affective experience and alternative narratives or perceptions of the world. (467)

The immediate consequence of these categories is that it places the cancer patient in a highly affective narrative with strong assertions to make. For instance, by using the army's pain indicator as a measure of cancer pain, Corby's assertion is that cancer is a battle. Corby is able to make this assertion without resorting to the metaphorization that Sontag warned against, and without resorting to the usual tropes of illness narration such as metaphors of struggle or metaphors of enlightenment after a traumatic experience. The digital medium is able to provide a supplementary means of self-expression for the ill that makes it a mode for intersubjective relationships. Jane Willet in "Imagining the Self" (2001) describes the ways in which the medical dossier, containing what is seen of and what is done to the body, is used differently by people. It is used as a resource tool for researchers, a site of study for practitioners and for the hospital administration, as databases to arrange logistics. But for the patient, it is a document that is codified by the institution, difficult to understand by the patient and an exposure of the "private indiscretions of the body" (Willet, "Imagining the Self"). By using transgressive textual strategies, Corby manages to turn this institutional codification on its head. His data documentary is both an attempt at taking charge of his own data in terms he can understand, and a satire of the medical dossier, mimicking the tiring bureaucracy of healthcare institutions. Humour plays a large part in Corby's documentary. Mary DeShazer in *Mammographies* (2013) identifies three methods of humour that cancer patients use in their illness narratives: "self-deprecation, self-division and self-assertion" (94). While employing self-division, as Corby does here, the patient is playing with dualism and incongruity. Dualism works here when Corby both criticises the objectification of the patient and uses the same method to re-humanize himself. The other dualism that is at play here is that Corby envisions the body as a surveilled entity that, when breaking down, produces not just biomedical data but also affective data that rebels against institutional surveillance. In technological terms, the availability of 'self-tracking' technology and the encouragement of

Web 2.0 has made the body ‘open-access’; not just fragmented for its own needs and wants but also that of a corporate and bureaucratic society that wants to appropriate it. Corby’s data documentary points to how the body continues to produce emotions as it degenerates in an ecology that is not only medical but also highly financial. Even as Corby was in hospital isolation during a stem cell transplant in July 2013, he continued streaming a daily data image to the Museum of Contemporary Cuts, forming an exhibition called “No Detectable Level”, streamed as a real-time data performance across Facebook and Twitter. Personal, everyday data becomes the body’s unappropriated affective voice, especially when (re)classified in Corby’s own lexicon. Division thus leads to self-assertion. Consider the wry categories he uses, for instance, in his stoicism index:

> 4.// Stoicism index daily data
>
> Key:
>
> Illness what illness: 9-10
>
> I feel fine: 7-8
>
> Grin and bare [sic] it 5 - 6
>
> Stiff upper lip: 4
>
> Wobbly lip: 2-3
>
> I don’t want to talk about it: 1 (‘Data Methods’)

Consider how this index is used to represent data logged over a month (screenshot from the website below, Figure 16):

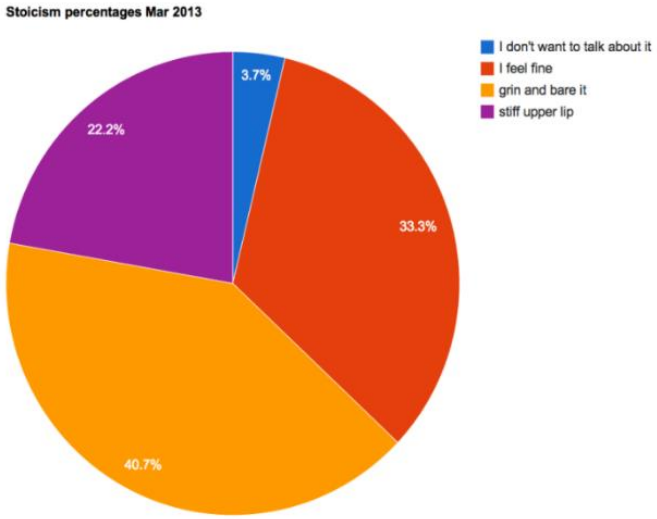

Figure 86 Affective categorization in Tom Corby's *bloodandbones*

Corby then reads the chart and explains: "Grin and bare [sic] it at 40% is identical to last month, whereas I feel fine is up from 18% to 33%. That's quite a leap. My stiff upper lip jutted out slightly less often this month but it didn't wobble once. Similar to the mood numbers I'm generally coping with rises in positive responses and slight drops in the grimmer end of the index. It will be interesting to see the indexes for April as winter drags on into months which it shouldn't trouble." ("March Round-up 2013," March 2013). The body and the text are both informed by each other in Corby's case.

The data documentary *contains* Corby's body. Spread across time and space as a whole (and still subscribing to presentism through the everyday journaling), the project incorporates affect, capital and material evidence like hats and pills (which travel around in exhibitions). Corby is taking ownership of his body this way. Corby uses the same manner of codification that the institution uses to objectify the patient to re-claim his identity. The process of codifying his illness in different forms is also a way to demystify the workings of biomedicine and different actors including family and economics to contribute to the ecologies of treatment. Corby is challenging the notion that patients are unaware of how to

use and interpret biomedical data, and at the same time making a comment on how the participatory movement often stems from the inability of healthcare systems to cater to the affective responses of the ailing body. Corby's degenerating body, embodied in data, literally interacts with other cyborged and physical bodies as it travels through museum exhibitions and blogposts. His blog is an aesthetic response and representation of therapeutic ecologies via affective and financial data categories: by codifying his data in his own terms, Corby reclaims his body, making the codified charts, graphs and images timestamps that cannot be appropriated – an artistic, copyrighted recreation of the data that converts the body's production into the ill person's property.

Dave deBronkart's blog attempts to mobilise the community to understand and demand their rights in this data ecology. A network of patients, doctors, health staff and software forms the assemblage in health databanks, where each actant actively indulges in different cognitive processes. In websites such as PatientsLikeMe, the assemblage functions in such a way: patients upload anonymized data, look for patterns and sometimes create their own clinical trials, with the software enabling them to form a community with patients with similar biological conditions. These biosocialities engage in knowledge building where biomedical data arises out of experiential narratives.

There are also databases that make use of non-human cognizers. Large databanks that can aggregate data and use software to detect patterns are examples of illness-conscious cognitive assemblages. According to Katherine Hayles (2016), a cognitive assemblage "performs the functions identified with cognition— flexibly attending to new situations, incorporating this knowledge into adaptive strategies, and evolving through experience to create new strategies and kinds of responses" (33). Here, Hayles uses assemblage both as a phenomenological category, whereby experiences, processes and perceptions that frame a narrative are viewed as assemblages, and as an analytic method, whereby interaction with

technology is analysed using assemblage theory.[21] However, while Hayles draws attention to nonconscious processes that are mapped effectively (or not) to form this assemblage, the socio-technological assemblages we see in databanks employ an illness-conscious cognition. These assemblages raise questions of human and technical agency and their distribution across legal, ethical, social and political modes. The cognizers in the case of health databanks are the patients and doctors on one hand and the software on the other. While the medical staff maintains (hopefully clean) electronic health records, the patient chooses to send these to databases such as Google Health. Google Health then traces patterns across all the data and produces meaning from these, consolidating for the patient a list of conditions, segregating these into ones that require most attention and those that do not.

The blog posts of Dave deBronkart, or ePatient Dave as he is popularly known, are ideal examples of the experience of being part of a(n albeit dysfunctional) cognitive assemblage. Hayles's cognitive assemblage is not only about distributed agency, but also about distributed responsibility. Thereby, when this responsibility is incorrectly operated, the assemblage fails. This is deBronkart's grouse with Google Health and the data providers from his hospital. DeBronkart narrates (2009) how his dependence on databanks like Google Health arose out of a need to consolidate his health data over a period in one place. Having a complicated medicine routine, ePatient Dave decided that an automatized chart that could bring together all the medication he needed to take every day for various ailments would be immensely helpful, and technological intervention would save much manual labour on the part of the nurses in his hospital. From Dave's description and his screenshots, Google Health was one such software that would store data that the hospital fed into it, interpret the data and contextually provide information to Dave to manage his health. The healthcare seeker would

[21] In his recent work "Re-Assemblage: Theory, Practice and Method" (2020), Bill Brown lists the various ways in which the word Assemblage, following its conception by Deluze and Guattari, is used. The assemblage could be an ontological category, epistemological, psychological, a material practice, phenomenological, or an analytical or aesthetic practice (279-280).

thus be able to manage a healthcare regime away from the hospital. Dave went along because he believed "in the power of 'mash-ups.' That's the ability to slap together two pieces of software (or data) that were created without knowing that the other one exists, and making something new out of them without anyone planning it in advance. Things can just grow in any direction people want" (*patientdave.blogspot.com* 2009). These mash-ups are common enough today, where we are able to use one app within another (for example, one can include a Youtube video in a Facebook post), but in 2009 these were unavailable, especially in healthcare.

The fact that various digital media are now interacting with one another and with humans to produce illness narratives is not only an example of a collaborative memoir but also an illustration of a transmedia storyworld, each new app adding to the narrative (the locus or origin of which is of course, the body) and together making a larger narrative. This illness-conscious cognitive assemblage is thus not merely a network with finite possibilities; its boundaries are porous, and the number of actants that it can have is ever expanding. Bill Brown (2020) describes the process by which an existing assemblage deterritorializes and reterritorializes into another existing assemblage, thereby forming "re-assemblage". The transmedial storyworlds we are talking about that contain illness-conscious cognitive assemblages in them ring similar to this concept. The heterogenous, material assemblage that illness data across time and space is, is pulled apart by humans and technology with cognitive (including interpretative) agency and re-arranged (and Deleuze and Guattari used the word *agencement* which could also be translated into *arrangement*) to detect patterns and produce a narrative.

The assemblage works on the principle of distributed agencies and relies on materialistic processes, though as Hayles points out about the role of active technological cognizers in *Unthought* (2017), a large part of the agency rests with the human. The analysis

of the cognitive assemblage cannot stop with material processes but must extend to those that hold the cognizing power over decisions. As other materialists keep pointing out (for example, Braidotti), the study of material processes should be used to expedite changes in both the political scene and within human beings. The role played by the hospital authorities in deBronkart's case is thus pivotal. Instead of his health data, the hospital fed in insurance claims data to PatientSite (his hospital's patient database). Google Health consolidated the symptoms incorrectly to show that deBronkart had disorders he did not have. deBronkart blogs about his reaction to this:

> An alarm: "! Requires immediate attention" [see screen capture at right]
>
> Okay, yes, HCTz is my blood pressure medication. But low potassium? That was true when I was hospitalized two years ago, not now. What's going on?
>
> . . .
>
> Yes, ladies and germs, it transmitted **everything I've ever had. With almost no dates attached.** (It did have the correct date for my very first visit, and for Chest Mass, the x-ray that first found the undiagnosed lesion that turned out to be cancer. But the date for CANCER itself, the big one, was 5/25/07 – four months after the diagnosis. And no other line item had any date. For instance, the "anxiety" diagnosis was when I was puking my guts out during my cancer treatment. I got medicated for that, justified by the intelligent observation (diagnosis) that I was anxious. But you wouldn't know *that* from looking at this.) (deBronkart 2009, participatorymedicine.org, original emphasis)

The screengrab (Figure 17) shows that Google Health had decided by looking at the data that the condition "requires immediate attention" and advised deBronkart to "discuss with[his] doctor soon". Cognitive, interpretative statements had been made; however, the data had not been verified, and hence misinformed patterns were shown. No distinctions were

made between present and past conditions; in total, the data interpreted was useless and dangerously inaccurate. These mistakes could have had huge complications, since apps like Google Health (now defunct) were used to manage medication by patients.

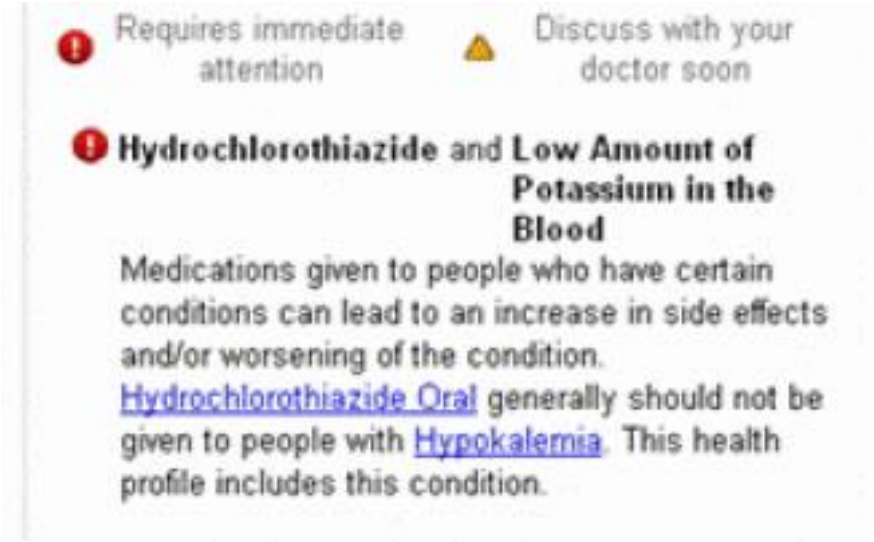

Figure 97 Screengrab of Google Health from ePatient Dave's blog: Mismanaged data and illness-conscious cognitive databases (April 1, 2009)

ePatient Dave's experiences of mismanaged data turned him into an advocate for patient rights over data and the movement called "Gimme my damn data!" was born. The role of these narratives in mobilizing action is important. DeBronkart explains his reasons: "Some have asked why I responded to all this by blogging instead of asking my hospital. Well, I did ask, and the only response I got was that '5,000 other people have pushed that button and nobody else has complained.' So, since this is obviously important, I went to the blog". Dave's blogpost appeared right when the US had passed its Economic Recovery Act in 2009, and the act set aside forty billion dollars for the adoption of electronic health records. The post was thus a timely reminder of what was wrong in healthcare data management systems. Dave's blogpost lead to further investigation and Google Health was ultimately shut down.

Dave's campaign extended to vouching for platforms like FHIR (Fast Healthcare Interoperability Resources), which he supports and advocates on his blog. FHIR is a standard

for exchange of digital healthcare data across platforms, and its website describes its position in existing healthcare thus:

> Healthcare records are increasingly becoming digitized. As patients move around the healthcare ecosystem, their electronic health records must be available, discoverable, and understandable. Further, to support automated clinical decision support and other machine-based processing, the data must also be structured and standardized . . . FHIR aims to simplify implementation without sacrificing information integrity. It leverages existing logical and theoretical models to provide a consistent, easy to implement, and rigorous mechanism for exchanging data between healthcare applications. ("FHIR Overview")

FHIR is another cognitive assemblage in the throes of mass roll out, but Dave's positivity about this is also because the decision makers here are the policy makers – FHIR is an application that will be mandated by the government across healthcare institutions, and will be free of cost. Dave uses the case study of a Stage IV colorectal cancer patient to argue his point:

> Being a programmer, Mike was able to use FHIR to pull data from all four hospitals, and (not unlike Kate) create his own graphs of the combined data, so each doctor visit at any hospital would start with *Mike showing the doctors* his combined data — absolutely the opposite of the traditional "only the doctor knows" visit. (8 June 2019)

One can see again how the mode here allows Dave to garner authority and be persuasive. By including hyperlinks in his post, and promising authentic images, the blog gains what Ruth Page has called a "social dimension" (43), deeming the blogger an expert. The transmedial ways in which Dave's *Gimme my damn data!* movement spreads are manifold. While Dave himself has written research articles, delivered Ted Talks and blogs actively on various

forums about the movement, playful narratives such as a rap song (http://motorcycleguy. blogspot.com /2010/09 /i-wanna-be-epatient.html) about the movement and a video song by popular American doctors also exist, besides mugs being sold with the phrase printed on them. The first lines of the rap song read: "*I wanna be an e-patient / just like Dave/ Gimme My Damn Data!/ 'Cause it's MY life to save!".* The latter becomes a "project" of its own by The American College of Medical Informatomusicology, and on their blog they write: "ACMImimi is inviting anyone wanting to promote access to their electronic health information to contribute to the creation of a music video of 'Gimme My Damn Data'" (March 5, 2012). Dave thus becomes an icon for a larger community. A movement begun at the grassroots by Dave, questioning existing hospital norms spirals into a larger movement, questioning existing policy.

Dave's blog lists therapeutic options that are driven by both biomedical data and avenues for social action. Dave lists resources in the form of support groups for different kinds of cancer on his blog, but most of his blog posts, through the language of self-help and empowerment, attempt to question policies that determine what rights claims patients have over the data that the body is constantly producing. While Corby's artistic voice wryly points to the commercialization of the body through the self-help movement by making the ill person's data a commodity of benefit, Dave examines and closely studies government policies such as HIPAA and technology such as FIHRR that allow the patient to own their data. These policy studies garner the most interaction from other patients. In Dave's posts about HIPAA (2010, 2013, 2016, 2020), one notices that his method of engagement with an audience is to make the policy digestible in a manner that they understand what the nuances of the policy are through accessible modes and discuss the ramifications. HIPAA (Health Insurance Portability and Accountability Act) was signed into law in 1996, and an important component was the mandate giving patients the right to inspect, review, and receive copies of

their medical records. By the end of the twentieth century, hospitals partnered with health technology companies to create patient portals, where health professionals would upload the patient's health data and which could be accessed by the patient.

In his blogpost dated 23 April 2010, Dave mentions his role "testif[ying] at a policy meeting" to discuss the communication of rights information to patients by health professionals, following which he decides to make his own summarization of the HIPAA, because "why wait for an act of Congress?" His summarization re-presents a video clip from Seinfield, an American sitcom from the 1990s in the context of the HIPAA. The clip shows a patient curious about something she chances to see in her medical record but denied access to the record when she asks the doctor. Dave says, "so when this episode was aired, Elaine was not entitled to her record. Today you would be". In other posts, Dave also vouches for patients who have been denied their records. The downside to a law such as HIPAA that on the outset appears to be only beneficial to the patient is that the hospitals can charge for these data records, asserting a bureaucratic ownership over the ill body once again. The Seinfield clip receives comments from angry patients who echo this sentiment:

> Some doctors [sic] offices have taken the part about charging quite seriously "Covered entities may impose reasonable, cost-based fees for the cost of copying and postage." My husband had a primary care doctor (that we fired after they made some serious errors in his care) who worked for a practice that insisted on $0.25 PER PAGE fee for records. This was even for sending those records directly to his new physicians [sic] office for continuity of care.
>
> I flat out refused to pay and wound up only getting his last set of labs sent (without charge). But honestly, I think that part of HIPPA [sic] is broken and needs to be fixed. (Stitch, April 23, 2010)

The caveats on health information privacy, the concealment of records by hospitals and the high costs demanded for medical data are also issues pertaining the ownership of the medicalised body (and what it produces during the process). While health information is important for medical treatment or to doctors for billing purposes, or to third persons in case of communicable diseases, making this subject to regulation brings up the much debated issue of the body-as-property. Health data can comprise various physical and non-material entities: both medical records containing information, and biological samples could be considered health data. Here one recalls the famous John Moore legal case of the 1980s in which Moore sued the doctor who isolated a cell line from his lymphocytes. While Moore's case was turned down, several states in the US do allot individuals the right to property of genetic material as well as reproductive material. HIPAA is a federal privacy rule, and while it gives patients access to and control over their data, they do not guarantee full control of ownership that property laws offer due, to its many exceptions and clauses. "Gimme my Damn data!" soon became DaM data, where DaM, meaning 'Data about Me' seems thus to ask if the definition of the human extends to data produced about the human, and if so, whether the informatic extension of the body should be a paid commodity to the one who owns it.

Dave's various means of talking about policy involve condensing the law for easier understanding, mediating personal encounters with the law by other patients, representing the patient in policy meetings, drawing examples from popular media to better understand the law etc. Individuals and groups indulge in sense making accounts that help them understand and counter health policy. His blog does not only have an impact upon the public's understanding of the law but also identifies the social and legal issues that arise from it. It creates a therapeutic citizenship where the stakeholders have direct access to policy decisions

through Dave's presence in policy meetings as a patient, and by listing therapeutic options and ethical claims that other patients like him have.

4. **Mediation and Process**

Some of the illness narratives studied in previous chapters could be considered transmedial, serving as autobiographical texts by the same person: Kalanithi's popular memoir was preceded by two moving essays called "Before I Go" (2015, Stanford Medicine) and "How Long Have I Got Left" (2014, opinion piece for *The New York Times*) which talk about time and mortality, apart from a couple of interviews on palliative care and on being a doctor-turned-patient; Engelberg's graphic memoir could be read in tandem with the verbal, online diary (https://miriamengelberg.livejournal.com/) she maintained until her death; Brian Fies's *MC* was first published as a webcomic, and could be understood better through the 'annotations' on his blog "The Fies Files" (http://brianfies.blogspot.com/) and similarly Gubar's memoir could be read alongside the ongoing series she writes for the *New York Times* called "Living With Cancer". Besides being paratexts that serve an annotative purpose to the main text, it goes without saying that the internet establishes communication between the author and an imagined community, author websites doubling as feedback and publicity channels (El Rafaie 189 -90). These 'texts' would demand a mode of reading that takes into account the various modes and media that are utilized, demonstrating how newer modes of narrative are being utilized to construct illness 'storyworlds'. The printed texts also give us a glimpse of their ill subjects possessing cyborged identities within the book itself, and contain instances of transmedial worlds where the narrator's story is taken forward by another's. For instance, Stan Mack draws Janet as often sitting by herself with her laptop (52, 62, 64, 69 etc). He speaks particularly of how she regularly e-mailed Kathryn, a member of her writer's group who also had cancer. In her communication with Kathryn, she often "revealed details she didn't always share with [him]" (51). Mack is performing a double function here – while

narrating his caregiving journey with Janet, he is also introducing to us a separate diegetic layer by making us privy to smaller autobiographical acts that Janet herself is a part of. The computer serves as a prosthetic memory device for Jane, and by extension to Mack, who reveals at the beginning of the memoir that he would be using various voices to piece together his narrative: Janet's, from her letters and emails; the recollections of friends, from their witness accounts; and those from cartoon strips he published about Janet's illness. Mack even makes us privy to the reactions he receives from readers in response to his brazen rendering of Janet's illness experience in a comic strip for *The New York Times*: "It drew immediate and mostly furious response. Apparently, people sitting down to their Sunday coffee, bagel, and paper did not appreciate being hit with a comic strip about cancer and bowel movements" (137). This is followed by snippets of these responses in a drawing of Mack looking through letters. *JM* is an example of collaborative writing where the process of mediation occurs on two fronts: mediation by memory, and mediation by the process of recording and inscribing this material. These are transmedial life narratives (Janet's story through memory and memory devices) and instances of community formation across different media (Janet's interaction with her support group over email, readers' interaction with Mack through letters) revealed to us within the scope of the material book.

Materiality can be considered a signifier of authenticity, as we have seen in several graphic memoirs and digital narratives such as *bloodandbones*. Nancy Miller's *My Metastatic Life* is also an example of this. Narratives such as Corby's and Miller's, in which the narrative interface plays an important part in shaping the autobiographical self, urge one to examine them as both texts and artifacts. What distinguishes these from the other digital narratives we are studying is that they function as online diaries. In the light of the emergence of more participatory media, the format of the online diary where one might log their lives

regularly has diminished. However, Miller and Corby make this logging of their life unique through the creative use of interface and organization (see Figure 18).

Online diaries today that combine various multimedia forms lend themselves to comparison

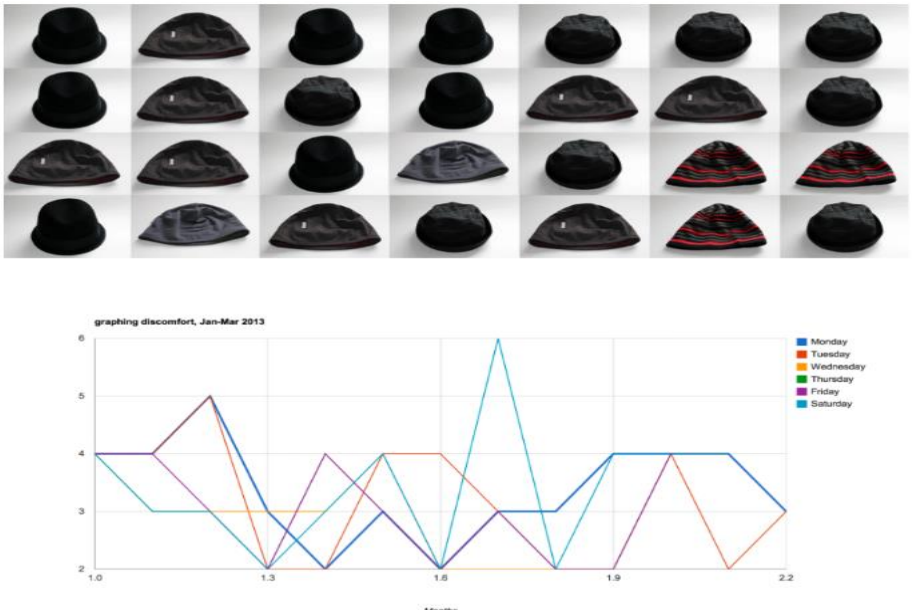

Figure 10 Interface as Database: Screenshot from bloodandbones.org

with other kinds of digital narratives: with performance, for example, if they include videos (like ePatient Dave), or with interactive fiction, considering its use of hyperlinks and handing over of agency to the reader to construct their own reading path. A "structural reading" of a diary-blog may encompass, according to Viviane Serfaty (2004), a study of *accumulation*, which is the collection of media material or data to build a persona; *open* endedness, which distinguishes the blog from a printed memoir as is a result of its episodic nature; a *double self-reflexivity* that addresses both the affordances of internet writing and the motivations of the writer; and co-production, which enables audience response to what is essentially a project of the self. The layout of the blogs is as important as the narratives themselves. They constitute the 'landscape' of the narrative, and it has been argued that the landscape is "a discursive construction", forming a readable text (Abercrombie and Longhurst, 78). The

visual grammar of Corby's blog is thus very scientific: he uses tables, graphs, and pie charts to consolidate his data: his blog *looks* like a database as well.

As Gunther Kress has argued, mode (be it font, colour or layout) establishes the stance of the author, both socially and formally (2010). Corby's layout forces one to adopt the reading pattern that one uses to read a table. We look both horizontally and vertically, and the lack of linear narrative throws us off, just as reams of illness data befuddles a patient. Thereby Corby takes a step back and explains his visualizations at times, tracking his progress through them. The lay public would most often find it tedious to decipher these pie-charts and graphs quickly and easily. Moreover, an over emphasis on one moment always runs the risk of not accounting for other elements in the data ecology. By explaining the transition between these scientific images, Corby adopts the method of iconophilia, which focuses on "the movement, the passage, the transition, from one form of image to the other" rather than the presences or absences within one visual itself (Latour 421). The changing, ill body is embodied via various modes and Corby, by explaining the movement between these mediations trains the audience towards a certain kind of scientific observation that relies not on one frozen image but is dynamic. Clearly, Corby's foregrounding of various mediations (such as health and army indexes, drawings, data from health banks, pictures of pills and hats, computer-generated charts) etc using affective terminology adds some sort of aesthetic pleasure to the reading of scientific data forms. This renders it both constructivist and realist. Corby's work employs a method of visualization that is scientific and aesthetic, presenting and re-presenting data.

Miller establishes her blog as strongly feminist and asserts her writer-self over her sick self. The project "My Multifocal Life" is only a part of her website, and most of it is taken up by literary musings. As Madeleine Sorapure says, "the images, visual presentation, organization, and navigation of the site should convey information about the author in a

manner that is consistent with the writing at the site" (5). Miller's website is a composite creation, much like the ill person's body is, and interestingly like a form many of her renderings take – the collage[22]. The collage, drawing from etymological roots in French meaning "gluing" or "pasting" ("collage, n." *OED Online*) again mirrors how the body is inscribed upon. Consider for instance two of Miller's collages: "A robot resects my right lung!" (2017), and "Last encounter with the Robot" (2018) to show how they put the composite nature of illness on display. The collages impress viscerally upon the reader the juxtaposition of steely technology and organic skin, both in the image they take and through the process. "A robot resects my right lung!" shows Miller on a gurney, the only visible parts of her body being her face and part of her abdomen. Over this the image of a surgical robot has been photoshopped as performing the surgery on her body. In continuation to this is another collage "Last encounter with the robot" which focuses on Miller's body. In a cut-out of the outline of her body, Miller pastes the anatomical image of lungs, with parts labelled in print as they would be in a biology textbook. However, the space that the left lung ought to occupy is empty, and the image of this lung (with labelled parts) appears outside the drawing. One cannot miss how the heart Miller draws in between the pasted image of the lungs is not anatomical but rather the popular rendition of a heart, immediately imposing the subjective over the scientific. The collage is followed by the caption, "**Since I'm not Pope Francis**, what will it mean for me to live with 2/5ths of my lung capacity gone, thanks to my last encounter with the robot (May 2018): cut up and cut out" (27 May 2018, emphasis in original). The last few words – cut up and cut out – are evocative of the process of creating the collage itself, and of affect, connecting self-reflexivity, the creative process and

[22] Graphic somatographies have adopted the collage as a means of self-expression in recent times. Dana Walrath's *Aliceheimer's,* a chronicling of her journey being caregiver to her Alzheimer's-diagnosed mother is a good example of this. It adopts the format of the journal for therapeutic means and uses the collage as its preferred mode. Reviewers have hailed it also for its role in arts education (Smith 2017).

materiality to embodiment, feeling distressed (to be *cut up*) and creating a sense of the multiplicity of selves.

We already considered in the previous chapter, how, looking at the reproduced photographs in *MC* alongside the actual photos in *The Fies Files* annotations makes the comic a complex, palimpsestuous rendering of memory. Speaking along similar terms again, how does knowledge of the process change the process of interpretation? Fies explains the complicated process by which he draws the image of Mom drowning in a sea of words, evoking the perfect metaphor of the ill person drowning in institution-driven medical terminology:

> Looking at this page today raises a couple of craft notes. First, I see I used the typeface "Comic Sans" for the words. Sorry about that. Back when I made this page I don't think it had acquired its infamous disrepute.
>
> Second, I wasn't yet comfortable with digital art tools. Pasting those words into the background behind my hand-drawn figures would've been a 10-second cinch in Photoshop. Instead, I printed out the words on paper, cut out the shapes of the figures with an Xacto knife, and rubber-cemented them to the original art! It looks OK in print but the original is a gluey mess. What a maroon! (Fies, 1 June 2015)

In these above examples of collage and process co-existing, the representations exist in a tripartite manner: there exists the knowledge (in the collages), the known (the illness that is represented) and the knower (the artist him/herself). However, in the very manner and matter that they represent, the collages question representationalism itself. Miller and Fies both acknowledge non-human agency in their craft notes. Miller's collage and caption acknowledge the role of robot and photoshop in cutting up and cutting out the body (human and text), the agency that even font has within text is pointed out by Fies. These are boundary

breaking practices that Miller and Fies use to embody the sick body. By admitting process within representation, these narratives lean from representation towards performativity, if the latter can be used to distinguish between the simple acts of saying and doing. Consider the landscape – keeping in mind how we have already drawn attention to Abercrombie's definition of it as a discursive construction – of Miller's blog as she posts about her lung resection (27 May 2018. See Figure 19). Benjamin's aura remains intact through Miller's hand drawn renditions of herself in her watercolour avatar. The materializing that occurs through making a *mark* on the page gives an event, according to Hilary Chute, "space and substance, gives it a corporeality, a physical shape— like a suit, perhaps, for an *absent* body" (2016, 27, emphasis mine). The presence of the ill body where biomedicine fails to account for it or accurately represent its voice is ensured by its materializing through the mark. Digital mediation is acknowledged specifically in the photoshop mentions and unconsciously in using the medium itself.

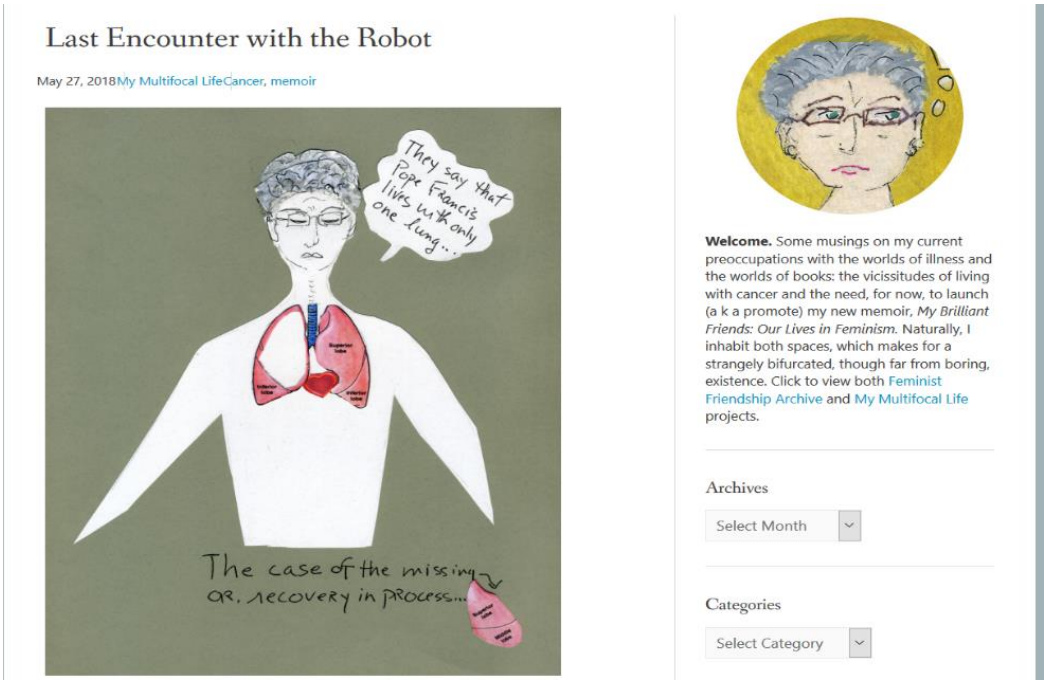

Figure 19 'Marking' multiple textual selves through collage in Nancy Miller's My Multifocal Life (May 27, 2018)

Even while displaying one post, the landscape is constantly urging the reader to pay attention to others, and the constant presence of her bio on the sidebar asserts her multiple

interests and bifurcated identity on every updated post. Elsewhere, Miller speaks about the intersectionality of the autobiography, critic and the world, i.e. of autobiographical relationality (1994), and this vein of thought is performed on her blog. That is, even while mediating her illness, the medium is drawing attention to the mediation itself. The writer is thus *doing* illness, and the blog becomes an autobiographical act, distinguishing itself from the printed book by promising some kind of seriality[23]. Meaning is produced, in narratives such as Miller's and Corby's, as Karen Barad suggests in her theory of agential realism, by "specific material (re)configurings of the world" (819). As with the described scenes from *Janet and* Me, the internet and the devices that allow the ill to access their community online and seek support and care become prosthetic devices they depend on. The decentered human and her/his symbiotic relationship with technology to perform identity makes the illness blog/ personal website a posthumanist space.

5. Transmedial[24] Autobiologies and Identity Assemblages

In this section, I argue first that new media narratives of life writing – and specifically illnesses – contain or are autobiologies, the modalities of which situate the illness communities formed in a therapeutic citizenship. I then argue that autobiologies are inscribed in assemblages of identity, where distributed agency is an important characteristic. In an age where lived experience is constantly being logged online through social networks like Facebook or Twitter, the formation of networks online to discuss one's illness is an emerging means of e-healthcare services. Anna Harris calls the genre of narratives of one's biological

[23] Miller's is one of the two cancer narratives (along with Gubar's ongoing series in the *NYT* called *Living With Cancer*) studied in this dissertation that are ongoing narratives and not retrospective chronicles of illness. While Gubar has a book on her ovarian cancer and the blog is more informational than personal, Miller's blog (at the time of writing this) is our only way to trace the trajectory of her illness.

[24] One way of looking at the word "transmedia" within the context of these illness storyworlds is through the word media itself, standing for both materiality and mediation. Thus, the ill body interacts with different material media through the illness experience: diagnostic technology, tracking devices, blogging interface/screen etc. (which do not interact with each other but add to the illness narrative) and then the dissemination of the illness narrative is through different media such as books, blogs, photographs.

state, published online, autobiologies, "the study of, and story about, one's own organism." Autobiologies are narratives that describe oneself at the molecular level, and in describing oneself as such, "they document a sense of self making through forms of biological practice and scientific experimentation" (62). While autobiologies represent biomedical culture since they are built around corporeality and symptoms, their existence in online networked communities like support groups, makes them representative of a digitally informed biomedical culture – a community of patients and caregivers who are relying on the internet not only for support and a sense of collective identity but also for digital literacy about illnesses that is increasingly patient generated.

The digital narratives studied are or contain autobiologies. An important feature is that healthcare occurs outside the clinic: the data monitoring or data interpreting devices are not institutionally managed or prescribed, but used as technologies of self-care. On Corby's website, the mood indicator and wellness data are sourced from organizations such as the WHO; Dave discovers his cancer trial based on a suggestion in a patient group; funds are raised for Sloan Kettering's research through an audience mediated by HONY. The second feature is that not all storytellers engaging with healthcare technologies are patients, and not all narrating selves are ill selves, though some are, and this defies the classical narrative structure of a pathography as outlined by Frank and others. For instance, HONY is narrated as an ethnographic photo project by Brandon Stanton, and Dave writes as a "former patient". Next, while they occasionally venture into posts about other cancer patients and cancer projects, the sites are focused primarily on the self. In fact, this could be a defining feature of these multimodal narratives – the narratives make use of transmedia to tell a personal story about the self (or stories about selves) to influence community research or activism. Finally, the illness storyworld is constructed across digital media – and this leads to the formation of community, though not necessarily communication with each other. An example would be

how #GimmeMyData or #FHIR are social movements that build a community, not necessarily around Dave's story, but about data rights advocacy; Corby sources his patient data from a database online where his hospital uploads his data and from open sources like the WHO website, portals that other patients also engage with; HONY's fundraising community works based on people's engagement with Facebook posts, not communication between the sick, Miller's blog is a collection of her reviews and thoughts about feminism.

These common identities are forged through indexing devices like hashtags. For instance, GimmeMyData is not just a means for readers and participants to categorize their own posts around the movement, but also an utterance to construct an interpretative frame. These phrases become, as Bonilla and Rosa term in their analysis of hashtag ethnography, "mediatized spaces" (6) Their example is also worth mentioning: following a specific call number in a library will lead you to a shelf full of related books. Search engines or search requests within applications (like Facebook) will similarly direct people to a myriad of posts about the catchphrase – "GimmeMyData" in this case. A valuable tangent here would be to look at indexing systems within the blogs themselves that enable the diffuse audience to split into ad-hoc publics. As has already been discussed, not all blogs are purely informational or personal; they are a combination of both. Thus, someone looking only for book reviews on Nancy Miller's blog, affect data on Corby's data documentary or ePatient Dave's posts about FHIR can easily do so with the help of indexing systems like 'categories' or 'tags' within the websites. The affordances of these mediatized spaces bear an agency of their own.

These are all important characteristics of autobiologies, as Anna Harris et al have suggested (2014, 2015). She says,

> Self-tracking devices producing personalised data are framed as giving us powerful insight into our true selves, as well as being a means via "feedback loops" of altering and optimising those selves. It is possible to create and inhabit an ongoing

> autobiology, narrating every daily ebb and flow, peak and trough, of our biological being. (78-79, 2015)

There is thus an everydayness in autobiologies, which makes them apt studies of the lived experience of illness. The autobiology is a contemporary method of inhabiting the 'reflexive project of the self' that Giddens talks about, where individuals are constantly writing and re-writing their own biographies to produce a sense of self. The chronological ordering of these self-narratives engenders the patient in shaping her self-identity by means of exercising control over her body. These narratives contain multiple selves that are remixed and repurposed. Situated in a culture of self-health and therapeutic citizenships, these selves mark a combination of care, control, will-power and surveillance. The combination of tracking the hospital's health data, along with the patient's own regimes towards good health in the form of graphs, lists and diaries, situates the cancer patient's life in a project of self-health.

Creative narratives such as Corby's data documentary or Miller's multimodal blog construct an imagined audience, i.e. patients present themselves as objects to be observed, thereby merging the borders between the subject and object of these narratives. The narrators are thus objects of both sousveillance and surveillance. The surveillance is an indicator of community engagement. These are diffused audiences. A diffused audience, according to Abercrombie and Longhurst (1998), is characterised by the breakdown of barriers between art and the everyday that arises out performative spectacles. Being an audience is no longer an exceptional event but happens all the time, since the media becomes constitutive of everyday life and the aesthetization of the everyday plays a part in this as well. While these digital narratives embedded in growing networks are examples of how diffused the internet-drenched audiences of present times are, Engelberg provides a commentary of this in *CMMSP* as well as she looks at life as a movie and "imagine[s] cameras panning over [her]", emphasizing that the ill person is a spectacle who is performing her illness all the time. This

performance is so entrenched into everyday life, more so through social media, that it becomes an invisible act that is both personal and public.

For instance, a reader responds on Corby's blogpost on hat data:

> Love the hats! I might have to follow suit and create my own hat, and scarf, exhibition. The joys of no/little hair!
>
> Mine used to be long and curly so I couldn't wear hats as they would just totally flatten my hair. Thanks for the inspiration. ("Kasa Gallery Istanbul, Body of Evidence Exhibition Documentation," March 2013)

There is a self-fashioning that occurs here, where the community of patients is learning from the changing, codified, affective states of Corby's ill body on his blog, and comparing their lifestyle with them. That illness can have an everyday, sartorial dimension is especially true for treatment regimes used on cancer patients. A memoir such as Lucy Grealy's *Autobiography of a Face* is an example of surgery that can disrupt and then re-write one's life story. Among the memoirs studied in previous chapters, *CV* stands out for the importance the narrator, a fashionista, gives to appearance. These are instances where the aesthetic presentation of the self can hold value for the reading community. Martha Stoddard Holmes, in her commentary on *CV* for the LitMed database, deems its allusions to popular culture and fashion especially pertinent to the cancer education of young women, who may find learning about and confronting the harsh realities of cancer relatable "if they can imagine the illness as something experienced by a hip woman with really great shoes" ("Cancer Vixen", 2008).

While these methods of self-presentation give the patient a sense of autonomy and control over a disease that dehumanizes and strips a patient of their personhood, I argue that in several cases, this reparative agency is one that is already entrenched in an ethics of failure. These narratives, by acknowledging that even while being the subject of the regimes, patients are the objects of various other agencies, not only situate the cancer patient in an assemblage

of distributed agencies, but also always foreground that there is no complete mastery over the disease. An example would be that once the patient begins to use a health-tracking device she is the object of what Katherine Hayles calls the technological will. Drawing from Leigh Gilmore's study of chronic pain memoirs, I argue that this is thus an agency *without mastery* that is embodied and exercised through narrating illness. These narratives, in Gilmore's words, risk "sacrificing the consolations of humanistic narratives that hold out hope for control and transcendence in the face of what is truly feared: the dissolution of self, the reminder of decay and death, a dependence on others through the loss of work, the financial stress of hospitalization and rehabilitation, and reminder of body as matter" (91). It follows that not all illness narratives would contain such an agency, but chronic illnesses like cancer demand a recognition of the human as more than a subject with bodily autonomy and point to the persistent agency of the non-human in forms such as the tumour, drugs or the presence of pain as a part of lived experience. Fear itself becomes an actant. It is worth repeating the paranoid statement made by a doctor in the HONY series, "Twelve thousand kids per year get cancer in the United States. But the extraordinary thing isn't that cancer happens. The extraordinary thing is that cancer doesn't happen more often." The anticipation of failure and uncertainty is an integral part of these narratives. Both Nancy Miller and Susan Gubar point to this failure in their blogs, and the importance of countering triumphalist narratives that institutions like the pharma industry proliferate. Miller writes,

> Last year, a friend began treatment for lung cancer with my oncologist, on my recommendation. She received standard chemotherapy, as I had. Then immunotherapy. I thought she was lucky to benefit from Opdivo. Both therapies failed. This brilliant, courageous woman was then given 6 months to live; she died within 6 weeks. Where is her story? (10 August 2016)

Miller's examination of how drug companies advertise clinical trials that do not work as proclaimed examines the capitalist agency of pharma companies. Corby's narrative similarly accounts for everyday expenses he incurs on his drugs. We recount Bennett's formulation of an assemblage of vibrant materiality "that runs alongside and inside humans to see how analyses of political events might change if we gave the force of things more due" (viii). Thereby these patients pay attention to various other agencies that influence their own, concentrating on the operations of drug trials and hence pharma companies, the beureaucratic mundanity of insurance forms, the flow of pills inside their body, the mechanics of health tracking software. ePatient Dave's advocacy for making data records accessible foreshadows the larger implications of laws like HIPAA. These various aspects that together constitute an autobiology, or these various actants, as Latour describes in his actor network theory, contain agencies of their own, which the autobiologies reveal in the narratives. In her essay on inscribed identities (2019), Sidonie Smith lists out various autobiographical agencies that are inscribed in a narrative: the multiple narrating 'I's; agencies of remembering : biological, in the form of synapses, psychic processes, cultures of remembering such as storytelling processes, memory professionals; agencies of production and circulation – writers, publishers, marketers etc; the agencies of the media of autobiographical inscription; formal agencies and agencies of accessibility; and finally agencies of reception, interpretation and afterlives ("Autobiographical Inscription and the Identity Assemblage"). Clearly the assemblage here is built along the three modes Deleuze and Guattari proposed in their explication of the concept of the assemblage in *One Thousand Plateaus*: semiotic, material and social. These agencies are also historically situated in the cultural advancements and laws of the land, making them important elements in the formation of the performative and historically shaped identities in autobiographical assemblages. For instance, biosocialities that are formed through narratives exercise a reparative agency. Their interaction with

biotechnology and the interpreting agency of the technology is a cognitive-technological agency.

These autobiologies are an emerging genre of narrative in a society that engages keenly with technology. It is worth mentioning here that in these autobiologies, the "human" remains important for political and ethical reasons. These narratives indicate not just the shaping and emergence of various subjectivities of the ill, but question and extend the boundaries of personhood, thereby offering a critique of the humanist conception of illness.

6. Conclusion

What *is* graphic medicine?

When Emily Waples titles her article on the graphic illness narrative, "Avatars, illness and Authority" (2014), one is struck by how we unconsciously impose the virtuality we see on screen onto the page. An "avatar", usually taken to signify one's on-screen persona, i.e. a cyborged identity, is not very different from a caricaturized self that speaks through speech balloons in a comic. The debate Waples runs in her introduction is also pertinent: are there ethics to making your ill life public? She argues that, while "[i]nviting audiences into the intimate spaces of illness, auto/pathographic narratives implicate the reader as a witness to the often uncomfortable vicissitudes of embodied experience" (156). There is also the proviso of privacy to deal with. A spate of debates has arisen in recent times about whether such "live" updates about one's illness contribute to the death of privacy or the proliferation of "affect-bites" in the media. For instance, Brian Fies chose to preserve the anonymity of his family by giving them generic monikers such as Mom, Kid Sis, Nurse Sis etc. Years after his book was published, when the strips went online again on gocomics.com as episodic webcomics, people wrote to him as if the narrative was unfolding in real time. Fies does not correct them – keeping both privacy and self-expression intact. These are avatars too, bringing one back to the reading of digital monikers into printed texts. Some of the narratives

studied clearly announce their 'graphic' nature before proceeding. Corby for instance, says on the page describing his project: "In this work the arrangements of data, number, image and object develops a deliberatively terse visual and informational grammar that seeks to capture both the bureaucratic mundanity of coping with serious illness and the *excess of feeling such situations produce*" ('About', emphasis mine). Dave is more forthright about the fact that this excess might not appeal to the readers. "Spoiler Alert", he says, "this stuff is biological and might seem gross" (1 April 2009). Contemporary illness writing, as has been emphasized more than once in this chapter, is clearly composed of more than writing merely in the conventional sense. It is an assemblage of several modes. The *graphic* nature could be a result of the circulation and reception, the use of the startling image, or the performance of an excess of feelings.

The third wave of autobiography criticism is motivated by an emphasis on *graphia,* or "the careful teasing out of warring forces of signification within the text itself" (Johnson 3). Smith and Watson narrow down the modalities of third wave life writing to performativity, positionality and heteroglossic dialogism. These modalities are employed to a greater degree in discursive practises that go beyond narrative or *telling*, and form the prime characteristics of digital media and autographics, both contemporary forms of life writing whose primary affordances arise out of their multimodal and intermedial nature.

To elaborate on this, let us consider the few but important similarities between the digital project *bloodandbones.org* and *Cancer Vixen.* The representation of the material conditions of illness is a stark similarity. Graphic medicine is known for its intermedial nature – the presence of intertexts in various forms, such as newspaper clippings, photographs, portraits etc. – and so are websites, to build on the likeliness between the two media. Where Marchetto uses the affordances of the comic form to represent her syringes in their actual size and shape, Corby puts up photographs of the hats he wears or watercolour

manifestations of his moods. In fact, Corby's project regularly travels around the world, which means that the physical hats and pills that are recorded on his websites are displayed at exhibition sites like museums. Both Corby and Acocella indulge in the visualization of science. These similarities encourage the argument that these new narratives of illnesses can also be classified into the category of the graphic somatography. We reiterate Couser's insistence on the recognition of corporeality,

> If the great advantage of the graphic memoir of illness and disability is that it features the body in the text, for greatest effectiveness—and affectiveness—the body ought to be recognizable as a thing of flesh, blood, and bone, a truly *corporeal* body. Presence of the body in whatever form appears to be a major qualifier for the same. (2018)

We must add to Couser's insistence on the presence of a corporeal body – and hence a more material representation – in a graphic somatography, the ability to depict the same corporeal body as morphing to represent changing states of illnesses. While the time-space sequencing of comics is a ready reckoner to understanding these changes, the episodic form that digital journaling takes also makes the changing body visible via its multimodal nature.[25]

The suggestion is that the term "graphic medicine" be no longer confined to the comics format, and that *graphic* also be considered in its connotation of the excessive. Multimodal data narratives with episodic narrative patterns like Corby's have more in common with graphic novels than meets the eye, and this should serve as impetus to explore porous generic differences. With digital narratives taking on the role of testimonies, and the definition of "narrative" itself getting more amorphous by the day, it is time to rethink what

[25] This line of argument for generic boundary bending can have several peripherals. One could also think of the animated film on the same colinear as the comic: *Egg* (2018), a 2D animated film of 12 minutes by Martina Scarpelli about her journey with anorexia falls neatly into the parameters of *graphic* life writing about illness.

Charon's 'Narrative Medicine' comprises as well. Narrative medicine must expand to include electronic health records, patient apps and online patient narratives.

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Chapter 5

Conclusion

This conclusion to my study of personal narratives of cancer across media first contextualises the cancer narratives in the present moment, that is the Covidian age, before tracing the major arguments made in the thesis. The narratives of cancer patients whose writings were already considered in the body of the thesis are briefly examined as they describe their lives as bodies-at-risk.

1. The Covidian Pathography: Cancer, Coronavirus and Comorbidity

In 1999, Anne Hunsaker Hawkins used the term "ecopathographies" to denote personal experiences of illnesses that connect to larger cultural or environmental problems. This percolation of the environment into illness stories is seen in a few of the memoirs we have considered: *CV* for instance dedicates a splash page to cancer clusters that could have been caused by "toxic garbage", "jet fuel" containing benzene dumped into drinking water, "pesticides" and "radioactive dust" (36). In another part it talks of 9/11 and whether its aftermath could have had an impact on her lungs, since she was a reporter on site. Engelberg makes a similar allusion to 9/11 in *CMMSP* and wonders if it could have caused her cancer. Gubar in *DW* provides statistics and data about both pollutants that can lead to cancer and genetic predispositions that minority groups like the Jews carry. The narratives here thus simultaneously talk of two different illnesses: that of the body and that of the earth, but more importantly, how these illnesses are porous and affect each other.

A few of the narrators studied in the thesis have been writing about their life during the pandemic through various platforms. Nancy Miller, Tom Corby and Susan Gubar have all written blogposts about their cancer in the lockdown year, 2020-21. We will look briefly at these narratives to understand the lived experience of those that fall into the category of 'being at risk' to covid-19, owing to comorbidity.

In the narratives we have studied so far, cancer has often been accompanied by other afflictions. In *MC*, a full-page panel depicts her state of depression after a six-week course of chemotherapy and radiation (47), an event the author considers important enough to double as the cover page of the memoir. Almost all the narratives have sections on chemo induced fatigue and depression. While some, like Gubar, distinguish between chemo-induced depression and depressive disorders that they have faced at other points in their lives, some need to include medication to treat their comorbidities. E-Patient Dave's issue with Google Health occurs after the app misreads the symptoms of his anxiety medication. Others such as Miriam Engelberg and Marchetto describe complementary therapeutic practices like hypnotherapy and visualization to quell anxiety. *MC* dwells briefly on a family history of tuberculosis which might or might not have made their mother's lungs more vulnerable when lung cancer strikes. Years after she has "beat cancer", it is still the intake of steroids for her cancer that leads to her death. The conclusion seems to be that illness makes the body more vulnerable to other illnesses, and a weakened immune system ages quickly, sometimes even before the body has, and cannot fight as well as it could before.

Nancy Miller's blogpost, called "My Cancer during Lockdown" (May 21, 2020), is a composite post consisting of collage and text. In the collage, Miller presents a framed, portrait of herself, a line drawing of her face donning a mask. A striking feature in the collage is the image of her lungs drawn into her brain, created with a material that appears like black gauze. At the bottom of the portrait, the printed words "Your Lungs Are a Battlefield" act as a caption. As with most of her collages, the simplicity of her line drawing stands out in contrast to the material appendages of disease, which in this case is not just cancer, but also coronavirus and the anticipation of it. Miller draws her cancerous lungs on her brain, showing us that the cancer is now on her mind, a source of anxiety.

In the accompanying text, Miller explains how the category that she has occupied for 8 years, that of a cancer patient, has merged into the category of "elderly person with an underlying health condition". Her anxieties now extend from her scan-to-scan existence to becoming "a fatal statistic" owing to her geographical location – a Covid-19 epicentre, and her biological age. Interestingly, Miller has never brought up her age in any of her diary entries before, but there is now an acute awareness that age renders her more vulnerable to the virus. Miller's focus then turns to categorization and its objectives. While identifying oneself with a category (often one that is underrepresented or misrepresented) is a way of challenging universalising and dominant categories, Miller finds herself in the cohort of "elderly with underlying health issues", a group she wished she did not belong to. Miller's post thus describes the double vulnerability that comorbidities can introduce into the life of an elderly, sick person during a pandemic.

Susan Gubar, in her *NYT* series *Living With Cancer*, starts from categorization and moves on to rights and the social conditions that prevent the mobilization of the vulnerable body-at-risk during a pandemic. Gubar introduces a second pandemic into the mix in her blogpost titled "Those Who Can't March Can Still Make a Difference," that of systemic racism. Gubar divides her narrative into two concerns: the first, her visits to the hospital for unavoidable cancer treatment, and two, her wanting to be a part of ongoing public protests and her inability to do so.

In the first part, she outlines the biomedical concerns for a cancer patient during the pandemic. Gubar describes a visit to the hospital where she has to remove her mask for her temperature to be tested, and is aghast at the risk the healthcare worker is exposing herself to by testing hundreds of people who might be asymptomatic and yet may infect her. Gubar is herself in the cohort of cancer patients who are at risk but cannot avoid visiting the hospital: they are either participants in clinical trials that could prolong their lives or need to undergo

chemotherapy, both of which they cannot avoid. Supported by research she links the reader to, Gubar points to how infected cancer patients could die within a month of contracting the virus, and how several experimental clinical trials have been cancelled worldwide so as not to expose patients to the risk of exposure. Cancer patients do not just risk infection by visiting hospitals, but those in the later stages of cancer are also missing out on treatment options that could prolong their lives. The "being-at-risk" category not only makes the patient vulnerable but also decelerates treatment, making the cancer worse. While this is one of the outcomes, of worsened physical state of things, there is also the anxiety that comes with delayed scan reports and virtual consults, which cannot make up for "the reassurance of a physician's hands palpating the body, and her smile when she completes her examination", taking away whatever the patient has learnt about the *dispositif* of the clinic so far (as discussed in chapter 1). Placed in a new category, the cancer patient has to both recount and relearn the ways to cope with an immunocompromised system.

In the second part of her narrative, Gubar moves from the biomedical to the socio-political import of the coronavirus for cancer patients who also wish to identify as active citizens. Written during the Black Lives Matter movement, Gubar expresses the helplessness of cancer patients and others also vulnerable to the coronavirus to attend public demonstrations. The sick role (Parsons) identifies the sick person as an unproductive part of the society, a category which arises, as Gubar's narrative explains, more often because of the inability of the physical body to attune to a non-inclusive environment than the lack of willingness on the part of the patient. Gubar's desire to be part of the protest against police brutality is cut short by fears about her already compromised immune system. While the specific protest she plans to be a part of arranges for the immunocompromised to follow the protestors in cars, Gubar wonders about several smaller details:

> But would there be adequate parking for all the people who wanted to attend in cars? How could I in good faith encourage my 92-year-old husband to accompany me into what would undoubtedly be a congested area? Would he be safe staying home alone or anxious about my safety? And what if I had to leave the security of my car? Courage failed me. Cancer was turning me into a coward. (June 24, 2020)

Fear and shame turn out to be the dominant emotions Gubar is left with: the fear of infection and shame about missing the protest. Gubar decides to look for other ways for a cancer patient such as she, to contribute to the protests/movement against racism. She lists several volunteering organizations that help underrepresented minorities navigate clinical trials, assisting Black cancer patients and volunteering for screening in impoverished districts. While Gubar does not describe how ageing patients might physically volunteer for these activities – the same issues that hindered participation in protests could crop up during these activities as well – she nudges the reader in the direction of research that exposes stark inequalities in treatment of Black cancer patients. Gubar's narrative contributes to the dialogue of what makes a 'model' cancer-citizen.

If the previous article focused on the social and biomedical impact of corona, the affective results of which were fear and shame, Gubar next focuses on what the fear or shame cumulatively lead to: loneliness. Gubar argues that fear and shame for the disabled or sick elderly have existed before the advent of the virus. Fear or shame as a result of stigma result in the old isolating themselves and staying away from crowded spaces, affecting their ability to socialise. This isolation, when enforced, such as during the coronavirus can cause early-onset agoraphobia in the elderly. DSM-V describes agoraphobia as being fearful or anxious about being in public spaces or outside the home; the fear arises because they panic that they may not be able to escape from the situation (190).

Gubar's fear stems from her husband's stay in a hospital when he breaks his knee, and when due to the ongoing coronavirus, the hospital bans all visitors. Unable to see each other or extend "tactile" care to each other, the narrative points at the inadequate or only partially adequate connectivity that virtual media offers:

> I could see only his head — if he managed to hold the screen up properly — not his surroundings; I could hear his voice — not see his body. Tethered to our separate devices, we could express but not assuage the helplessness we felt at not being able to solace each other. (June 30, 2020)

That the elderly might also suffer from a technological handicap is an important factor. Gubar uses the word *tethered,* a word used more often to refer to tying up animals to prevent their mobility, but also in technology to refer to the process of connecting one's phone to the internet. Virtual connectivity does nothing to assuage the limbo that being bodies-at-risk places them in, tethering them to isolation instead. While all the memoirs we have studied so far have indicated that the ill need and appreciate the company of loved ones and a strong support group in close proximity when faced with the prospect of death, corona, ironically, makes this impossible and is a threat to the sick. A consequence of this is that the elderly do not just face the prospect of loneliness while self-isolating but also the very real fear of dying alone. It is this thought that echoes in Gubar's last sentence in the article, that away from her husband, she sits "with a bitter foretaste of bereavement in [her] mouth".

Across these three narratives by Nancy Miller and Susan Gubar, one identifies a few prominent themes. The first is that these narratives are built around the biologically determined categorization of the elderly sick person as the body-at-risk, and the sociopolitical language of vulnerability as being most pertinent to the elderly. The narratives are built via a comparison to other healthy people: the categorization occurs according to the language of the immune system, that is the biopolitics now depends on who has a stronger immune

system versus the other. For example, Gubar's concern with what she can to contribute to the BLM movement stems from seeing "her healthy friend Judith", and the "youthfulness of the organizers".

But in the case of cancer, the body-at-risk is already considered elderly. In Gubar's *DW*[26], we see how biologically, cancer accelerates bodily time for her, making her feel elderly:

> Although at sixty-three I have never experienced any serious illness or disability, overnight I become an old woman. Worse, I have become my mother with all of her ninety-three-year-old frailties . . . It is horrible since I had resented my mother's dependency. (64, 65)

Sociopolitically, ageism is a determining factor in the under-treatment of elderly cancer patients, where chronological age is considered a "proxy" for other comorbidities and frailty (Lawler 1). In her book-length studies of ageism in America (2011, 2017), Margaret Gullette asserts that dehumanization is an inevitable outcome when people question the value of the aged, providing other astonishing statistics about how undertreatment is a major cause of poor elderly health (4). The cancer patient at risk for corona finds themselves experiencing ageing on two levels: one, the aged immune system and the other, biological age. According to the UN Secretary-General's Policy Brief "The Impact of Covid-19 on Elderly Persons", elderly people over the age of 80 are likely to die five times more than the global average. Among the broader effects of the pandemic for the elderly, the report includes "health care denied for conditions unrelated to COVID-19; neglect and abuse in institutions and care

[26] In *Shame and the Aging Woman* (2016), Brooks Bouson places Gubar's memoir among writings by other sick women who speak of embodied shame, i.e, "shame about the visible signs of aging and the health and appearance of their bodies as they undergo the normal processes of bodily aging" (v) being accentuated by the state of being ill. However, Gubar's acute awareness of age is more visible in her narratives about coronavirus in her blog.

facilities; an increase in poverty and unemployment; the dramatic impact on well-being and mental health; and the trauma of stigma and discrimination" (2).

These inequities in healthcare manifest affectively in the narratives, which forms the second prominent theme. The narratives indicate a fear of mental health deteriorating, a fear of anxiety, depression and from Gubar's narrative, agoraphobia. These are comorbidities. A comorbidity could refer to any "distinct clinical entity that coexists with or occurs during the clinical course of another illness or condition" (Brown et al. 1). Chronic illnesses are often accompanied by other clinical conditions. For instance, every narrative studied has indicated the use of complementary healing techniques such as visualization therapy, hypnotherapy or meditation to quell anxiety.

Narrative typologies are already emerging out of the present pandemic situation. I propose that life writing by bodies-at-risk, as shown by these narratives by cancer patients, displays an acute consciousness of health disparities and consequently, registers the need for 'anticipatory care'. This consciousness – of the fragile and immobile self as a mere social observer and not participant, arises in comparison to those who are not immunocompromised. This anticipatory care, as Carol J. Adams anecdotally describes, is personal, in opposition to professional or collective care, and is learnt "in the work of it". Adams proposes that one must now reimagine our lives around the pandemic, "toward our own deaths, thinking ourselves toward a possible role of caregiver or care receiver" (April 5, 2020). This notion of anticipatory care is accentuated in an already ill person. Gubar's consciousness makes her aware of the plight of others around her: now that she has to protect herself, she thinks of the nurse exposed to several strangers every day. These narratives are thus firmly situated in the category of the porous ecopathography that we began with.

2. Summary, Scope and Limitations

In the thesis, I have read different illness narratives produced by the cancer patient, caregiver or a collaborative author for the ways in which the narratives make use of the medium to re/present their illness experience to challenge medical authority, reflect scientific culture and create communities. I read these narratives through various theoretical frameworks exploring the affordances of the genre, sociocultural studies of the body and embodied identities. The chapters trace the liminal spaces that the ill person occupies and which question conventional binaries: they are based around the borders of the extreme and the everyday, the visible and invisible, and the individual and community.

In Chapter 1, I traced a short history of the 'body' memoir and situated it within the memoir boom of the late twentieth and twenty first centuries. I made the argument that illness narratives are cultural phenomena that respond to scientific developments of the time. I thematically and theoretically contextualised this study of representations of cancer. The chapter also laid out the hypothesis and scope of my thesis.

In Chapter 2, I located the trauma of illness in the shared/ divided space between extremities and 'normalcy'. The chapter demonstrates that the narrators foreground the construction of the ill body in both material and abstract ways, and see the self as abject, monstrous and residing in the site of the illness. The concepts of the "foreigner" in the context of the biological and social signages of cancer were studied. The chapter identified the game metaphor as a motif to describe this liminal space between the extreme and the everyday. I argued that extremity manifests in bodily and domestic spaces, and in objects of mourning such as photographs and letters, rendering them uncanny. I then focused on the shifting temporalities experienced by the ill person and their use of fabula time and narrative time in the memoirs to indicate "cancer time". The chapter argued that the narrative

reconstruction of everyday spaces and actions to incorporate extremity helped the writer regain agency and a sense of identity.

Chapter 3 studied the patient's response to medical imaging, the body's mediation through new media and photography and the reproduction of these images in the memoirs. This 'technological terrain' was studied across texts. The chapter demonstrated that the graphic narrative conducts an informatization of the body by incorporating and writing (drawing) over scientific images. I proposed that the remediation involved in revising medical images and making them subjective is ekphrastic in nature. The chapter argued that since the process of remediation in the graphic pathography contains demonstrations of, and responses to the codified versions of the body, it could be classified as biomedia. Besides remediation, the chapter also delineated narrativized affective responses to medical imaging in the form of scanxiety and self-fashioning. I also argued that the incorporated photographs in the texts performed the double function of evincing the disruption caused by the disease and documenting a scientific culture in which the circulation of images is pivotal to meaning making.

In Chapter 4, I dealt with questions of community formation engendered by the multimodal affordances of digital media. Through a social semiotic approach, both the biosocial implications and the semiotic features of the narratives are studied. The chapter demonstrates that collaborative and transmedial storytelling involving both human and nonhuman actants can be used in collectivising projects that can be used to create empathetic communities and generate therapeutic capital, forming therapeutic citizenships. The chapter traced different kinds of therapeutic citizenships: ethnographic on the one hand, such as the Humans of New York series, rights-citizenships, such as ePatient Dave's blog, or everyday online journals such as Nancy Miller's *My Mutifocal Life* and Tom Corby's *bloodandbones* project. I also traced how the use of interface to shape the autobiographical self, renders these

narratives as both text and artefact. The narratives keenly acknowledge the presence of distributed agencies, especially that of the nonhuman to give 'the force of things' more due in the posthumanist space of the narrative.

Though this thesis focuses exclusively on contemporary prose, graphic and digital life-writing around and on cancer, these ways of seeing can be extended to the performance, circulation and reception of other illness narratives across media and a global network as well. Physician memoirs, institutional patient stories, such as those in the American Cancer Society's website or digital games such as *That Dragon, Cancer* for example have strong narrative structures that could be studied within a similar framework. Narratives of cancer, the 'emperor of all maladies,' become ur-texts in studying the ill person's interaction with science and the society at large, in locating the human in the 'technologised terrain' of medical advancements and last but not the least, in identifying the vulnerable group's efforts at claiming rights.

The narratives under study contain highly individualistic voices, although the blogs by Gubar and ePatient Dave and the collaborative webcomics by Mewhorter are exceptions. Most of these memoirs give us interesting ways to study unique experiences of cancer while universalising suffering and vulnerability: for instance, Kalanithi's memoir is a highly moving account of how literature, especially poetry, helps him traverse the shifting temporalities in a cancer patient's life, but does little to talk of voices outside this universal bubble that are less privileged. Through the feminist stance in her memoir, Gubar acknowledges her privilege as an academic and draws attention to data about vulnerable groups, and this is amplified in her monthly blog about living with cancer. One limitation of the narratives in this study thus is a lack of lived experience that speaks about racialised or class-based injustice, a theme that Audre Lorde's memoir, for example, spoke strongly of.

ePatient Dave and Mewhorter are able to be more inclusive in this sense, since their works are collaborative and constantly account for different voices.

To conclude, the focus of the study was to delineate narrativized common rites of passage that cancer patients experience and the aesthetics of representing these. The study has explored narrative, aesthetics and community by examining first the ill person's subjectivity as seen through their responses to a changing body and everyday spaces and time, through to a study of the mediation of the body through new media and finally describing the dynamics of community formation as engendered by the mediation. The thesis ends by positioning the illness narrative in the present moment, positing possibilities for a pathography that emphasises the porosity[27] between the environment and the body.

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[27] Susan Squier, in an essay titled "Scaling Graphic Medicine: The Porous Pathography, a New Kind of Illness Narrative" for the edited volume *Pathographics* (2020), situates the personal illness narrative on multiple scales to include multiple illness stories that are "co-ocurring within and around the human story". While Squier concentrates on graphic narratives about climate change and its ramifications on human health, her framework could as easily be used to study the illness stories during a pandemic.

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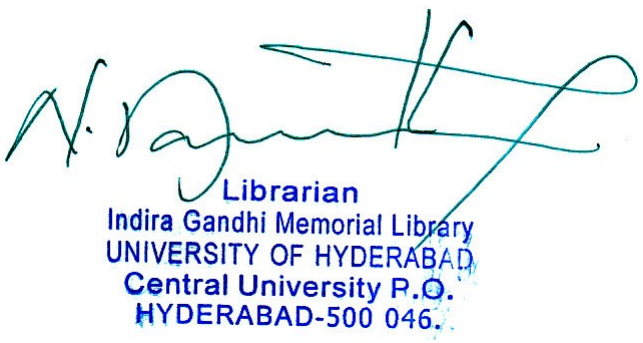
The Cancer Imaginary: Body, Community and Image in Life Writing

by Meenakshi Srihari



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Editorial

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Data Matters: The Informatized Body in Cancer Narratives

Meenakshi Srihari
University of Hyderabad, India

Abstract

The informatization of illness in the form of databases, scans, and reports results in the absence of affective data. The vulnerability caused due to illness leads to an *excess* of feelings that the scientific and often bureaucratic mundanity of medical records refuses to capture. How can the personal illness narrative supplement this absence of subjectivity in informatized medical representations bereft of affect? Reading the rendering of biomedical data in Tom Corby's digital data documentary *bloodandbones.org,* Marisa Acocella Marchetto's graphic somatography *Cancer Vixen*, and Brian Fies's graphic caregiving memoir *Mom's Cancer*, this essay argues that the ill person encounters data presented by the medical institution – made objective through the authority of science – and counters it through a textual refashioning of the self. I identify this palimpsestuous layering of affect as *ekphrastic* and study the formation of the cancer patient's narrative self via ekphrastic remediation.

Keywords: Affect, data, remediation, ekphrasis, graphic medicine

Introduction

> "Another part of me flew like a big bird to the ceiling of whatever place I was in, observing my actions and providing a running commentary, complete with suggestions of factors forgotten, new possibilities of movement, and ribald remarks."
>
> Audre Lorde in *Cancer Journals (*1997*,* p. 30*)*

Medical imaging has enabled the transformation of the invisible body into the visible. The mapping of the body, perhaps begun by De Vesalius's 1543 text *De Humanis Corpora Fabrica* through to the 'art' of dissection during the Enlightenment and the Foucauldian spatiotemporal disciplining of the body has followed different philosophical notions of the body. One specific notion that they lead to is that technologies – the word stems from *tekhne,* or art and craft – to map the body contributes to its informatization. The discovery of X-rays offered a mapping of the body different from the anatomical gaze. X-rays were built explicitly around decoding processes and filtering to help with specific diagnoses. This then led to the discovery of other imaging devices, such as CT (computerized tomography) scans, MRIs (Magnetic Resonance Imaging), and PET (Positron Emission Tomography) scans. Diagnostic technology, as part of a larger ecology including charts, databases and such records, takes part in informatization of the body, "with the opened body on the operating table, and the various TV monitors and biomonitoring equipment surrounding that body as its main tensive site" (Thacker, 1998).

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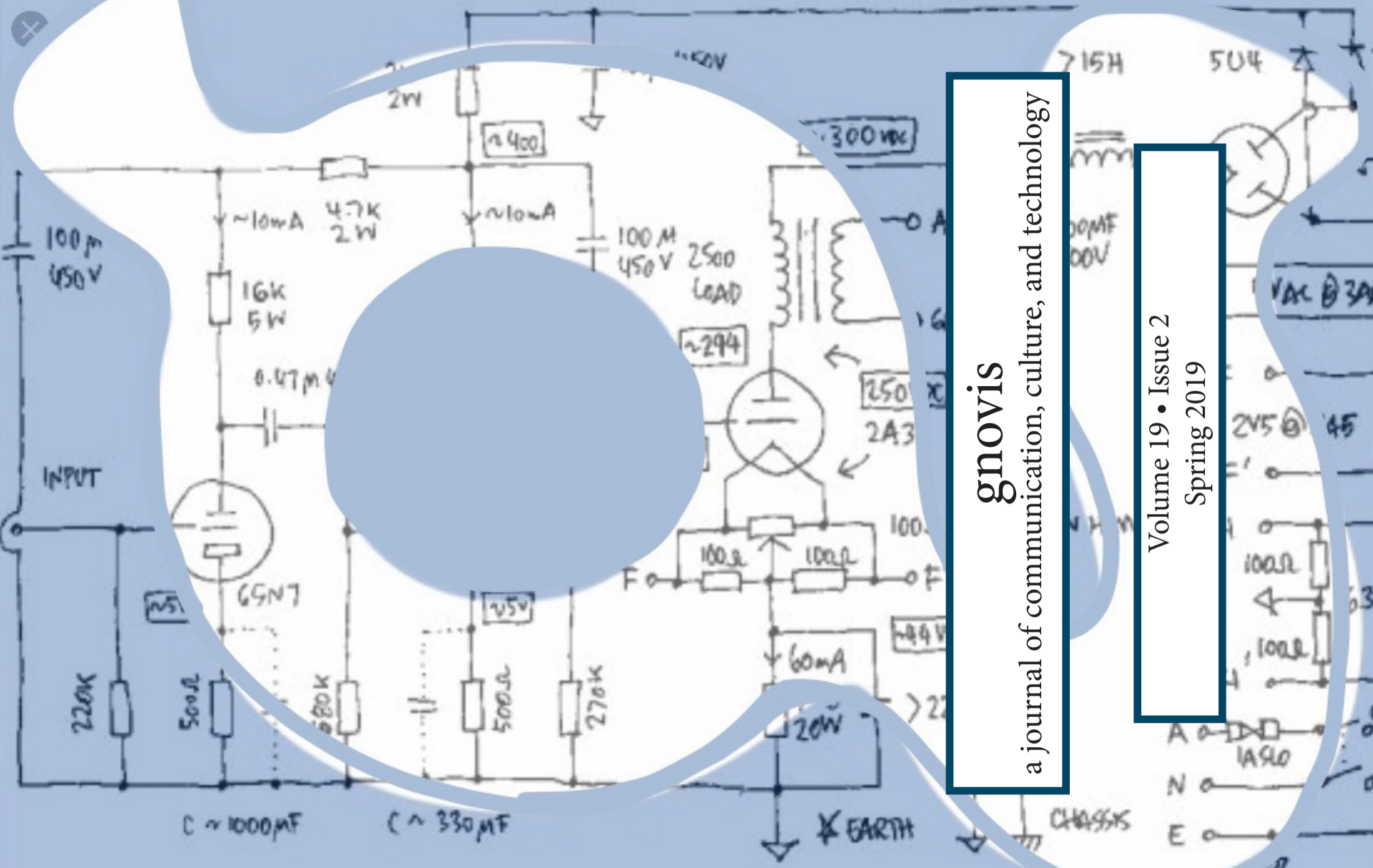

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Contents

CERTIFICATE *of* PARTICIPATION

THIS ACKNOWLEDGES THAT

Meenakshi Srihari

HAS SUCCESSFULLY COMPLETED THE

ALLIANCE SUMMER SCHOOL IN MEDICAL AND HEALTH HUMANITIES
Consortium of Humanities Centers and Institutes Health and Medical Humanities Network

JUNE 17-19,
2019

SIGNED, *Loren Wolfe, PhD*
CHCI Health and Medical Humanities Network
Columbia Global Centers | Paris

CHCI MEDICAL HUMANITIES

COLUMBIA GLOBAL CENTERS | PARIS

Madame Meenakshi Srihari, PhD Scholar
Department of English
University of Hyderabad

April 18, 2019

Dear Madame Srihari,

You are cordially invited to participate in a two day conference at Reid Hall, site of the Columbia Global Center | Paris, titled: CHCI Medical Humanities Network "Health Beyond Borders", as well as a three day summer school session following this conference.

Reid Hall is located at 4 rue de Chevreuse 75006 Paris, FRANCE.

The dates required for participation are June 14 – 19, 2019.

We do hope that you will be available to join us.

Sincerely,

Brunhilde Biebuyck, PhD
Administrative Director

Tel +33 1 43 20 33 07 Fax +33 1 43 20 52 96 paris.cgc@columbia.edu globalcenters.columbia.edu/paris

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CHCI Summer School Acceptance

Liz Bowen <elb2157@columbia.edu> Mon, Mar 4, 2019 at 8:29 PM
Cc: Arden Hegele <ardenhegele@gmail.com>, Loren Wolfe <lw2505@columbia.edu>

Hello,

We are delighted to accept your paper for the CHCI Health and Medical Humanities Network Summer School, to be held at Columbia Global Centers | Paris on June 17-19, 2019. Information about registration for the Summer School and Summer Institute is available at https://events.columbia.edu/go/CHCI. We are happy to provide a $100 discount code for registration for the Summer Institute (June 14-15) to Summer School participants (with code sumschpart). The deadline for registration is **May 15, 2019**.

Please contact Liz Bowen (elb2157@columbia.edu) with any questions.

All best,

--
Liz Bowen
Poet / author of Sugarblood (Metatron 2017)
Assistant editor, Synapsis: A Health Humanities Journal
Ph.D. candidate
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Balvant Parekh Centre for General Semantics and Other Human Sciences

IX Annual Seminar

The Enigma of Story: Lived Experience, Time and Narrative

(An International Event)

14-16 March 2018

Certificate of Participation

This is to certify that Meenakshi Srihari of Department of English, University of Hyderabad participated in the IX Annual Seminar organized by Balvant Parekh Centre for General Semantics and Other Human Sciences on the theme: "The Enigma of Story: Lived Experience, Time and Narrative" during 14-16 March 2018. This year, the event was organized as a seminar-workshop comprising lectures by the faculty, interactive sessions and activities. Craig Irvine and Maura Spiegel from the Program of Narrative Medicine at Columbia University, New York were the resource persons.

The participant made a presentation titled: "The (Bio) Social Network - Narrative, Trauma and the Digital"

Bini B.S.
(Convener of the Seminar)
Academic Fellow and Program Officer, Balvant Parekh Centre for General Semantics and Other Human Sciences, Baroda

University of Hyderabad

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EN801	Critical Approaches	4.00
EN802	Research Methods & Dissertation Writing	2.00
EN823	Ireland and British Literature: The Long Nineteenth Century	4.00
EN824	On Narrative	4.00
EN805	Language, Culture and Critical Theory	4.00

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7	17HEPH07	LALDUHTHLANA	EN812 PASS	EN813 PASS	0345				

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EN813	"Primary Texts: Readings"	2.00
EN814	Reading Fiction	4.00
EN815	James Joyee: A Bibliography	2.00
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