Slow Engagements: Patient's Perspective in Narratives of Chronic Illness

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Dedication

For my grandmother and mother

Abstract

This dissertation examines four chronic illnesses in narratives of personal experience with these illnesses and how they are represented in different forms of cultural production, i.e., novel, documentary, video film, and memoir. I argue that narrative attention to the experience of illnesses like PTSD, thalassemia, HIV, endometriosis speaks to a "social chronicity", which is a significant space of investigation for interdisciplinary fields of health studies and care work. The focus on the chronic is an effective mode to engage with illnesses and attendant transformations that are experienced over a long period of time and often on a collective scale among marginalized groups. Thus, the chronicity of an illness experience and their narratives unfold in relation to particular histories that are embodied, social, and transnational. These histories are important to be addressed in order to understand porous definitions of a "disease" and various contexts in which notions of "health" are cultivated. Borrowing from concepts in health humanities, medicine, and memory studies, I examine literary descriptions, visual images, and figurative language to suggest these patients' perspectives work towards performing an ethical sabotage of grounded understandings of health and care work. I call such processes in narratives "slow engagements."

Specifically, I examine the following texts: Hilary Mantel's *Giving Up the Ghost* (2003), Dorothy Allison *Bastard Out of Carolina* (1992), and Richard Fung's *Sea in the Blood* (2000). These texts are analyzed both in the light of the above mentioned particular health conditions but also how narratives seek to broaden medically legitimized definitions. The introduction reads current literature in the fields of medical and health humanities which has increasingly valued the role of narratives, and has suggested that medicine, too, as a field is deeply reliant on "interpretation" of a patient's medical condition (Herndl 1993). Utilizing this fundamental intersection between medicine and literature, the introduction focuses on how the contemporary turn in literary criticism towards negotiating the "materiality" of a phenomenon can be brought into conversation with narratives that are engaged in exploring the materiality of an illness experience through a close analysis of its social and political contexts. The following chapters read each of the texts with a close attention to how an experience of a chronic illness is discussed and the multiple narrative and stylistic lenses that are used to investigate the nature of that experience.

Abstract in German

Diese Dissertation untersucht vier chronische Krankheiten in Erzählungen, die persönliche Erfahrungen mit diesen Krankheiten zum Thema haben und ergründet, wie sie in verschiedenen Formen kultureller Produktion, d. H. im Roman, Dokumentarfilm, Videofilm und in Memoiren, dargestellt werden. Ich behaupte, dass die narrative Aufmerksamkeit bei dem Erleben von Krankheiten wie PTSD, Thalassämie, HIV und Endometriose für eine „soziale Chronizität" spricht, die ein bedeutender Untersuchungsraum für interdisziplinäre Bereiche der Gesundheitsforschung und der Versorgungsarbeit ist. Der Fokus auf chronische Erkrankungen ist ein wirksames Mittel, um mit Krankheiten und damit einhergehenden Transformationen umzugehen, die über einen langen Zeitraum hinweg und häufig auch auf kollektiver Ebene bei marginalisierten Gruppen auftreten. So entfaltet sich die Chronizität einer Krankheitserfahrung und die daraus hervorgehenden Erzählungen im Bezug auf bestimmte verkörperte, soziale und transnationale Geschichten sehr unterschiedlich. Es ist wichtig, sich mit diesen Geschichten zu befassen, um poröse Definitionen einer „Krankheit" und die verschiedenen Kontexte zu verstehen, in denen Vorstellungen von „Gesundheit" gepflegt werden. Ich entlehne dafür Konzepte aus verschiedenen Bereichen der Gesundheitswissenschaften, der Medizin und der Gedächtnisforschung und untersuche ausgewählte literarische Beschreibungen, visuelle Bilder und bildliche Sprache, um die Perspektiven dieser Patienten auf eine ethische Sabotage eines fundierten Verständnisses von Gesundheits- und Pflegearbeit hinzudeuten. Ich nenne solche Prozesse in Erzählungen "langsame Engagements".

Im Einzelnen untersuche ich Hilary Mantels **Giving Up the Ghost** (2003), Dorothy Allisons **Bastard Out of Carolina** (1992) und Richard Fungs **Sea in the Blood** (2000). Diese Texte werden sowohl im Lichte der oben genannten besonderen Gesundheitsbedingungen als auch im Hinblick darauf analysiert, wie die Erzählungen medizinisch legitimierte Definitionen erweitern wollen. In der Einleitung wird aktuelle Literatur aus den Bereichen Medizin und Gesundheitswissenschaften gelesen, in denen die Rolle von Erzählungen zunehmend gewürdigt wird, und es wird darauf hingewiesen, dass

auch die Medizin als Bereich stark von der „Interpretation“ des medizinischen Zustands eines Patienten abhängt (Herndl 1993). Anhand dieser fundamentalen Schnittstelle zwischen der Medizin und der Literatur wird in der Einleitung beleuchtet, wie die aktuelle Wende der Literaturkritik zur Aushandlung der „Materialität“ eines Phänomens mit Narrativen in ein Gespräch gebracht werden kann, die sich mit der Erforschung der Materialität einer Krankheitserfahrung und der Analyse seiner sozialen und politischen Kontexte auseinandersetzen. In den folgenden Kapiteln wird in jedem der Texte genau darauf eingegangen, wie das Erleben einer chronischen Krankheit erörtert wird und welche vielfältigen narrativen und stilistischen Mittel verwendet werden, um das Wesen dieser Erfahrung zu untersuchen.

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Sustainable Pain: Chronic Illness and the Politics of "Description" in Hilary Mantel's *Giving up the Ghost* (2003)

"A Talisman Against the Dark": Ashamed Subjectivity and Figurative Language in Dorothy Allison's *Bastard Out of Carolina* (1992)

Politicized Patients and the Dialectic of "Loss" in Richard Fung's *Sea in the Blood* (2000)

1.1 Introduction—Grieving Health and Care

On 27th June 2013, *Slate*, an online magazine on current affairs in the United States, published an article titled "I don't feel your pain: a failure of empathy perpetuates racial disparities"; in this article, the writer, a researcher in global health studies, makes an argument based on his study to understand what he calls "racial empathy gap" in the U.S. The interviewees were asked to describe their feelings from when they saw visuals of people from different racial and ethnic origin in pain, and they indicated how they related to other's pain depending on their racial and ethnic background. A white person's pain is taken more seriously, quickly heeded to by health professionals as the article goes on to suggest, whereas when it comes to an African American or a Hispanic person there is an implicit bias that ethnic minorities, particularly African Americans, can brook more pain than others. As Jason Silverstein's piece notes, the problem is about stereotypes and racial prejudice but it is also structural, so not only are health providers quicker in prescribing pain medication to white patients, drug stores in white communities are 52 times more likely to store opioids and pain medication than stores in non-white communities.[1] The following month, the National Public Radio (NPR) discussed the article with the writer under the title "Study: Whites Find

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[1] Discussing ways to "induce empathy to get people to care", Silverstein notes, "[s]ome of the problem is structural. We've also known for some time that pharmacies in nonwhite communities fail to adequately stock opioids. In a 2005 study, Michigan pharmacies in white communities were 52 times more likely to sufficiently stock opioids than in nonwhite communities. But this does not fully explain the problem. When pain medicine is available, minorities receive less of it. Medical personnel may care deeply about treating the pain of minorities. Even so, they might recognize less of it—and this may explain why the pain is so poorly treated." ("I don't feel your pain" [27 June 2013])

Also, see NPR's "Black Mothers Keep Dying After Giving Birth: Shalon Irving's Story Explains Why" (7 Dec 2017). Discussing the "racial disparity across incomes," Renee Montagne writes, "In recent years, as high rates of maternal mortality in the U.S. have alarmed researchers, one statistic has been especially concerning. According to the CDC, black mothers in the U.S. die at three to four times the rate of white mothers, one of the widest of all racial disparities in women's health. Put another way, a black woman is 22 percent more likely to die from heart disease than a white woman, 71 percent more likely to perish from cervical cancer, but 243 percent more likely to die from pregnancy- or childbirth-related causes. In a national study of five medical complications that are common causes of maternal death and injury, black women were two to three times more likely to die than white women who had the same condition."

Black People Feel Less Pain." This headline, however, not only disregarded the "I" of the *Slate* article, but also identifies its concerns in terms of an alarmist rhetoric that only speaks to the white liberal subject's moral panic in the wake of his failure to empathize with others in pain. The NPR discussion as well as the study concludes that "induction of empathy" is possible and necessary to repair the racial empathy gap, and this could work to eliminate socially circulating prejudices as well as structural problems in medicine and healthcare. I refer to this title to make a rather simple point that I will explore in different sections in this dissertation: if a certain kind of narrowed down notions of "health" and "healthcare", i.e., not just not being immune to racialized pain but a culturally and historically precipitated notion of such an "immunity"—an inability to empathize—itself is a kind of pathology, then, how can life writing, health, and medical humanities, interested as they are in challenging limited notions of pathology, disease and understandings of illness, read patient's accounts in a way that resist such a narrowing and keep our notions of "health" significantly open-ended?

Although the issue of "racial empathy gap" has been widely discussed in fields like critical race studies in terms of "white fragility" and "white innocence" (cf. DiAngelo 2011; Wekker 2016), I refer to this article because of two interrelated reasons: NPR's coverage of this article was important because the broadcasting network discussed a structural problem in terms of its social implications in everyday life, and thus communicated the issue without sentimentalizing a health and medical issue in terms of an "individual's narrative" of suffering, which the mainstream media often tends to do.[2] Yet, the attention to academic

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[2] See Robin DiAngelo's essay "White Fragility" (2011), which examines the notion of "whiteness" in the North American context. She writes, "White people in North America live in a social environment that protects and insulates them from race-based stress. This insulated environment of racial protection builds white expectations for racial comfort while at the same time lowering the ability to tolerate racial stress, leading to what I refer to as White Fragility. White Fragility is a state in which even a minimum amount of racial stress becomes intolerable, triggering a range of defensive moves. These moves include the outward display of emotions such as anger, fear, and guilt, and behaviors such as argumentation, silence, and leaving the stress-inducing situation. These behaviors, in turn, function to reinstate white racial equilibrium. This paper explicates the dynamics of White Fragility" (54).

Also, see Gloria Wekker's *White Innocence* (2016). Wekker's work discusses the legacies of Dutch colonialism and how The Netherlands as a "small" and "benevolent" nation functions as an ideological construct to form the notion of a "Dutch racial exceptionalism"; this alleged exceptionalism and cultural amnesia is celebrated and publically legitimized during the country's annual Christmas celebrations with figure of "Zwarte Piet" (Santa Claus's underlings in blackface) research (Silverstein is also a doctoral student in anthropology) in the media came with a price: the title of Silverstein's essay "I don't feel your pain: a failure of empathy perpetuates racial disparities" had crucially referred to the implicated position of the researcher who held interviews with his informants and showed visuals of people in pain, and this title reaches out to a history of situating the "I" of health and medical humanities. The impulse to engage with this "I" is important because it helps us to derive a notion of a "practical ethics of care" (Holt, 323) when used by a health provider or a researcher.[3] Thus, in the following sections of this introduction I will show how and why this "I" demands a special attention in the

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parading the streets of several cities in The Netherlands. Although Wekker's work is not related to the North American context, her contribution in regards to the racialized notion of "innocence" is widely recognized in critical race studies and resonates with Silverstein's related finding that "whiteness" is overwhelmingly successful attaching itself to humane feelings (a belief in "innocence," for instance) from those who witness "whiteness-in-pain."

[3] Suggesting that the practice of narrative medicine as extremely important while situating the "I" of medical humanities literature, where doctors write about their experiences with patients, as an act that he finds problematic, Terrence Holt, a health provider and a literary scholar, suggests, we need to work with this "I", track its historical emergence, and engage with it in a way that denies the "safe distance" of being above the fray, as it were, just like the doctors writing about patient's experiences are not (323). He locates the emergence of "I" of the practice of narrative medicine in the literary and creative movement of the 1960s (in the post-Vietnam era), New Journalism. According to Holt, "Rather than leading to connection, the New Journalists' "I" merely gestures toward engagement while actually refusing it, identifying with the crowd in order to hide from something larger lurking outside, asserting individuality in order to deny contingency on historical forces, and thereby obfuscating an uncomfortable entanglement in possibly insoluble ethical dilemmas. But rather than observe this from a *safe distance* and accuse the New Journalists of bad faith, we might more profitably observe that in doing so we merely repeat what we condemn, deploring from *afar* the unavoidable consequence of any attempt at social critique. We are never above the fray. Journalists, doctors, even literary critics are part of what they examine. And our involvement extends even to the mixed motives and shameful pleasures that accompany the most virtuous acts. By the end of this essay, I hope to show that this contradictory fragmentation of impulse is not necessarily a trap; indeed, if recognized as an inevitable part of ethical discourse, it offers a ground that actually enables a practical ethics of care" (Holt 323; emphasis added).

Also, a new politics and practice of reading this "I" that I'm arguing for is thus urgently needed because this "I" traverses a large terrain that includes health, medicine, and various conceptions of "the medical" (Atkinson 73) in life writing narratives. "The medical" is something variously experienced in everyday life, and the experience of this view of what is considered as "the medical", "pathological", or a "disease" in important to be reexamined. A new politics of reading that must reevaluate these constructs.

context of health humanities, which is focused on the patient's perspective, medical humanities, which is closest to the health provider's attention within an institutional context and can make certain desirable changes at a practical level, and, of course, autobiographical narratives, which locates the "I" as an "enunciatory site [at] a point of convergence of autobiographical politics and the politics of memory" (Smith 41). The "I" that speaks to health research in general is hard to be tracked and harder to be wholly dismissed but needs to be strategically accounted for; this is because "[g]iven the health humanities agenda of representing the underrepresented, the danger also involves misrepresentation, getting the other's meaning or story wrong, or even claiming the power of that story for one's own purposes or benefit" (Garden, 79). Thus, while an grieving admission of "I don't feel your pain" from the perspective of a health researcher is crucial, it needs to be complemented with literary ruminations of this "I", that is, particularly those that speak from or engage with a patient's perspective. Indeed, as the article suggests, a "feeling" has to transpire for the racial empathy gap to be dismantled; when empathy fails, a paralyzing admission of its failure cannot help but only retains the status quo in and beyond medicine intact, and when the status quo as such remains unchanged, it has an effect that on how and on what terms bodies and lives are medicalized. Staying with this "I" of a health humanities perspective, even when it grieves its inability to empathize and locates this inability as a common cultural "condition", which, in turn, signals a collective notion of health ("global health", for instance), is crucial. The examination of health, an inquiry into what it perceives and encounters as "the medical", and kind of historical and social factors that lead to the production of an inability of empathize with racialized and gendered others in pain are important to be examined for a "collective health" to be restored. Research in health and reflections on a collective notion of what it means to "have one's health", i.e., in terms of an ability to empathize or have an (un)limited access to pain medication because of the implications of having one's residential address in certain neighborhoods is, thus, deeply connected to how autobiographical narratives that subjects of illness, researchers, caregivers situate the "I" in various narratives they produce. In examining health research and, indeed "research" on health itself, as evinced in the researcher's incapacitated voice of "I don't feel your pain", as narratives, it bears repeating that such narratives need to be read as referring to certain life-worlds or what medical geographers have called "spatialities of health"

(Atkinson, 75).[4] At the same time, what strikes me is the literary character of Silverstein's title on *Slate*; it is not unlike a researcher's everyday lament that is both insouciant and concerned about the topic of her research, engaged and disengaged, excited and bored at the same time, and still captures the effects of structural and slow violences in the sentiment expressed in "I don't feel your pain" in terms of an (in)ability, a condition. But this need to reach out to a different register of narration which comes close to what we may provisionally call dwelling with a "your" in a figurative vein, which got lost in NPR's discussion of Silverstein's work, is telling of an cross-disciplinary dialogue against the narrowing down of epistemologies that health researchers, health providers, and medical humanists have articulated in various ways. The recourse to a different register of narration is surely laudable, but I am not interested in evaluating the literary merits and demerits of Silverstein's study but what it speaks to, what it asks for, and how it is circulated for wider consumption and awareness.

Borrowing from the health humanities, medical humanities, and concepts of life writing that I glean from the narratives I read, I argue that it asks for "slow engagement." The slow engagement that I am interested in examining is not entirely about my engagement, or a researcher's engagement, with the literary and film narratives I analyze. Slow engagement, I argue, is present in how patients with chronic illnesses write about their experiences. Narratives of such slow engagements are important to be read to supplement ways in which medicine and health researchers produce concepts of reading and interpreting

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[4] According to medical geographers, spaces that construct and produce definitions of "health" call for a "kind of critical engagement, [which they] suggest, is far more fundamental to any evolution of the medical humanities. Critical engagements with "the medical" which open out and interrogate the multiple ways in which "the medical," medicine and health are encountered and experienced are not only important and desirable in their own right, as we will show, but would also facilitate recognition of the breadth and vibrancy of medical humanities research without the need to draw disciplinary lines around particular types of work. In order to advance such critical engagement, and in the context of this special issue, we will draw on the debates within one social science field, that of human geography, from the late 1990s and into the early 2000s. A "critical" geography specifically attends to the situated nature of health and health practices in both space and time, and as such challenges conventional treatments of context as either backdrop or determinant. So it is from "critical" geography, we suggest, that the medical humanities can draw their inspiration without jeopardizing the openness and heterogeneity of the field" (73).

illnesses (Garden 2015; Charon 2008). Given that health humanities scholars recognize that "medical practice is not strictly speaking a science" because its methods of engagement with the patients are "deeply interpretative" (cf. Hawkins and McEntyre qtd. in Herndl, 595), it is important to revitalize our practices of interpretation. In so doing, I focus on the plurality of genres and narrative strategies that the "patient's perspective" (Banerjee 2018) underscores in a semi-autobiographical novel, a memoir (both by survivors of chronic illnesses), and an autoethnographic video narrative from the point of view of a caregiver. Borrowing from Mita Banerjee's work, slow engagement, I suggest, offers a *new politics and practice of reading.* This practice of reading is enabled to make those interested in questions of "health" literate in regards to the challenges that our pursuits towards health (Mantel 2010) face in daily life—what kinds of grief must our pursuits towards health be endured and inhabited to become healthy through narratives?

Slow engagement emerges from literary studies and autoethnographic practices because it borrows from their methods of close reading and reflects a keen attention to descriptive language. An attention to descriptive language is crucial because "description" of a set of symptoms of an illness is the first form in which patients give an account of themselves. The importance of making room for descriptions, listening to narratives formed in the process, to see where they come from, and where they go can hardly be overestimated. Qualitative analysis demands that we do not just domesticate by "tolerating" patients' perspectives, as if silently waiting for these narratives to end because the interview time between the health provider and the patient is violently cut short due to a cost-effective logic in medical practice at work, so that "we" can impose our fixed modes of knowing these perspectives and how they describe complicated experiences of diseases that are yet to be named and defined.[5] Also, if cost-effective measures, particularly the distribution of time

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[5] On 14 March 2016, when then newly established doctoral program, Life Sciences–Life Writing, at the University of Mainz and the University Medicine hosted its first conference "Kosten-Nutzen-Gesundheit?" ("Cost-Effective/Benefit-Health?"), one of the concerns that most talks raised was around the issue of how the notion "health" could be distinguished, if not wholly redeemed, from the logic of cost-effectiveness. Most talks referred to the issue of cost-effectiveness as an instituted principle in the medicine, and highlighted it as an important barrier in receiving healthcare in the German context.

I refer to this title to make a rather straightforward point that I will explore in different sections in this dissertation: if a certain kind of narrowed down notions of "health" and "healthcare" is what the life such measures generate, get in our way of engaging with the patient's perspective in an beyond a clinical context, how could qualitative approaches patients' perspective in narratives challenge such a foreclosure of possibilities in terms of the insights they routinely bring forth? Yet, I will show, this question does not have an easy answer when we think of the patient's perspective in texts and how sufferers and caregivers represent "chronic illnesses" because narratives of chronic illnesses often reflect upon a social chronicity, a kind of chronicity that intersectional analysis of health and illness must take into account. As a health humanities perspective would suggest, literary analysis contributes to medical humanities perspective through its interpretative skills of texts, engaging with these description for the transformative potential they bring forth is thus crucial. If examined carefully, as I will show, perspectives offered in descriptive language could contribute to meta-analytical examination in evidence-based medicine and make doctor-patient interactions more democratic in terms of opening up to possibilities of thinking of "health" is not something that a body possesses or does not possess, but something that accrues meaning in through interrelationships with other bodies (Atkinson 77), and from histories through which definitions of an "ill body" is produced. Slow engagement, thus, is not just interested in language games in the postmodern style that does not offer a possibility for a desirable and practical ethics of care; instead, it is aware of a shortened temporality within which practices of knowledge production and engagements with chronic illnesses work but speaks to these practices and engagements in its own language, this is a language that "makes time" in the wake of being silenced.

As a health humanities scholar Susan Squier suggests, unlike medical humanities, health humanities needs to "move beyond the walls of the clinic to consider how race, gender, class, ability, ethnicity, and nationality—to name but a few of those mutually imbricated intersectional identity categories—shape the healthcare we receive" (cf. Squier, 346). This is not to suggest that these fields are not connected; they are, because if health humanities does not share the insights it derives from its intersectional analysis with the institutional platform that medical humanities, a tertiary and a precariously funded branch in

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writing and life sciences (at least in their idealistic versions) is interested in challenging then it is important to read narratives that resist such a narrowing and keep our notions of "health" significantly open-ended.

medical education (Herndl, 595), occupies then the promise of developing an ethics of care is not fulfilled. But how might a cost-effective logic of "practical ethics" in medicine be sustained in an examination of health that lies at intersectional notions of the body, often in spaces that the clinical context is not enabled to take into account? Health humanities cannot be guided by what is arguably medicine's onto-theological fetish for a "concrete, physical body" when it attempts to engage with literary narratives and life experiences that, indeed, question such a limited understanding of the body. Discussing Anne Hawkins and Marilyn McEntyre's *Teaching Literature and Medicine* (2000), Diane Herndl writes,

> "Most courses in literature and medicine in medical school settings have not kept pace with scholarship in the field in finding ways to incorporate various theoretical approaches…" (7). They offer a paragraph to explain why it is almost impossible to get medical school students or doctors to deal with theory. But without a poststructural paradigm, I would argue, it is hard to get anyone to understand what it means to locate disease or disability somewhere other than in a concrete, physical body. I hope you will allow me to postpone a discussion of why we might want to do this. (595)

Indeed, older debates between radical constructivist insights and historical experiences of the body seem to be problematically taking over a field where remedy, amelioration, healing and a reconstitution of subjectivity have a direct impact on long-term suffering. While I agree with Herndl's insights that a poststructuralist insight is needed to challenge the tyranny of a "medical gaze" (Greenhalgh 2001) that is always in search for wounds that bleed and suffering in the terms of the imagined resilience of a martyr, as evinced in cancer narratives, for instance, I also want to suggest that "grief" in relation to pursuits of health and healthcare has a materiality that is not easily identifiable in terms its "concreteness" and "physicality" but provides us with an imagination of what wounds could also be like and how certain layers of suffering are talked about as they are mobilized in narratives.[6] In order avoid an impasse between radical constructivism and what needs a health provider's attention, however, we could focus on how chronic illnesses are discussed in terms of first-person and autobiographical narratives and those who witness illnesses from the point of a caregiver. The narratives I read produce a slow engagement that works through such a terrain where the "concrete, physical body" is seen as fully sedimented through historical discourses of

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[6] See Barbara Ehrenreich's "Welcome to Cancerland: A Mamogram Leads to a Cult of Pink Kitsch" (2001), pp. 43-53.

gendered pain and medicalization of race, sexuality, ageing, and entropy. In narrating these bodies, we need to track how "grief" in relation to bodily and psychic health emerges in the texts. If, as Roland Barthes writes, "[a] text is not a line of words releasing a single 'theological meaning' (the 'message' of the Author-God) but a multi-dimensional space in which a variety of writings, none of them original, blend and clash. The text is a tissue of quotations drawn from the innumerable centers of culture" (Barthes, 146), we perhaps don't need to celebrate the "multi-dimensional space" and its polymorphous character in and of itself, as Barthes writing in 1967 urged us to do, but see the production of multi-dimensional space is fraught with negotiations between the gendered, ableist, and racialized experiences of the body in terms of their mediation in autobiographies and a concomitant play with signification that defers arriving at what I will discuss as the "ultimate referent" of chronic pain, a deferral which nevertheless provides us with a map to conceive of a practice of the ethics and healthcare. Thus, how may we think of a narrative's intellectual labor in producing a "slow engagement" with a chronic condition in a way that negotiates between deferring arrivals at an ultimate referent of pain in the radical constructivist vein and, at the same time, recognize "our culture is socially constructed along medical lines to begin with" (Bérubé, 341), and the "biological materiality of the body is susceptible to a finite (and sometimes severely delimited) number of constructions"?[7] How far can autobiographies of many shades help in this endeavor?

1.2 Slow Engagement Against an "Epistemological Narrowing"

The fields of medical and health humanities are challenged with a conceptual crisis, namely, how might we think of at least the double, if not multiple, lives of the body in the clinic and

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[7] See Michael Bérubé's "Afterword: If I Should Live So Long." In: *Disability Studies: Enabling the Humanities* (2002) Bérubé writes, "whenever we get too blithe about the possibility that social constructions can be constructed otherwise, too complacent in our belief that we can change a socially constructed world by the end of next week, we need to remember [...] that there's a there there, that the biological materiality of the body is susceptible to a finite (and sometimes severely delimited) number of constructions. It's also worth remembering that most of our culture is socially constructed along the medical model to begin with" (341). As Diane Herndl also notes, disability studies as a field is overwhelmingly influenced by radical constructivist notions of "the body," while medical education tends to focus on the "concrete, physical body", which has led a severe lack of communication between the two kinds of expertise and both fields could be tremendously benefitted if a conversation could take place.

kind of spaces it occupies beyond the clinic. This is the debate between the particular and the general experience of a "disease." It refers to the somewhat archaic medical misconception of a "disease" experienced by everyone who is afflicted with a said disease in the same way, that is, its "generalizability" vis-à-vis a "nomothetic mythology" of the disease, "which assumes a uniformity of experience in a diagnostic category" (Hawkins, 15). This is not to say that medical humanities is not interested in examining the different sites in relation to which bodies accrue meaning, but due to its methodological and institutional proximity to "positivist measures" (Squier, 335) of biomedicine that pervade in medical practice, medical humanities could benefit from the intersectional analysis that health humanities can offer. Similarly, borrowing from medical humanities, health humanities could locate the particular character of suffering as an actualization of a pathology limned in everyday suffering and however remotely speaks to a diagnostic category. Just as a text is not to be solely imagined as a product of a sociohistorical context but could be a response to certain developments in the history of science (Banerjee 2018: 8), an actualization of a set of potentially pathological conditions need not always correspond to the generalizable experience of a disease but could be suffused in everyday suffering in a given spatiality of health. For example, US-American writer Dorothy Allison's reflections on post-traumatic stress disorder (PTSD) are useful to examine how the concept of PTSD resonates in relation to domestic traumas in the Appalachian culture as opposed to the battlefront where PTSD originated. Such a reading of Allison's text has to be worked out between the medical humanities agenda of locating the illness experience in conversation with certain diagnostic criteria and a health humanities perspective of examining the intersectional dynamics of Allison's reflections on the materiality of PTSD and psychic grief in general. Given that thinking of the body in terms of the vectors of power that give a particular body its meanings is not in the interest of biomedicine because, at a fundamental level, biomedicalization is about "governance," it is urgent that we think of such complications in texts through the lens of both health and medical humanities.[8] As Squier goes on to suggest,

> Although unevenly distributed, biomedicalization has played a crucial force in shifting the task of Western medicine from the control over disease and illness to the

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[8] Biomedicalization has been defined as the "process by which all of life has come to be under the governance of biomedical technologies" (cf. Clarke et al., 161), and is said to affect "at all life scales, from the microscopic to the macro-institutional, from the individual to the population" (Squier, 335).

> transformation of human life (Squier 2004). While the accomplishments of biomedicine are undeniable, they are shadowed by its failures. In its increasing focus on positivist measures, biomedicine has not been fully able to grapple with those aspects of experience that can't be expressed in scientific or quantitative terms. In short, the crucial ambiguities of life have often escaped it (Squier 2007: 335).

Health humanists offer an intersectional and democratic definition of "health", and because this definition is attuned to the patient's perspective it can address the "crucial ambiguities of life" that often escape biomedical regimes of knowledge formation. As health humanities scholars suggest (Squier 2007; Herndl 2005), the idea is not to replace or criticize medical humanities for its lack of a compelling critique of biomedicine, but to create conversations between the two fields. At a fundamental level, this would be a conversation in which both fields are able to take each other's insights seriously- and work with those- and not be guided by fixed curative ideals that are predicated either on ideological notions of a "concrete, physical body", on the one hand, or an anti-social or negative bent of postmodern thought wholly defined by specificities of a condition and not directly interested in seeking cures for social suffering, on the other. How can health humanities with its focus on suffering, as opposed to "pathology", enable this? How could narratives that circumscribe the materiality of grief help in this regard- and offer a mode of communication between health and medical humanities? Health humanities, as Rebecca Garden (2015) suggests,

> Focus[es] on suffering rather than pathology and recognizing the social determinants of that suffering, the health humanities advocate on behalf of the person who seeks healthcare and whose biological manifestation of illness and disability may be addressed by healthcare but whose psychic and social suffering are not. I am using the term *health humanities* deliberately here to more fully recognize professions other then medicine and to recognize the authority of non-professionals, patients themselves and their intimate circles of support and care. (77)

A recognition of the authority of non-professionals, a focus on suffering rather than pathology, and an examination of how social and psychic determinants of suffering work align the project of health humanities to the patient's perspective in autobiographies. Also, through such a perspective we may be able to address the "epistemological narrowing" that is a challenge to both health and medical humanities. Such a narrowing is reflected in these fields particularly due to a shortened temporality organized by a cost-effective logic that narrative medicine and medical humanities are interested in repairing (Charon 2008); and analysis of illness narratives and pathographical literature (Hawkins 1993) that have shaped the field of health humanities has also increasingly and unquestioningly "used [canonical] texts and acceptable methods for textual study as it has professionalized" (Squier, 337-38), which has led to an overemphasis on certain "epistemological assumptions" that typically subtend aesthetic and socioeconomic structures that canonized literature celebrates (338). Both these methodological tendencies produce what Squier calls an "epistemological narrowing." Health humanities need to be revitalized by taking into account diverse forms and genres in which illnesses are discussed and clinical practices and protocols as reflected in narrative medicine could help in this regard. This is because a similar desire to move away from an epistemological narrowing and concomitant foreclosure of possibilities is present among practitioners of narrative medicine as well: as Rita Charon writes, "[t]he healing process" is one that "begins when patients tell of symptoms or even fears of illness—first to themselves, then to loved ones, and finally to health professionals" (65). There are multiple stages in the way to healing, engaging with notions of healthcare, and an urgent need to broaden the notion of health in a way that recognizes health is not just one thing, but one that gains meaning in relation to other bodies, narrative strategies, and diverse subject-positions in a given health narrative. Health humanities could do well to recognize and engage in a dialogue with medical humanities because the tendency to pluralize the notion of an "illness" and view healing through an aspect of interrelationality are present in certain components of medical humanities as well, namely narrative medicine. The question then is: *how can this dialogue be enabled through autobiographical narratives that practice diverse forms of storytelling and are self-conscious documents of the illness experience, and could work as an antidote to the tendency in medical humanities scholarship to pay lip service to the patient's perspective (owing to its proximity to biomedicine) and the health humanities problem to obscure its own (epistemological) assumptions of "health" through its isolated reflections on "suffering"?* As Eric Cassell notes, "a shift is now taking place in medicine away from a primary concern with diseases towards a focus on ill persons" (81). Health and medical humanities could benefit from autobiographical narratives that work in complicated ways in this regard.

Following Alfred Hornung's (2010: xii) suggestion that, non-canonical literature, narratives in the visual medium, online material, and experimental forms such as an autoethnography, for instance, are thus crucial for this kind of a methodological resuscitation because through their "experiments" with form and style subjects of illness and pain assume an agency in narratives, a sense of agency that does not wish for mastery (Gilmore 2012) but, I suggest, through a "slow engagement" is able to discern between the two and offer an alternative imagination of "health" and conditions that suffering (de)limits. An important way in which both these fields could productively question each other's methodological assumptions is by focusing on the issue of frameworks that need to be constantly shuffled to engage with hitherto unknown forms of suffering and borderline experiences. This would be the productive way in which the fields could enter into a conversation with one another, but before we get there we also need to realize the terrains of health studies and medical humanities are replete with ethical quandary of various kinds. For instance, the issue of medical practitioners writing about their experiences with patients corresponds to an "established tradition of confessional writing by doctors" (Holt 319) and often gets in the way we engage with patients' narratives. This is because we, as consumers of doctors' autobiography, reflect a "certain doubleness in our reception" (Holt 319) of such narratives because they carry a first-person element to it. As Terrence Holt, a physician and a literary scholar writing from of a medical humanities point of view, suggests:

> On the one hand, then, we have mass publications holding up medical autobiography as something remarkable; on the other, we have an established tradition of confessional writing by doctors. What makes the element of autobiography in narrative medicine remarkable, it would seem, is not the thing itself, but a certain doubleness in our reception of it. It is something we regard as a novelty even when it has become a commonplace. This now-you-see-me-now-you-don't quality, as Michel Foucault has famously observed, marks public-private boundaries generally. Here, however, this uncanniness points to something important in the relationship between narrative and medicine, between medicine and doctors, between doctors and patients. There is something here we do (not) want to see. (319)

According to Holt, the culturally ingrained belief in figure of the "doctor" as a paternal, godlike is so strong that when we come across an "element of autobiography" from this figure, we are more than willing ignore what is it exactly that attracts us to the moment when a "doctor" takes recourse to the genre of autobiography. There is an element of voyeurism here in regards to our curiosities about what happens during a surgery, a titillation that we do not want to think about, but what I am concerned about it how such a problematically harnessed sympathy and attraction towards the genre of "doctors' autobiography" could risk deflecting the attention from patients, caregivers and their narratives. Thus, if we (even as literary critics) are a part of the intellectual climate in which we examine cultural discourses of illness and health as objects of our studies from various standpoints, why am I turning to patient's narratives of chronic illnesses? What do these narratives have to offer us that an overemphasis on well-meaning doctors' autobiographies, particularly because of the way we receive and approach these narratives, cannot?

I will argue that patients' narratives of chronic illnesses, as they reflect on racialized and gendered pain, speak of a "social chronicity" that comments on the imbrication of doctors, authority figures, and power structures these figures refer to. As literary scholar Burton Pike has argued, autobiographical narratives carry an element "extrospection" (342), which is to say, these narratives "take their present experiences and attitudes as representative of certain forces at work in their culture." There is an element of meta-commentary in autobiographical narratives that the patient's perspective brings forth. Reckoning with these cultural forces in relation to certain attitudes is necessary for the narratives of chronic illnesses I read, and in so doing these forces form a dialogue between an "illness narrative" and the "social chronicity" that shapes it. The ideologically implicated position of figure of the physician is a part of this social chronicity that the patient's perspective is able to highlight and criticize. We will get a glimpse of this imbrication of the figure of the doctor and an authority figure of the "father" (which the law recognizes as the sole "guardian" for a minor's pain-stricken body in Dorothy Allison's semi-autobiographical novel) in the texts I examine, but most clearly the critique of the paternalistic figure of the doctor is taken up in Hilary Mantel's and Richard Fung's texts.

1.3 Slow engagements, the autobiographical "I", and the porosity of definitions

If, contemporary evidence-based medicine and notions of healthcare that we consciously and unconsciously practice in our daily lives suggest a shift, an estrangement from an understanding of medicine that combined "science and philosophy" to a "scientific realm governed by evidence-based practice" (Squier, 337-38) in a post-Enlightenment culture, how can autobiographical narrative through its "extrospective analysis" of chronic illnesses which arrests influences of certain cultural attitudes and forces work in service of repairing this estrangement? It is important to examine how the autobiographical "I" works in relation to a porosity between prevalent definitions of a condition and how narratives of an illness experience strive to transgress limits of those definitions at they encounter them. While definitions, of course, belong to institutions and disciplines that produce them (Morrison 1987), I also want to examine how autobiographical narratives of illness engage with the limits of definitions by highlighting their porosity and, in this way, seek for more expansive understandings of an experience of illness. This porosity suggests a potentially shifting boundary that can address a dialogue between health and medical humanities. Illness narratives as we will see will often speak of the experience of illness in relation to venues in everyday life and memoryscapes that bear remote but tacit connections with the illness itself. I want to suggest that this porosity speaks to the possibility of a repair work that would include a dialogue between health and medical humanities in the sense that it requires us to think of scientific issues through the lens of philosophical speculations. The autobiographical "I" in the texts I read (*Giving Up the Ghost*, for instance) labor to engage in a repair work that is about creating a dialogue between the health and medical humanities. Besides a practical conversation that can improve the kind of healthcare we receive, this dialogue also needs to be conceived on the basis of introducing philosophical questions in regards to how gendered experiences are sensed in relation to what I will explain in the following chapter as a "physical world" (Merleau-Ponty 1945). In so doing, these autobiographies of illness respond to the disciplinary chasm between science and philosophy in evidence-based practices and knowledge formation.

To be sure, I am not suggesting that we do not need evidence-based practices to bring chronic illnesses to some kind of amelioration but only suggesting that the autobiographical narrative cannot be wholly instrumentalized in service of a scientific realm managed by evidence-based practices and myopic notions of the body. Autobiography in its varied forms and styles must discuss a certain "I", an ontological address, because it has to tell a story where characters correspond to a certain sociohistorically choreographed structures of power and experiences. Yet this telling of a story of a certain "I" is not condemned to its "is-ness", how things are, but could things could in fact be otherwise. This is the work of imagination and language that autobiographies underscore and mobilize through their narratives as they bring about an alchemical shift by narrating human experiences. Thus, on the one hand, autobiographies are, by definition, about an "I" which mediates between experience and reflections on it through a language in a way that challenges the porous boundaries of known definitions of illnesses; and in similar vein, even though medical practice cannot be "medical practice" without being able to define a disease, certain branches of medicine like narrative medicine, for instance, have suggested that an experience of a "disease" and processes of healing are not limited to individualized notions of a body (Charon 65) but ought to be considered through the body's relationships to other bodies and histories. Autobiographical narratives of chronic illness register an excess of experience that speaks to the fractured relationship between science and philosophy, a relationship that has fallen under the critical radar of evidence-based medicine, but, if addressed, could work to repair prevalent notions of "health" that are not taken into account in evidence-based practice (i.e., ability to empathize with others in pain).[9] Thus, how may we come to terms with an "impulse" in patients' perspective of chronic illnesses that not only resist a generalizability of a disease but also demands to be read as a counter-narrative to reevaluate the terms that define "cure" and "health" as such? And how can autobiographical narratives of chronic illnesses, particularly the excesses of an illness experience they represent, be read in a way that serve as a dialogue between science and philosophy through this very impulse? If a dialogue between science and philosophy is in no uncertain terms good for our understandings and practices of health, we need to explore how this dialogue is enabled in a "layer of philosophy" that is to be found in narratives of the afflicted "I" of illness narratives. This layer, a "substratum" (Braidotti, 1421), as I will explain, refers to the porosity of definitions, the disciplines that produce them, and is a site of constant negotiations.

Slow engagement as evinced in the patient's perspective in narratives I read is crucial in this regard because it is works to address the (sometimes latent) impulse in autobiographies that are not just about various stories of the "I" but how those stories speak to a notion of cure, bodies and illnesses that evidence-based medicine comes to define and problematically monopolize. These "excesses" of the stories of a narrator of chronic illness, I suggest, are important to be held on to because they speak to a relationship between science

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[9] According to neuroscientist Antonio Damásio, "Autobiographies are made of personal memories, the sum total of our life experiences, including the experiences of the plans we have made for the future, specific or vague. Autobiographical selves are autobiographies made conscious. They draw on the entire compass of our memorized history, recent as well as remote. The social experiences of which we were a part, or wish we were, are included in that history, and so are memories that describe the most refined among our emotional experiences, namely, those that might qualify as spiritual" (210).

and philosophy, or more particularly, an *impulse for philosophy* that is to be found in the excesses of narrating the afflicted "I" (Das 2014).[10] This impulse for philosophy emerges from a porous space between a medical definition, a concept of a disease, and an individual's experience of a disease, a space that speaks to the fraught relationship between science and philosophy, general and the particular experience of a disease, and health and pathology. For example, critics working in response to a similar issue on how to distinguish between a "disease" and a "disability" (Herndl, 594) have offered a model based on several factors such as time, agent, goal, discourse, and representation to create a productive conversation between the patient's perspective of these aspects of a condition and the medical establishment's definitions of these terms.[11] The problem, as we learn, is not addressed if we think in terms of zero-sum logic, so to speak, of how may we respond to reflections on such a distinctions between operative definitions of a "disease" or the sum total of reflections of the experience of a disease or disability in autobiographies that typically locate the afflicted "I" somewhere on a spectrum between operative definitions and excesses of experiences at the peripheries of a given definition. The problem is also definitely not addressed if we ignore these excesses of experience because they are not "useful" in regards to evidence-based practices and definitions. The texts I read engage with a "philosophical layer" in autobiographical narratives that can accommodate the tensions between a definition of a disease at its limits in relation to excesses of an experience, excesses that literature and philosophical ruminations reflect upon but are deemed superfluous to the medical gaze. Thinking through these excesses beyond recognized definitions is important because they respond to the work of repair in service of evidence-based scientific knowledge and its estrangement from philosophy. Autobiographical narratives of chronic illness thus offer a

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[10] See Veena Das's "Introduction" in *Afflictions: Health, Disease, and Poverty* (2014). Das traces the "afflicted self" of the illness narrative in Christian mystic and philosopher Simone Weil's reflections of "suffering"—"a suffering that goes beyond physical pain and beyond even ordinary suffering" (1). Das's ethnographic project aims to examine how sufferers, who do not long for a Christ-like figure to save them but "sometimes call on God" (2), can sabotage the experience and sensibilities generated by the concept of "affliction."

[11] Diane Herndl suggests, "if all disabilities are seen as illnesses, then it becomes almost impossible to refuse medical interventions aimed at eliminating difference. Below I list five topoi in distinguishing disease and disability: Time/duration: ontological state versus temporary condition; Agent: patient definition of condition versus practitioner definition; Discourse: within what context? Who is in charge?; Goal: cure versus accommodation, access, empowerment; Representation: as tragedy, end-of-life-as-we-know-it, difficulty, or change of mode" (594).

space for an inquiry into how could excesses of an illness experience that suggest not only a limitation of medical definitions but could productively address their inherently porous character that lie between definitions and those who get defined, between prevalent medical knowledges/definitions and that which is perceived as "the medical" by the defined person. This porosity is negotiated in texts in a way that asks for operative definitions, cures, without which evidence-based medicine cannot be itself, and open-ended inquiries that strive to engage with the philosophical underpinnings of living with chronic conditions. *In the process, a kind of critical engagement—a slow engagement—takes place that can only be appreciated in relation to a temporality of slowness of a repair work (as opposed to a temporality of curing an illness through pills, drugs, and scans) that, however remotely, tries to link science to philosophy—a link that is worked out in autobiographical narratives and one which is in no metaphoric terms good for our collective understanding of "health." Slow engagement with the porosity of definitions as encountered in the autobiographies I read is, thus, equipped to question the internalized scientificity of a "critical" gaze that either views evidence-based practices as a panacea for having one's health on a collective scale; or, is mired between a false dichotomy of having to choose between technologies of amelioration that are meant to lessen chronic pain at a bodily level, on the one hand, and autobiographical excesses of an afflicted "I" that merely indicate the limits of dominant definitions, on the other. The term "slow" also embraces and recognizes disparaged knowledges – feelings, knowledges, and worldviews that are cast aside by legitimized knowledge systems.* Focusing on this porous character of medical definitions of diseases (as opposed to their obviously limited understandings) is then a productive way to create a dialogue between health and medical humanities. We will get a glimpse of such textual mediations with medical views of endometriosis, PTSD, HIV, and thalassemia in the texts I examine.

In its recourse to different registers of self-narration like descriptive language, auto-ethnography and figurative language, in finding a "solace in autobiography" (Banerjee 2018), slow engagement of the autobiographical self provides a narrative that has crucial philosophical underpinnings. Borrowing from feminist materialist philosophy, I define "philosophy" in relation to a "layer of desire" that it comes to disavow—as an "unspoken and the unspeakable desire for thought, the passion for thinking, *the epistemophilic substratum on* *which philosophy later erects its discursive monuments*" (Braidotti, 1421; emphasis added).[12] In this formulation, philosophy reflects a problem around its own practice, and it is a conundrum that replicates the problem of disciplinary definitions that threaten to ignore those who get defined by them: philosophy, too, cannot "be philosophy" when it stays with what it acknowledges as "ontologically there" but is required to depart from it, "propositionally exclude [due to] the necessity of a philosophical utterance." This is a "scientific" character of philosophy, and one that is reflected in the issue of the denied porosity of medical definitions. However, between the ontological presence, which is disavowed in the "activity of philosophizing" and, by definition, affirmed in an autobiography, lies a "substratum," a layer that testifies to a love of knowledge but has to yield to "proper philosophy."[13] In my analysis of this philosophical layer of autobiographical narratives, I will examine how this layer- one through which philosophy actualizes itself by disavowing it- is sabotaged by the afflicted "I" of the autobiographies that I read. This is a sabotage of free-floating medical definitions of diseases that that sufferers and survivors encounter. Such an act of ethical sabotage is available to this "I" because subjects of contested and chronic diseases refer to this layer and the desire for knowledge that it represents in order to challenge

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[12] According to Rosi Braidotti, "There is such a thing as a prephilosophical moment in the establishment of a philosophical stance, a moment in which one chooses for philosophy. This prephilosophical moment of desire not only is unthought, but remains nonthought at the very heart of philosophy, because it is that which sustains the very activity of philosophizing. We are faced here with the problem of what is ontologically there but propositionally excluded by the necessity in the philosophical utterance. There is the unspoken and the unspeakable desire for thought, the passion for thinking, the epistemophilic substratum on which philosophy later erects its discursive monuments" (1420-21). Braidotti belongs to a group of philosophers who have strongly identified with the positive uses of literature to better understand the material turn. She is critical of deconstructive takes on literature and reads literary texts to locate the intersections between philosophy and literature.

[13] Following Braidotti's comments, between the recognition of presence of an "ill body", an ontological location, and autobiographical excesses of the afflicted "I" there lies a "moment" (Braidotti, 1420), one in which the ill, gendered, racialized, or differently-able subject can "choose for philosophy", or what I understand as the philosophical layer of the autobiographies I read. This layer, or what Braidotti goes on to clarify as a "substratum", reflects a love for knowledge, and is thus "epistemophilic"; at the same time, it is "nonthought" component at the heart of philosophy that, paradoxically, enables the activity of philosophizing (1420).

institutionalized knowledge (Epstein 1996). Afflicted subjects, we will see, meticulously attend to their embedded and embodied locations of subjectivity to provide a counter-narrative to the dominant definitions, institutionalized notions of health and care, and what they experience as "the medical" in and beyond medicine.[14] This epistemophilic substratum prior to yielding to "proper philosophy" marks an interstitial space between philosophy, embodied experiences as narrated in autobiographies, between disciplinary lines across definitions and those who get defined, which, in turn, could form the basis of dialogue between health and medical humanities. The autobiographies I read recognize this space between the narratives of an afflicted "I" and the "unspeakable desire for thought, a passion" that wishes to be otherwise. It is a transformation that is imagined by the enduring subjects of chronic illness, and this desire for a transformation could serve to bridge the disciplinary chasm between science and philosophy. Recognizing this desire for knowledge of a different kind in autobiographical narratives is important because in engaging with this often unspoken desire for knowledge allows us to understand what I will discuss as the "emotional intelligence" of illness narratives, an intelligence that evidence-based practice is yet to recognize. Thus, I ask: how can autobiographies work to repair the estranged spaces between the philosophical utterance and the fact of an embodied experience that is only partly recognized in medical definitions of a "patient's perspective", and again largely ignored when we deny the porosity of those definitions in terms of how they are textually mediated?

1.4 Chapter outline

Chapter One: In this chapter I will examine the role of "description" in a patient's perspective. My text of analysis is English writer Hilary Mantel's 2003 memoir *Giving Up the Ghost: A Memoir.* Mantel's chronic illnesses of undiagnosed endometriosis, which is connected to prolonged periods of medical neglect because the chronic pain due to

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[14] Also see Anne Hawkins's concept of a "pathography", which speaks of "moments of illumination and understanding." Hawkins writes, "Pathography can be seen as *re*-formulation of the experience of illness, as the artistic product and continuation of the instinctive psychological act of formulation: it gathers together the separate meanings, the moments of illumination and understanding, the cycles of hope and despair, and weaves them into a whole fabric, one wherein a temporal sequence of events takes on narrative form" (24-25).

endometriosis was often viewed with "hysteria" among medical practitioners and/or was stigmatized as the "career woman's disease" (Carpan 2003). Mantel's formal style of writing about her chronic pain is tied to the "contested" history of the disease among medical practitioners. This chapter traces her style, its politics, and its critique of medical practices in relation to a social context where gendered pain is ignored, discredited, or silenced. Mantel's use of a layer of chronic pain that can be talked about, written and mobilized in narratives is what I call "sustainable pain." I understand this term as Mantel's method, and I argue this method of talking about her chronic pain enables her give due credit to the form of "description," which is a reviled and gendered register of narration in the medical practice and considered to be a superfluous part in a patient-health provider interview. Her focus also allows her to introduce a new way of talking about memories in what is a very late contribution to the genre of memoir.

Chapter Two: In this chapter I analyze US-American writer Dorothy Allison's semi-autobiographical novel *Bastard Out of Carolina* (1992). I focus on the writer's use of figurative language to represent a story of childhood sexual and physical abuse, experiences of PTSD, and generational poverty in Appalachian culture. Specifically, I track the child narrator's negotiations of a history of shame and poverty and how this sense of shame is addressed in the project of "making literature" out of an experience of social abjection. Writing about violence and the project of making literature in the wake of being violated is important for Allison, I discuss how this importance is worked out in the child narrator's slow engagements with varied facets of everyday life in her community: economic violence, domestic traumas that shape PTSD far away from a scene of a combat experience where it was first recognized, and her attachments to various members of her community vis-à-vis the experience of a largely unfamiliar chronic condition. In making literature from the debris of shame and abjection, I argue, Allison underscores the need to talk and write about such histories is crucial to their amelioration.

Chapter Three: In this chapter I read Canadian video artist Richard Fung's *Sea in the Blood* (2000)—a twenty-six minute long video narrative by a video artist, essayist, academic, and a cultural critic. Fung's story discusses his deceased sister's chronic illness with thalassemia (a congenital blood disease) and his partner's HIV from the points of view of family member and a caregiver. He draws on histories of immigration, the AIDS epidemic in North America during the late 1980s, and face-to-face interviews with his mother, Rita Fung, the primary caregiver to his sister, and other family members. The theme of this video narrative, besides chronic illnesses, is also the issue of "loss"- of losing family to different types of chronic illnesses. I examine the video from the point of the "politicized patient" (Diedrich 2007) of illness narrative. This patient is one who needs to be imagined in relation her stories, her experiences, and those around her. While retaining distinctions between sufferers, caregivers and first-person accounts of suffering and caregiving, as a health humanities perspective requires us to do, I suggest, Fung's works creates an important dialogue between the politicized patient of illness narrative through his reflections on the issue of "loss."

Conclusion: In conclusion, I connect the new politics of reading, close and even distant, reading in these chapters and what it means for the dialogue between health and medical humanities. I end with the idea that reading and writing can have a therapeutic effect on the subjects of chronic pain and that reading is indeed a kind of repair work. Acknowledging Eve Sedgwick's notion of reading in service of repairing an "inchoate self", I conclude with the idea of how the sufferers that I discuss in this dissertation offer a way to think through slow engagements, narratives processes with diverse experiences with illnesses. Such engagements with histories of illness are important because they are instructive to reconsider chronic illnesses in a new way, i.e., not just from a sympathetic point of view but also perhaps from a point of commitment to social and material histories that shape chronic illnesses.

~Chapter One~

Sustainable Pain: Chronic Illness and the Politics of "Description" in Hilary Mantel's *Giving up the Ghost* (2003)

No one can have fibromyalgia. Fibromyalgia is just a word we use to represent the situation of someone complaining about widespread chronic pain, fatigue, and sleep disturbances. […] It's not a disease, it's a description.
Luiz Claudio da Silva, "Fibromyalgia: Reflections about Empirical Science and Faith" (2004)

2.1 Introduction

The English idiom "connecting the dots" means to come to understand different facets of one's experiences through a close examination of events, incidents and accidents in one's life. We connect the dots to make sense of our experiences, we use stories, heard, remembered and told, as dots waiting to form a picture to understand what they mean and why we want to hold on to them. Connecting in this context is an uncertain task that is influenced by a necessity to comprehend a particular set of questions or concerns, to know and, at least in part, to find solace in the knowledge that will have arrived once a narrative is constructed. The work of connecting these dots and its explicit reliance on the metaphor of a "picture"—a word-picture—that is waiting to happen is, however, somewhat misleading because it largely conveys the idea that our experiences, good, bad, and ugly are represented as narratives that are entirely about "our" experiences that can easily form a picture; is there a risk in the notion of a "word-picture" taking over our readerly attention in such a way that it draw us into the big picture, so to speak, its brilliant pointillism, without allowing us to remember the labour of constructing this picture? Is there a multiply mediated risk of alienation from the processes of forming this picture when tend to take a "critical distance", a distance that keeps us transfixed with the accumulation of points—if so, what would a intelligent *and* embodied way of accounting for this labour be or look like? What would be the larger implication of such an intimacy, an intimacy where critical interrogation of experiences (particularly painful experiences) is carried out by subjects themselves? This chapter will investigate the issue of the experience of "the medical" and the mode of "autoethnography" as practised in a memoir. Specifically invested in the genre of a memoir at the turn of the new century, Hilary Mantel's memoir *Giving up the Ghost* (2003) is a narrative of the writer's experience of undiagnosed endometriosis that the writer experienced in her adulthood.[15] I examine this experience of what was formerly a "contested disease", a disease that was not known to the medical community, from the points of the connections and disconnections that the writer strikes in order to define the social experience of the disease in her own terms. Auto-ethnographic language is mobilized in a way that is of importance to both literary criticism and qualitative analysis in medicine studies, herein lies the "enlightenment value" of the text that we risk forgetting if we do not pay attention to the *register of description* in Mantel's text.[16] Descriptions of gendered exclusion, I argue, do a work that remembers the pain of exclusions in and beyond medicine, experience of bodily pain, and is not paralyzed by these. Instead, these descriptions carry an affective intelligence informed by pain that risk getting forgotten in a culture that devalues "raw descriptions"–as opposed to "cooked analysis" (Oliver 2016)—in gendered terms.[17] Descriptions have an analytical intelligence that needs to be explored -and this analysis borrows from and, in turn, hopes to contribute to such a dialogue.

In the context of medical ethnography in illness narratives, the picture that is formed in the process assimilating these experiences are never just the subject's private experiences nor can they we explained with "big concepts" like biomedicine.[18] Concepts, as we know, reveal themselves in very different ways in everyday life and illness narratives because they describe everyday experiences of the body are no exception to this. Thus, the representations of illnesses as medical ethnographers have shown often underscore the messiness of lived experiences and their interplay with big concepts.[19] This aspect of illness narratives resonates with life writing narratives because even in their highly stylized and "fictionalized"

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[15] It's important to note the date of publication of Mantel's memoir because, as Leigh Gilmore suggests, the memoir has become "the genre" of the new millennium because the United States now has "a culture of confession" (Gilmore 2001: 2).

[16] Cf. Mita Banerjee, personal conversations. 2016

[17] See Kelly Oliver's opinion piece in *The New York Times*, "Education in the Age of Outrage". 16 Oct. 2017

[18] See Kathleen Stewart on the notion of "big systems" in her essay "Weak theory in an Unfinished World" (2008). I am borrowing the term "big concept" in line with Stewart's description of "big systems." I will return to Stewart's notions later in this chapter.

[19] See Arthur Kleinman, Veena Das, and Margaret Lock. *Social Suffering* (1997) and Veena Das's *Afflictions: Health, Disease, Poverty* (2014).

spaces these narratives come into being with recollection of a particular set of experiences and try to make sense of it by placing it diverse contexts; this play with memory is denied to the narrative if we do not engage with the affective intelligence it works with. There is a simultaneous presence of fact from having a disease, living with pain, a deep interest in legitimizing and, at least in part, overcoming this pain according to the established terms of pain management. By problematizing the implied and fuzzy category of "illness narratives" in relation to a new way of practice of memory I am interested in exploring how Mantel's memoir complicates this category by highlighting the role of remembering, by particularly blurring the divisions between the "ailing" period in her story and the "healthy" part of her narrative. This narrative plan of the memoir to examine diseases and pain from the point of health and physiological stability in the narrator's life from the standpoint of iatrogenic distress has larger implications. This chapter will explore these implications are negotiated in Mantel's focus on providing "descriptions" of her experiences. I will investigate the politics of these descriptions through memories to frame the experience of a chronic disease like endometriosis.

2.2 Approaching an "illness narrative"

I want to begin this chapter on a somewhat confessionary note: I found the text of my analysis for this chapter, Hilary Mantel's memoir *Giving up the Ghost* (2003), a difficult and often frustrating text to comment on from the perspective of the thematic concerns of this dissertation. When the project of conceived, my most important research question was: how do illnesses tell stories? And although I have remained committed to this question in my analysis, I could not help but realize that this question was posed with a certain amount of critical hubris and an assumption that illness narratives speak to "us" merely to be heard in the way we as readers grant them an audience. In reading Mantel's text, I stand corrected that our ways of hearing these stories need to shift simply because illness narratives speak in different registers. Mantel's memoir did not speak to me in the way I was willing to read it. The text in fact even while it does describe a chronic gynaecological condition like endometriosis, its "unruly" (Weinstein 1997) style made me confront my own assumptions about what I was trying to read into Mantel's style of narration—does my seemingly generous desire to read illness narratives get in the way of what illness narratives, particularly gendered experiences of chronic pain have to offer?[20] What happens to the illness and/or pain narrative when we detach it from its rhetoric of lament and see it from the point of view of an intelligent dialogue with medicalization, an intelligence that is informed by pain and imbricated with the process of writing? But what comes before this understanding and attribution of an "intelligence" is a far more simple but persistent problem is that an illness narrative poses is the "adaptive value of narrative", or one that allows us to construe a problematic equation between "narrative" and "health" (cf. Eakin 130).[21] As Paul John Eakin (1999) suggests, the "ability to construct narrative is in itself a good", even an unquestionable good, is a specious assumption that suggests the ability to come up with narratives will guarantee social integration, health, and a depathologized identity.[22] In this view, the notion of a "narrative" is a value-laden term and not a neutral one—the result of engaging with narratives through the lens of this implicit value is that we (as readers of illness narratives) tend to view all illness narratives petition – through what we perceive as their lamentation- to be included in the same definition of "health" and "depathologization." Here, the added layer to the genre of the memoir in Mantel's work is crucial because it takes the discourse of illness (and the imagined lament of an illness) elsewhere. While I do not want to abstract formal features of the text from their material contexts, I find myself taking these features of representation of illness in Mantel's memoir seriously because of what these aspects of the text do in relation to larger discourses in medicine. The aesthetics of discussing illnesses is not detached from the themes of the text but this aesthetic takes need of forming a dialogue with medicine in a way that has been hardly analyzed; this is an aesthetic of remembering a life narrative is influenced by a need to know, a need to assimilate dissonant social and bodily experiences in registers that are often perceived at odds with one another. In so doing, the text demands a reading that conventional uses of literature in medicine has not provided because illness narratives have not been read outside the form of a "lament" that needs to be recognized and sympathized with, but also demands a commitment to engaging with their formal structures in terms of how they speak from the

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[20] See Arnold Weinstein's essay "The Unruly Text and the Rule of Literature" (1997).

[21] See Paul John Eakin's *How Our Lives Become Stories: Making Selves*, p. 130.

[22] Ibid.

experiences of wrong medical diagnosis and medical neglect etc. Drawing from sociological accounts of "social suffering" (cf. Kleinman et. al., 1997), I suggest, illness narratives like Mantel's *Giving up the* Ghost requires its readers to break away from the critical tradition of thinking of narration of illness as a lament that seeks a quick remedy but carries a "peripheral cunning" (cf. Manivannan 2017), or an affective intelligence as I put it, is crucial for both literary studies and narrative approaches to medicine.[23]

This intelligence of chronic pain disrupts the culturally ingrained tendency to think of memoirs of illness through the lens of a lament, or speaking from the position of sheer anger.[24] This tendency is also influenced by a collective attitude to view diseases as a "fall", a fall from the grace of perfect health that is already pathologized in the way we engage with this fall, so to speak. In effect, it does not enable us to think of autobiographical narrative voices beyond the physical constraints of the narrators. Such an imagination of "health" and "sickness" obscures our understanding of what narrators achieve by discussing chronic illnesses, it also stabilizes the notion of health as "one thing" and not a notion that accrues meaning "through the relation between bodies rather than as something that a body is or is not" (cf. Atkinson et al., 77).[25] The role of the genre of the memoir in this context has not been adequately explored. In Mantel's memoir, we see a concerted attempt at making sense of social and familial histories in a clear way; this becomes a method of engagement with "remembered events" for the narrative. The memoir, for instance, trails off after describing scenes that do not add up, but in their failing to do so, the text offers some questions around why, for instance, certain aspects of a patient's life (in the wake of the diagnosis of her disease) and the narrator's life need to be read in association with one another.[26] As Mita

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[23] See Vyshali Manivannan's "'A Way of Life That is Not Entirely Unfortunate': The Peripheral Cunning of Chronic Pain' (2017), p. 24.

[24] Sue Baier's and Mary Zimmeth Schomaker's *Bed Number 10* (1989) has been interpreted in this way. See Anne H. Hawkins's *Reconstructing Illness: Studies in Pathography*, p. 7.

[25] See Sarah Atkinson et al. "The 'Medical' and 'Health' in a Critical Medical Humanities" (2014), p. 77.

[26] The question of accommodating "patient's perspective" (*Betroffenperspektiven*), as Mita Banerjee suggests, has raised important questions about can bring about a genuine dialogue between medicine and life writing. As Banerjee writes, "Recent studies in aging research, as in longevity studies and centenarian studies, have drawn attention to the need for extended interviews, for supplementing

Banerjee (2018) suggests, we need to question how accommodation of the “patient’s perspective” because this perspective may in and of itself not be enough if we think of it as that of a sick and ailing body’s; to the contrary, we should ask, what could we do with this perspective if we think of qualitative analysis and literature in terms of bodies with vibrant imaginations.[27] Borrowing from Banerjee’s suggestion, we may say, qualitative analyses requires a careful attention to details, so the recourse to literature to reach out for diverse notions of “cure” and “health” by attending to those details is in itself a recognition that we need to supplement prevalent models that heavily rely on quantitative approaches that serve to accommodate patient’s perspective without effectively listening to them. Thus, working with extended interviews, life review narratives, and (in)directions made possible by literary texts cannot fulfil their promises and potentials if we do not pay close attention to what they underscore. Close reading is crucial; an understanding of the politics of the text’s engagement is imperative; and thinking against our habits—both of traditional literary criticism and from the perspectives of hard facts of quantitative studies and rational-scientific discourse—indispensible. As Banerjee notes, when we view illness narratives merely as “patient’s accounts” we tend to slide into or rely on categories that these narratives struggle against or speak in relation to. Thus, it is important to look for tensions within the category of illness narrative to see how these narratives are more aware of how they have been read and heard and for what purposes. The point of the patient’s narratives is that these narratives see medical care, the notion of “trust” in medical practice and the larger politics within which this trust is gained and utilized, and doctor-patient interactions as not removed from social and cultural mores that influence medicine. Rather, experiences and memories of these influences (as they emerge in everyday practice of medicine) are not simply a complaint against the ideology of medicine but an integral part of how these violent experiences are a part of experiences of illnesses, and they need to be explored for a genuine conversation and

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quantitative through qualitative analyses. In this revision, then, life-writing narratives may prove powerful documents for upsetting the dichotomy, and the erstwhile hierarchy, between medical experts and laymen and—women” (8).

[27] Ibid.

reconstitution of the subject to take place.[28] From a medical standpoint, these deep memories of the patient when she was not heard are important to be addressed because they address a listener that is, in part, imbricated with social histories and gendered practices of which medicine, now afforded an urgent role to "cure" the patient, is left comfortably unaware of its own complicities. In order to underscore and challenge this violent characteristic of an amnesia, *Giving up the Ghost* activates deep memory to make explicit how medicalization cannot be engaged without lived experiences. The recourse to description here is not just to talk about personal experiences but to highlight a kind of living that, however remotely, needs to be engaged with to come to understand the incipient intelligence of the patient's perspective. In this context, it's important to note that although it establishes itself as a "memoir" its self-declared generic certainty belies the very experience in relation to which this memoir enunciates itself: a severely compromised life that is deathlike. The phrase "giving up the ghost" means to die when it is used for a living person and it also means to cease to "function", which connotes an object-like state of existence. In the context of this memoir, there is a dual message: it is both a memory of dying (as a living being) and a memory of having ceased to function as an object as medicine understood the living being to be, that is, due to medical neglect, abuse of patient perspectives by not considering these perspectives seriously enough, and prolonged iatrogenic distress. The certainty about the genre of the memoir lies in an intricate relationship with the kind of "dying" that the title refers to and belongs to a living person and non-living matter alike; in this way, the question of genre formation and the role of memory to find a way to be alive and find "health" are tied to notions of making and re-making of a subjectivity. This memoir represents anger, grief, and recounts the story of a narrator in a way that requires us to question why intensely personal family narratives are juxtaposed alongside her experience of medical abuse and undiagnosed endometriosis while often drawing on connections and commonalities between these scenes of experiences to a speculative language. If I seem to suggest that I am of the opinion that a "memoir" and a "fictional" work are not completely opposite to each other in its construction, it is because I am borrowing from Siri Hustvedt's (2014) idea that "all

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[28] See *Healthcaring: From Our End of the Speculum* (1976). Directed by Denise Bostrom and Jane Warrenbrand, the short film discusses how male physicians not taking women's (often undiagnosed) medical conditions seriously as a more recurrent problem in medical practice than it's recognized.

autobiographical conscious memory are forms of fiction."[29] The complications that arise out of such a troubling of the categories of "memoir" and "fiction" are useful because they create a space that is important to be recuperated for analysis of illness narratives as crucial resources to come to terms with patients' perspectives. Ascribing an element of fictionality to the life writing narrative, a memoir or an autobiographical piece, then, is not to deny the lived experiences but to appreciate how the act of writing in the wake of marginalized experiences assumes a significance that is important for the purpose exploring the triadic relationship between writing the body in pain.

In this regard, Mantel "descriptions" are important because they carefully sift through diverse temporal and spatial contexts that then counter the gendering of descriptive language in and beyond medical discourse; at the same time the attention that is elicited in this descriptive language is significant because it attests to the rhetorical force of the conscious memory of writing. This is a force that distinguishes this memoir—published in 2003—from the kind of autobiographical texts that worked to politicize gendered pain in the 1980s and 1990s, which was a period when writing around issues of unrecognized conditions and psychic pain flourished in Anglo-American women's writing.[30] At the same time, as Mantel writes in a review of US-American writer Siri Hustvedt's autobiographical work on her "delayed grief reaction" in the wake of her father's demise, *The Shaking Woman and the History of My Nerves* (2010), "Illness does not necessarily produce insight. Mostly it does not. It must be endured, accommodated. Our struggles towards health can accommodate what looks like disease."[31] Thus, in ascribing an "emotional intelligence" to this memoir, I

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[29] See Siri Hustvedt's workshop discussion—"Why One Story and Not Another?"—at the *PEN World Voice Festival of International Literature* (28 April – 4 May 2014) in New York, N.Y. <https://www.youtube.com/watch?v=ADdw0yO0lnI>Web. 10 Jan 2018

[30] For instance, Canadian born writer Charlotte Vale Allen's *Daddy's Girl* (1980) was initially rejected by publishers when she wrote the novel, her first, in 1971, which was soon after her father's demise. The novel discusses lived experiences and emotional effects of surviving incest; it corresponds to the social trajectory of the reception, denial, and politicization of gendered pain in autobiographical writing. This novel's critical and mass reception is just once instance of how gendered pain and writing has been accepted (or not) over the course of these decades.

[31] See Hilary Mantel's review of Siri Hustvedt's *The Shaking Woman and the History of My Nerves* (2010) on *The Guardian* (30 Jan 2010): <https://www.theguardian.com/books/2010/jan/30/siri-hustvedt-shaking-woman> Web. 10 Jan 2018

am not interested in essentializing the experience of illness in terms of a mystical language, but only suggesting that the memoir reflects a concerted and calculated effort in thinking through her experiences in relation to what she remembers, which is uniquely Mantel's achievement, and needs to be distinguished as an established writer discussing her autobiographical experiences (in her only memoir till date) in this regard. I will be discuss how owing up to the writer's credentials (as evinced in Mantel's and Hustvedt's works alike) has been used for strategic purposes to enter into a conversation with medicine and rational-scientific views of human life. There is a feminist politics to claiming one's established identity as a writer from one's embedded locations and enfleshed subject-positions (cf. Braidotti 2015).[32] Furthermore, with close textual analysis of her descriptive language I will show how Mantel's text offers an attention to details of the experience of having undiagnosed endometriosis; this attention is important because it allows us to come to terms with the suffering and a concomitant creative potential that is present in patients' perspectives. It remains to be seen what this creative potential has to offer to us and to research in health humanities at large.

2.3 The politics of attention in description

Descriptions are usually viewed as often circumventing the issue or narrating a set of experiences that amount to what is perceived at least from a rational-scientific view as being superfluous. Descriptions risk being perceived as besides "the" point because the topic or condition that a piece of description undertakes often takes a detour; in regards to literary narratives, this detour works in terms of a labour to provide a "fictional" account of a lived experience. But if we, for instance, take the constructed and self-conscious fictionality seriously, how could we, then, better understand lived experiences through the partial account of lived experiences? Besides valuing individual lived experience, could we also then learn from the creative practices that sufferers participate in a way that does acknowledge their pain as well as their representation of illnesses for what they have to

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[32] For a discussion on a "situated practice" in the context of feminist politics, see Rosi Braidotti's essay on "Punk Women and Riot Girls" (2015). Braidotti suggests, "One has to start from micro-instances of embodied and embedded self and the complex web of social relations which compose the self. A situated practice." <*http://www.performancephilosophy.org/journal/article/view/32/63*> Web. 10 Jan 2018.

offer? Critics working in the field of autism studies have analyzed creative practices of low-functioning autistic individuals (cf. Banerjee 2018).[33] Similarly, we need to examine the poetics and politics of descriptions in illness narratives because they retain a close association with the cultural politics of description and scenes of their devaluation and exclusion, especially to think through what descriptions hope to achieve. How does this particularly gendered register of narration form a dialogue with how the emphasis on "description" has been read in critical discourse?

Mantel's descriptions, I argue, disrupts the prevalent notion of illness as an "event" that sufferers' narratives and patients' perspectives simply relay without influencing the interpretation of this event through particular genres, i.e., the memoir views the manifestation of a disease like endometriosis and its social implications from the perspective of something smaller than an event that cannot be made legible from the perspective of narratives that an institutionally recognized term like a "disease" suggests. This is also why we need to heed to extended reviews of the lived experience of illnesses in the age of biomedicine. The accrual of pain, medical neglect (inadvertent or not), and changes in one's experience of a gendered body are seen not as always already fully fleshed out events that the subject of this disease experiences in Mantel's memoir; instead, the institutionally validated processes through which a social experience of a disease comes to be perceived as an "event" and given attention are deconstructed in the text by examining scenes of bodily dispossession in diverse contexts. With the advent of a postmodernist sensibility, however, as Mark Seltzer (2011) notes, the critique of grand narratives has brought with it a prolonged attention, a "decelerated gaze" towards small-scale events or "non-events" (cf. 27).[34] What gets

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[33] See Mita Banerjee on Tito Mukhopadhyay (autistic individual) and his mother Soma Mukhopadhyay's collaborative work in regards to finding sufferer-oriented models of expression for individuals with what has been contentiously called "low-functioning autism." Cf. "Temporalities in Life Writing: Tito Mukhopadhyay's *Beyond the Silence*" in *Medical Humanities in American Studies: Life Writing, Narrative Medicine and the Power of Autobiography* (2018).

[34] Mark Seltzer (2011) writes of an "incrementalist turn" in the following terms: "This is a turn toward the minor and the scaled-down (in professional fields—the humanities and the social sciences—that are institutionally doing the same). Hence, for example, with respect to the novel, there is a turn to the study of minor characters; with respect to affect, minor feelings; with respect to political forms, little resistances, infantile subjects, minute, therapeutic adjustments; with respect to perception, the decelerated gaze and a prolonged attentiveness; and so on. These forms of one-

legitimized as a bodily or psychic event and is consequently endowed with medical attention which is attributed to known diseases needs to be carefully examined to better understand the different faces of chronic pain that cannot be readily gauged in medical terms. The attention to the smallness in and against grand narratives, however, is not merely a reaction to prior approaches in theorizing processes of globalization (and to which biomedical knowledge is closely tied), as Seltzer suggests, but does an important work: they arrest events as they become events. If memoirs, by definition, sift through the smallness and minutiae of events, what should we make of Mantel's memoir that focuses on the notion of the "incremental", which strives to legitimize social experiences of a having particular illness in a particular body? To discount this project as a wholly reactionary act against institutions and postmodern acclimatization to globalization, as Seltzer does (27), then, seems reductive to me. Instead, I want to provide a more generous reading to texts such as *Giving up the Ghost* and how they engage with the so-called incremental turn in cultural productions, particularly in memoir writing- and think through the productive work that this "decelerated gaze" to her past brings forth. Is it possible to conceive that in the act of sifting through memories *Giving up the Ghost* actually stumbles upon the "quasi-ness" of illness experience, an experience that is particularly relevant to examine "contested diseases" like endometriosis, fibromyalgia, and chronic fatigue syndrome that were not recognized due to a gender bias in medicine, and still continues to haunt proper diagnosis of such diseases? And if so, how are we to make of the conditional nature of the illness experience in relation to narratives that, however remotely, influence medical discourse? These complicated connections are never just formal features of the unruly text that is *Giving up the Ghost*, but bear profound significance in regards to Mantel's illness narrative could inform narrative approaches to medicine.

2.4.1. A note on methodology

In terms of methodology for this chapter I will discuss the "quasi-evental" character of the pain narrative in *Giving* through Veena Das's (2013) and Kathleen Stewart's (2011)

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downmanship—a turn from large events to small (non)events—are the reverse side of the one-upmanship of recent academic acclimatizations to globalization" (cf. Seltzer 727). Specifically interested in game theory, postmodernism, and microsociology of interactions in Patricia Highsmith's crime fiction and psychological thrillers, although Seltzer identifies the trend of incremental turn in contemporary literature and criticism he has little use for it because he is not interested in minority subjects' (the subject of illness experience, for instance) engagement with the incremental turn.

problematization of the notion of "big concepts" and its effects on everyday life later in the chapter. In so doing, I will suggest how this narrated illness experience needs to be taken into account in narrative approaches to medicine, particularly meta-analyses in evidence-based medicine (EBM) to improve well-established methods in medical practice.[35] The ethnographic critique of "big systems" (cf. Stewart, 75) and terms prefixed with a "bio" (for instance, biomedicine, bioethics, etc.) is well taken because these concepts tend to conflate fully fleshed out and epochal events in medical history (such as "biomedicine" and "bioethics") with everyday and social experiences. But while ethnography as a field describes "others" and what it witnesses through ethnographic accounts, life writing and auto-ethnographic narratives, by definition, speak for themselves. In other words, I borrow from postmodern literary theory the recognition that the turn to incremental thought to understand cultural processes is not only perhaps pervasive but also productive to understand embodied experiences that subjects of certain illnesses discuss. Furthermore, postmodern attention to formal structures and minutiae in and of narratives enable me to account for the literary force of *Giving up the Ghost*, thus I question the critical tendency to view illness narratives and experiences as either stultifying in its "anger" toward medical violence that they engage with or a "petition" to be heard by medicine and, thus, be remedied according to well-established curative models. Being replete with these affective legacies of the narrator's illness, the text achieves something significant by situating these affects in a hybridized register in relation to specific descriptions from where they emerge.

The autobiographical aspect of the narrative in *Giving* becomes "a form of fiction," in Hustvedt's (2014) term, and assumes a literary force that then can supplement a remarkable blind spot in biomedicine: the overwhelming focus on events and construction of diseases as physiological events risks betraying the purpose of reflexivity and meta-analyses in evidence-based medicine. I turn to disciplines like ethnography and anthropology that value the important work that can be done through "description" as a register that is not valued in Western medicine; finally, I attribute this description to its place in a literary

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[35] According to a medical student (studying for the M.D. degree) at the Universitaetsmedizin and the University of Mainz, Anna Petasch, "meta-analysis and well-constructed randomized controlled trials (RCTs) are the highest form of knowledge evaluation and production in the pyramid of evidence-based medicine" (2017).

account, a highly unruly memoir, to see how Mantel's description of her illness experience address the quasi-eventalized substrate of her experience to write with chronic pain.

2.4.2 Description and affective literacy in a contested illness

> The jumpiness of things throwing themselves together has become an object of ordinary attention. That's why models of thinking that glide over the surface of modes of attention and attachment in search of the determinants of big systems located somewhere else are more and more like road blocks to proprioception than tunnels that yield understanding (75).
>
> Kathleen Stewart, "Weak Theory in an Unfinished World" (2008)

A certain kind of affective and grief literacy is urgently needed to come to terms with chronic pain and illness narratives can offer this literacy; in Mantel's memoir, this is done by not just appealing to their readers' sympathetic ear but by demanding a commitment (Sen 1977) in terms of how closely we read can be used to engage with embodied experiences, private spaces within which such experiences take place.[36] The invitation for a critical engagement to the reader is a necessary strategy for illness narratives because these highly self-conscious documents that are aware how their narratives will be read and interpreted (cf. Das, 211). Narrators of illness, as Veena Das (2013) notes, are aware that their individual experiences cannot be "assimilated to the templates others have of what it is to suffer", thus, they are compelled to invent their own strategies, their own techniques of visibilizing marginalized experiences that, hopefully, leave an indelible impression on their readers. The stakes of visibilizing these experiences and the need to make them recognized are too high for bodily and psychic conditions that are not institutionally recognized because of the direct material advantages that can be achieved, but also underscore a notion of a reparative justice for marginalized subject-positions which could enable greater access to one's subjectivity. Narratives of endometriosis, fibromyalgia, and chronic fatigue syndrome roughly follow the same sociocultural trajectory and are informed with this narrative principle, but, of course, emerge with diverse narrative strategies and physiological symptoms (Greenhalgh 2001).[37] In this section, I want to briefly talk about how *Giving up the Ghost* engages with broader conceptual issues of this chapter through its formal techniques. The dissertation's focus on

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[36] See Amartya Sen's "Rational Fools: A Critique of the Behavioral Foundations of Economic Theory" (1977), p. 327.

[37] See Susan Greenhalgh's *Under the Medical Gaze*, p. 8.

chronic illnesses in life writing narratives is redefined by examining how the formal structures in Mantel's text speak to the notion of the "chronic" and aspects of certain illnesses that cannot be imagined through any particular concept but lie at the intersection of several—namely, chronic, illnesses, and gendered pain. While "chronic" as a temporal marker is typically perceived as passive endurance of pain, the "contested" aspect of endometriosis in the last few decades, for instance, suggests such contests detract us from being attentive to a kind suppleness that narratives need to work with pain, or use pain in a way that can provide a critique of medicine's and dominant imaginaries of pain. The subject of pain, chronic pain, the imaginary suggests, not being able to "master" pain cannot be an "agent" in any way (cf. Gilmore 2012: 83, 95). At a fundamental level, these notions stem from the idea that pain is wholly paralyzing or antithetical to the production of new ways of thinking about pain and the notion that "thinking" and "pain" are entirely opposed to each other. But pain narratives are unique in the way they respond to their challenges, so it is not surprising that Mantel's text observes the demands of attending to chronic and contested pain in intersecting ways: she identifies how the contested nature of the disease in popular imagination and in medical knowledge is in dialogue with the chronic aspect of a pain that is sustained through gendered practices, this is why the text belabours with scenes that it argues need to be read in relation to one another. *Giving Up the Ghost* is clear on focusing on processing and writing through pain than just examine pain from "big concepts," it works with relations, past and present, institutions and individuals, and health and illness. Towards the end of the memoir, and after having provided snapshots of her childhood and adulthood as a subject of pain, Mantel writes,

> I am not writing to solicit any special sympathy. People survive much worse and never put pen to paper. I am writing in order to take charge of the story of my childhood and my childlessness; and in order to locate myself, if not within a body, then in the narrow space between one letter and the next, between the lines where the ghosts of meaning are. Spirit needs a house and lodges where it can; you don't kill yourself, just because you need loose covers rather than frocks. (*Giving*, 222)

Writing is akin to reconstitution of the narrator's pained self (Prodromou 2015); this, however, does not make the act of writing an entirely or blithely optimistic project but makes its refamiliarizations with instances of pain as space of persistent critique.[38] Writing in Mantel's text is an "*attempt* to seize the copyright in [herself]" (*Giving*, 71; emphasis added). Writing is a bodily act for the subject of pain as evinced in *Giving*: "[w]hen you have committed enough words to paper you feel you have a spine stiff enough to stand up in the wind. But when you stop writing you find that's all you are, a spine, a row of rattling vertebrae, dried out like an old quill pen" (222-23). We need to think what it means to "take charge", "attempt to seize", to "locate [oneself]" in relation to the spectral ghosts of meaning that reside somewhere between the words of a text on pain. Writing follows the sentiment of writing back or speaking truth to power in Mantel's text; in this sense it is not unlike a traditional pathography, which, as Anne Hawkins (1993) suggests, "restores the person ignored or cancelled out in the medical enterprise, and it places that person at the very center" (cf. 223). A restorative project, the subject of pathographical literature and unrecognized illnesses seems to find a voice of her own at the precise moment when it writes: writing and forming a narrative in this genre amounts to becoming "healthy" (Eakin 1999), getting better, but, at the same time, it seems Mantel's self-declared "memoir" denies this project to become an entirely positivist one but remains obdurately attached to memories, quasi-events that require new ways of reading. What is achieved in accessing these memories through material specificities of remembering is, however, useful to imagine with the needs and desires of this subject of pain. Thus, true to this notion of "restoration" the writing that emerges in this process is committed to healing, takes recourse to memories and persistence of pain in an intelligent way rather than be defeated by it.

One way to appreciate this reworking of pain in this narrative is to see how a defamiliarization of events is produced in descriptions. In the process, the narrative becomes something akin to "ethnography" of the narrator's memory. It is ethnographic because it describes, it shows more than it tells (although this distinction does not hold at certain points), but also because it provides accounts for *why* these descriptions are necessary to be read as a part of a narrative of a contested and chronic disease. As readers, we cannot appreciate the importance of these aspects of the text as simply responding to concepts like biomedicalization of our lives but see how these big events assume a particular shape and

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[38] See Amy-Katerini Prodromou's *Navigating Loss in Women's Contemporary Memoir* (2015), p. 143.

texture in *Giving*'*s* descriptive accounts. By providing a particular shape to events, be it in from the narrator's childhood or her grief of childlessness due to endometriosis, *Giving Up the Ghost* allows us to think how experiences of illnesses needs to be tracked in a way that asks what gets underscored as an illness experience. Events of medical abuse are no longer "events" in this writing but become what medical ethnographers would call "quasi-events" (cf. Das 2). Experience of such quasi-events, as ethnographers remind us, "is not a transparent category," its "opacity" is much more difficult to track it in narratives than it is typically assumed. The labour of tracking this kind of an experience requires a process of deliberation and staying with the scenes through the slow and sustained attention of descriptions. We may come to terms with how experiences of certain events are dissected and not just how the narrator encountered them. Medicine's engagements with chronic pain of endometriosis are read as something smaller, more intimate, and seen as resonating with the subject in a way that shows how these events of being silenced, not being heard, never assume the stature of the event as such. They are, to the contrary, smaller and nearly illegible events, almost becoming events but failing to be so at the same time. In recognizing these the "quasi-ness" of such events in Mantel's memoir, I suggest, we may be able to explore the complicated role that description as a modality plays in this patient narrative in *Giving Up the Ghost*. Descriptions in *Giving*, then, are never mere descriptions, but need to be read as rejection of the understanding of experience that is problematically satisfied by simply [pointing] to explanatory models as if terms such as "biomedicine" can explain how it affects everyday life. The experience of medicalization of bodies is, thus, not like encountering an object (a chair or a table, as Das notes [3]) that one could easily point and identify. These require an analysis that descriptive language, extended examinations through various qualitative approaches, and literary texts can do very well. These descriptions necessarily, and however remotely, remain in conversation with how grand narratives of the "illness experience" are produced through practices in medicine. Reading experiences from different points in the spectrum that is an experience is crucial because in this way diagnosis of disease can incorporate an ethical component in its formulation of what it perceives as "pathology" and what it aught to consider as "non-pathological." Furthermore, in so doing, literary narratives provide an affective literacy for their readers, a literacy that is crucial to advance interdisciplinary dialogues.[39] I borrow from contemporary ethnographic analysis because of the field's emphasis on descriptive language and commitment to problematize the narratives of medical interventions (via potentially monolithic concepts) and bodily or mental conditions in specific life-worlds. It is through description, we may say, we can observe how the narrative "jumps," what motivates and affects the narrative "I" in pursuing the implications of certain memories in relation to others, particular embodied experiences through the lens of others. Yet ethnography of observed others as conducted by medical ethnographers and theorists and ethnographic endeavours in relation to an autobiographical memoir are not at all same; thus, in order to recuperate this auto-ethnography of pain in a strictly unruly text like Mantel's I try to understand what is to be gained by engaging with not so much how chronic pain is "narrated"—because narration often slides into a paralyzing notion of a lament—but how it is affirmed and sustained, and, I ask, what are the implication of sustaining this chronic pain in the formal strategies deployed in the ethnography of this memoir and for creative and curative practices at large?[40]

2.4.3 Sustainable pain "after" memory fatigue

In this section I will examine how a focus on sustainability of painful memory is predicated on the material contexts of the act of remembering. This focus seems to crucially discern between memory and the politics of remembering in an illness narrative. In so doing, *Giving up the Ghost* as an illness narrative does not correspond to the issue of memory retrieval, which is conventionally explored in memoirs, but mobilizes a practice of remembering which engages with chronic pain through its descriptions. According to the International Association for the Study of Pain (IASP), the distinction between chronic benign non-

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[39] I would like to acknowledge Dana McClain's initiative for organizing a roundtable on the issue of "grief literacy" at the annual meeting of the Northeast Modern Language Association in Pittsburg, PA, (12- 15 April 2018). McClain's roundtable discussion—"Becoming Grief Literate: What Humanities Can Teach Us About Mourning"—is scheduled for 13 April 2018.

[40] The issue of using pain and drawing from the creative forces of pain risks romanticizing it and, at least for skeptics, tends to construe the idea that subjects are enabled to pursue a perverse pleasure in their pain in this way. This, however, cannot be more different from the notion I am trying to convey here: chronic pain is still painful but not wholly paralyzing for a subject is a fairly simple idea, but meets resistances of all kinds when we attempt to identify this dynamic for real life subjects that autobiographies represent, perhaps because there is an incipient moral universe that pain brings forth and one which "chronic pain" is at odds with.

neoplastic pain (CBNP) and chronic intractable benign pain syndrome (CIBPS) is "*the patient's capacity to cope adequately*" (cf. Baszanger 91; emphasis in original). The duration of pain is also taken into account to distinguish CIBPS from "true" chronic pain (91).[41] I acknowledge that institutional platforms for the study of pain have to work with verifiable data or so-called "common denominators", but the creative processes that are in conversation with pain (life narratives in particular) do an important work in terms of supplementing empirically verifiable investigations of pain in service of established curative models. And it bears highlighting pain remains one of those sensations that medical technologies cannot verify with tests, numbers on a scale, etc., it is determined through palpation, by observing the facial reactions of the patient and how she describes it (cf. Manivannan, 36). Thus, my concern is with the issue of "adequacy" in regards to the expectation of coping with pain as the patient describes it; besides being a relative term, the question of adequacy calls for a large range of possibilities through which subjects could come to terms with their pain. While critical approaches towards the issue of adequacy have tended to dismiss how important this is both for subjects of pain and experts who are interested in engaging with pain through all its complexity largely because "adequacy" invariably leads us to ask the default of position of the subject (so, "whose adequacy?"), approaches guided by such questions have not fully examined how the issue of adequate coping suggests a reworking of pain on a daily basis as lived experiences is also about inventing strategies of survival. Instead of dismissing a generalization posed by the issue of "coping adequately" I want to examine how sufferers' experiences can be acknowledged without dismissing bodily pain and its unique demands in regards to amelioration and mechanisms of coping. The term "adequate" resonates with the concept of sustainability, particularly the way in which narratives of chronic pain perform an intelligent engagement with issues of sustaining affects through the formal structures of the text. Sustaining a negative emotion, pain or grief, means addressing it through its partial and rhetorical traces in narratives, through the opacity with which negative emotions (like pain) enunciate themselves and are subsequently endured. Thus, if the chronically pained body is webbed in its relations with the outside and the inside of the body, pasts and the presents of the body, and the public and the private body, it is by sustaining and connecting the emotions that the

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[41] See Isabelle Baszanger's *Inventing Pain Medicine: From Laboratory to the Clinic* (1998), p. 91.

body incurs at these sites that are important to ultimately dismantle its repeated splitting into identities that are as if disconnected from each other. A total focus on "authentic memory" tends to split the identities into what they "were" and they "are", whereas a partial focus on memory, particularly fallibility of memory, recognizes the task of remembering in relation to the spatial and temporal contexts of remembering as its primary goal.

Sustaining pain in order to make readers' pain- or grief-literate and to have pain recognized should not be viewed as being selling out to institutional structures because such a view would see pain narratives in terms of a problematic logic of either being either "paralyzed" or being trying to "get over" pain.[42] Such a polarization of chronic pain is unsatisfactory. Chronic pain needs to be conceived as working in sustainable ways because these pains organize very different life-worlds in relation to the sites and bodies they emerge from. As a concept that has primarily gained attention in the social sciences and environmental humanities, sustainability has not been clearly conceptualized in memory studies; borrowing sustainability in terms of how emotions and affects, particularly negative ones, are sustained in a creative ways requires us to account for its partiality and its traces in narratives. Thinking of creative energies being sustained through pain also allows us to acknowledge that sufferers who write about their experiences are not limited by their identities but meticulously explore the "moorings of [their] identities" (Banerjee, 14). Particularly in the case of life writing narratives, the concept of sustainability of chronic pain is important because it allows us to account for the coexistence of pain and contingent relations. Sustainability can envision the chronically pained body in terms of its awareness of its "interrelations to others" (cf. Braidotti, 311), precisely because of the compromised conditions it inhabits. Chronic pain in this memoir needs to be conceptualized from the perspective of sustainability of pain because written in 2003, *Giving up the Ghost* is a

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[42] I am grateful for this point on the "anxiety of selling out" to Mita Banerjee. Banerjee discusses this in detail her upcoming monograph, *Medical Humanities and American Studies* (2018), when she writes about the collaborative role of the humanities and the life sciences and how humanities could benefit by "re-importing" its tools and methods. Sustainability, as a predominantly social science and ecocritical concept, can be introduced in literary narratives to examine how projects of endurance of pain fulfill certain promises that masculinist reification of embodied pain cannot; this concept, thus, has immense potential to explore narratives of chronic pain in general and Mantel's narrative in particular.

memoir about a woman's bodily pain and her childlessness that comes after at least two decades of memory writing in women's literature which witnessed experimental forms of representing pain. While I cannot do justice to the range of these forms of memoir writing in other media than the written text, I wish to underscore the return, so to speak, to the written word in *Giving up the Ghost.* Why is a self-declared "memoir"—the title of the work reads *Giving up the Ghost: A Memoir*—readily, perhaps even decidedly, a memoir, which is to say, besides suggesting it has autobiographical elements what else does the term do to the narrative at large? Furthermore, and in embracing this genre how is this text responding to decades of memoir writing in women's literature and illness narratives prior to its arrival and, in turn, contributing to this sub-genre? *Giving* acknowledges and identifies with the tradition of memoir writing on pain that came before it while, simultaneously, working with chronic pain to addresses the gender politics and a crisis of signification that contested diseases like endometriosis, fibromyalgia, and chronic fatigue syndrome brought about for medicine (Barker 2005; Greenhalgh 2001). It departs from a traditional view of memoir writing, that is a view which conflated mobilization of negative affects like pain and understood all endeavours at memoir writing as essentially traumatized. Sustainability of chronic pain is a heuristic project—it is speculative about its material conditions, curious to learn more about the interrelations of the body in pain, and it does not confine itself with the satisfaction of having mastered it in writing about it. It imagines identity in terms of becoming *with* pain while acknowledging that the embedded aspect of being in pain, and an ontologically unstable subject-position occupied by the subject of chronic pain (Gilmore 2012) is thus deployed in service to sustain and reflect upon it. But then again, how can pain be sustained in order to socialize it? Unlike memory, chronic pain is more conducive to repair work and sustainability that is evidenced in narratives because pain, by definition, aims to ameliorate itself, while memory (particularly negative memories), often obdurate, has its "anti-social life" (Reading 2017) and could prefer to shun mnemonic company besides its own.[43] The

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[43] Not unlike the concept of "memory," chronic pain can only be socially recognized when it's "transmitted" (Wickham 1992), which necessitates it to be articulated in the first place. And the pain (which traverses the same path of "social memory" [Wickham 1992]) is also intensely aware of its "other"—forgetting of pain—just like memory is haunted by an anxiety of forgetting and being forgotten by institutions that need to pay attention to it (Reading 2017). Cf. See Anna Reading's keynote lecture "The Anti Social Life of Memory" at the symposium titled *Mnemonics Summer School 2017: The Social Life of Memory.* The lecture was delivered on 09 September 2017 at the

presence of chronic pain in Mantel's text wrests "memory" out of the scenes and uses memory for future-oriented purposes of sustaining attention to the scenes in memory. The politics of remembering memories of bodily pain and its concomitant denial in medicine should not be imagined in terms of a "rigorous memory practice" (Halberstam 87) haunted by the denial of the "entropic force" of memory that is used to compensate by remembering and thus denying all aspects of the human habit of forgetting. Chronic pain marks a different territory altogether: it is not remembering for the sake of "not forgetting" but remembering is comfortably at ease with forgetting a part of and in some cases all facets of some memory. Sustainability in this vein admits of having a fallible memory but works with what it left of it, its residues and traces, in not a melancholic vein but in an affirmative way. Speaking of the difficulty of retrieving her childhood memories of fatal accidents in the family that kills her grandparents or incidents of varied significance that shapes her childhood perception, she writes, "I wouldn't agree either that it doesn't matter what you remember, but only what you think you remember. I have an investment in accuracy" (24). Yet, she distinguishes this "investment" from the accuracy itself:

> I know, too, that once a family has acquired a habit of secrecy, memories begin to distort, because its members confabulate to cover the gaps in the facts; you have to make some sort of sense of what's going on around you, so you cobble together a narrative as best as you can. You add to it, and reason about it, and the distortions breed distortions. . Doctors used to say babies didn't feel pain; we know they were wrong. We are born with our sensibilities; perhaps we are conceived that way (24).

The tendency to think of memory and remembering through rigorous memory practices (most often constituted by minority groups marked by race, class, gender, and sexuality) as a sacrosanct act because it is readily viewed as "oppositional knowledge" tends to ignore the complicated processes and politics of remembering.[44] It also fetishizes memory retrieval as an unquestionable good that can well be put into uses that are far removed the specific life-worlds they emerge from, for instance, memory retrieval in the context of an stable "I" does not correspond to memory practices in relation to the subject of chronic pain who, by

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University of Frankfurt, Frankfurt, Germany. <*https://electure-ms.studiumdigitale.uni-frankfurt.de/vod/clips/qDISzeyA47/quicktime.mp4*>

[44] See Jack Halberstam's "Queer Betrayals", *Queer Futures: Reconsidering Ethics, Activism, and the Political* (2013).

definition, occupies an ontologically unstable position (Gilmore 2012). Thus, the importance of forgetfulness and partiality of this kind of memory practice is important because these aspects allow us to read memory in a new way. Deeply critical of “geological metaphors” (*Giving*, 25) that memory narrators were traditionally inclined to use to talk about pasts, Mantel is suspicious of the idea that the more our pasts are temporally distanced from us they become “hardest to reach.” It is not that one has to “prospect for them with the help of a hypnotist, or a psychotherapist” (25); to the contrary, she views memory like a “spreading limitless room”, a “great plain” or “a steppe, where all memories are laid side by side, at the same time, like seeds under the soil.” The narrator suggests we tend to “forget” these memories not so much because they are temporally or spatially far away from us but because of their proximity and familiarity. Enigmatically playful with her own writerly conviction that does not stick its own promise of not wanting to borrow from geological metaphors to describe her notion of memory work, the narrator talks about “memoryscapes” as a great plain, a steppe, but it is not so much of using almost geological metaphors—of “excavation”—what the narrator hints at is the familiarity and the intimate knowledge of all memories. Memories can be as familiar and, indeed, too familiar like the rooms we live in, and they can be as expansive and predictable as a flat landscape interspersed with seeds just below the surface. In recasting her conception of memory (even if in a slightly altered terms) an intimate knowledge that doesn’t require an external aid, the narrator seems to suggest what it means to be an apprentice to memory work. To work with distortions and partiality of memory is to put into centre of this text *why* would the narrator take recourse to memory in the first place, what triggers and sustains this act of remembering. This prospect of remembering is thus not concerned with what it is being remembered, or the “fact” of memory, but the processes of remembering it; the facts are, as it were, too familiar like seeds under the soil that are sown in regular intervals. The importance of the text is to honor the facts, that is, be invested in its accuracy without being paralyzed by it. Transposed on to a narrative of chronic bodily pain with effects that requires experts’ and institutional recognition, this facet of memory- that is, of it being intimately known to the subject who recounts it, not so much to narrate that which makes a particular memory but to find how remembering is sustained and to what end. Memory is different from remembrance in this sense that it does not happen in space and time like remembering does (Parr, 1); sustaining memory requires paying attention to its embodied aspects and the spaces and timeframes that are produced while remembering it.[45] What is sustained in remembering a memory is thus always "partial" in this sense because its goal is not so much to provide an accurate copy of the memory but work with its distortions and (re)tellings. Sustaining particular memories is an achievement in Mantel's text because it breaks away from a particular tradition of writing about memory work, a tradition that has arguably contributed to what cultural critics have described as a memory fatigue owing to rigorous memory practices that minority groups initiated to come up with memory narratives over the period when this genre was a fairly popular mode of narrative in the 1990s (cf. Farrell 1998; Halberstam 2013; Huyssen 2003). Mantel's text reworks this cultural mood of fatigue and negativity that had encroached in memory narratives, and she challenges this cultural and critical mood by focusing on processes of remembering. In the process of recounting partial memories that are not so much about exactitude of what is being retrieved but what the partial memory does to the larger narrative, Mantel's narrator underscores how sustaining and connecting memory with their spatial, temporal, and corporeal dimensions in remembrance is similar to an ethnography that is important to come to terms with an illness experience. We will see through close analysis of the text how *Giving Up the Ghost* brings these two apparently diverse methods to recuperate the sustainable aspects of memory in a way that captures embodied experiences of endometriosis.

What is common to both ethnography and a memoir, despite their different temporal affiliations, is that they make partial narratives and this sense of partiality is consciously reflected in texts that emerge form their narrative strategies: a memoir remembers pasts through the lens of the present, and ethnography describes immediately observed present in relation to the spatial and temporal specificities of a context that may have been in the past but not necessarily always. The narrator of a memory narrative talks about her (and others') pasts but in a way that does not claim "truth" outside a form of fiction that is all autobiographical narrative, to use Hustvedt's words. Similarly, the ethnographer is interested in forces, textures, energies and transitional qualities of the scene she is attempting to describe and situate the constructed and socially choreographed nature of the scene through

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[45] See Adrian Parr's "Introduction" and "Desire is Social" in *Deleuze and Memorial Culture: Desire, Singular Memory, and the Politics of Trauma* (2008), pp. 1-33.

observation. Partiality, rhetoricity, mnemonic experiences that emerge while remembering, and an acknowledgment that large-scale events do not form anything more than a shadow on our lives are a method for both these genres. Yet things happen in the zone of a shadow, and shadows, after all, do not entirely negate visibility but play with it. Owing to the self-conscious character of ethnography, ethnographers have highlighted how this genre traces the ways our vision gets directed in terms of a "jumpiness" from object to object (Stewart 2011) and a movement that speaks to our sense experiences, particularly when the site in itself is not intelligible (insofar as certain scenes and sites require "more" intelligibility than others). This jumpiness speaks of the way ordinary attention span is distributed, but also could potentially identify gaps between the sign and the meaning, between the (big) object or a concept that casts a shadow and what happens in the zone of the shadow. In memory narratives, if the object is "the pasts", its negotiations in writing through processes of remembering takes something away of their monumental stature of events in the form of writing lived experiences. The events are carefully chipped away, deconstructed, as it were, and we typically get descriptions of an exercise of processing events.

In *Giving up the Ghost*, however, this classic move of memory narratives is also not entirely applicable. Mantel's narrator speaks from the limits of what Andreas Huyssen (2003) calls a "memory fatigue" in contemporary culture and speaks to the alternative kinds endurance of memory narratives after its peak periods in production, an endurance that persists not because of uses of memory as trope in cultural productions but in the wake of a particular style of engaging with memories.[46] If the period after the Vietnam War (1955-75) witnessed saturation in the production of narratives of historical and domestic trauma in Anglo-American writing, the last decade of the century witnessed a growth in memory narratives that generated a fatigue in terms of the reception of these genres (cf. Farrell 1998; Huyssen 2003; Hustvedt 2014).[47] Although it is hard to periodize memoirs or examine why

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[46] See Andreas Huyssen's "Introduction" in *Present Pasts: Urban Palimpsests and the Politics of Memory* (2003), pp. 1-10.

[47] See Janice Williamson's *Crybaby!* (1998) for an account of "domestic trauma" in relation to intimations of incest that she experiences as an adult. And Michael Cimino's 1978 film *The Deer Hunter* is a classic example of the experience of "post-traumatic stress disorder" in the wake of the Vietnam War (1955-1975). It is important to read war traumas and combat experiences in relation to domestic traumas because interpretations of cultural productions from this period remind us traumas are not only incurred at the war front but in private spaces as well. Also, the inclusion of PTSD in the

writers take recourse to particular genres at a specific time, it seems reductive to me memoirs as a genre would remain tethered to any particular time period solely due to the demands of the literary market without changing or reflecting upon its styles of narration. Also, writers choose to write memoirs for very different purposes; in Mantel's case, for instance, *Giving up the Ghost* is her only work in autobiography and most of her work that has been lauded is in the area of "biographical-fiction" or historical fiction—for instance, *Wolf Hall* (2009) and *Bring up the Bodies* (2012). It is, thus, interesting to speculate why a writer who was already a literary success before she wrote her one and only memoir, *Giving up the Ghost*, and, it must be said, never ventured into the area of autobiographical writing since, chose to take a detour into this field before returning to her forte of biographical historical fiction. Although I am reluctant to deduce any causal logic here, I highlight this point from Mantel's career to problematize the incipient charge of ideology critique that critics have brought against memoirists and writers of autobiographical fiction in the 1990s and those coming directly after this period: the charge is that of catering to a literary market that had already witnessing an increase in production of memoirs of traumatic memory.[48] Such criticisms, however, do not allow me to take the formal structures of *Giving* seriously; at the same time, while it may be (and is quite likely) the case that Mantel's career bears the mark of a flourishing literary market at the turn of the century, it does not answer why the process of writing as a woman is organically attached to her family and illness narratives in the text, and how this association informs the narrative strategies she chooses to explore in the text.

In other words, recognizing these organic associations that this memoir creates allow us to see that written in 2003, Mantel's memoir does something new with the genre itself: it uses chronic pain in a register that suggests pain is more than an evidence of an injury or the illness of endometriosis itself. Chronic pain is thus defined in this register even from its embedded and enfleshed locations and the narrative's arrival and meditations on the

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Diagnostic and Statistical Manual-IV has had to explore the tacit (and often direct) connections between these seemingly different theatres of traumatic experience. Also, see Hal Ashby's *Coming Home* (1978)—a film based in 1968, it dwells on the PTSD from the point of view a disabled veteran and his lover.

[48] Kathryn Harrison's *The Kiss: A Memoir* (1997) has received such criticism. Cf. See Julie Rak's essay "Identity's Industry: Genre and Memoirs" (2010) In: *Auto/Biography and Mediation*, pp. 173-182.

"ultimate referent" of chronic pain, I suggest, is productively deferred owing to its postmodernist inspirations. At the same time, to suggest *Giving Up the Ghost* as Mantel's only autobiographical work is in any way more authentic to her concerns as a writer and a cultural commentator would be a mistake because this view would not take her reflections on the act of writing from the standpoints of a woman and a patient seriously; it would rely on privileging her writing as a patient more than her experiences as being a woman or a writer, whereas, we know from *Giving*, that these three aspects of her writing intersect in her memoir all along, intersections that position the narrator as a social critic precisely when she's also, of course, a memoirist.[49] I highlight this because *Giving* is not a traditional memoir that can be explored from the perspective of what Huyssen (2003) reminds us as a temptation "to think of trauma as the hidden core of all memory" (8); it does not privilege the autobiographical voice of the subject of illness over the voice of the woman writer but claims the space of the unruly memoir as a "site of discursive performances" (cf. Weinstein, 3). The incremental trauma of medical abuse in this context cannot explain everything in terms of what Mantel does because it would deny the creative forces that the narrator undertakes in *Giving* from the her embodied experiences, descriptions, of a formerly "nameless" disease that spoke to her bodily and mental states because of particular set of social conditions. The narrator's pursuits to investigate endometriosis when it was not recognized as a disease needs to be viewed from multiple angles to understand why lack of diagnosis in certain contexts has implications that exceed health-crisis; can such an embodied distress be reflexive, can it lead to creative pursuits through sustainability of pain and descriptions when this mode of narration is denied any form of legitimacy in medicine? Through narratives she is able to bring forth an affective literacy for her readers who would not have recognized the way her body's stories are connected to her personal narratives that have not much in common except for the notion of a "body" itself. For instance, in order to describe her wrong diagnosis, she writes:

> When you turn and look back down the years, you glimpse the ghost of other lives you might have led. You think of the children you might have had but didn't. When the midwife says, 'It's a boy,' where does the girl go? When you think you're

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[49] Also, Mantel's collection of short stories *The Assassination of Margaret Thatcher* (2014) like her historical fiction *Bring up the Bodies* (2012) have been read as a major commentary on the contemporary political culture and the class politics in the U.K.

> pregnant, and you're not, what happens to the child that has already formed in your mind? You keep it filed in a drawer of your consciousness, like a short story that wouldn't work after the opening lines (20-21).

Jumpy associations, if we may call them, are germane to Mantel's project in *Giving up the Ghost* because she is interested in the intersections between gender, medicine, and society and how women's experiences of chronic pain cannot be interpreted without reflecting on the intersections of these broader categories; however, she does not give a straightforward account of her experiences in any way. She sees her experiences in diverse context through altering lenses: she revisits her "healthy" childhood from the point of her ailing adulthood and her sick body from the perspective of "health" and that she has known for years. In effect, there is a flutter, a jumpiness of sorts at a very literal level, but, more interestingly, a slowing down of the narrative to focus on defining the social experience of having an undiagnosed illness in a particular body. The narrative belabours on these "shadow zones" that cannot be explained with the help of concepts like "gender," rituals of gendering, or the experience of a "false pregnancy" due lack of diagnosis at the onset of endometriosis, but lies somewhere at the interstices of gendering in and beyond medicine and how subjects define the chronic nature of enduring this grief in personal narratives. How is this memoir, then, doing a different kind of work here? We may say that by addressing pain through the lens of sustainability of that layer of pain that can be talked about and mobilized for writing this text consciously disaffiliates itself from a direct way of narrating pain. Mantel's task is committed to a literary ethnography that defines the said contested disease in relation to a social imaginary that resonates with her pasts and her present. The experience of a painful sensation—the midwife saying, "it's a boy"—is experienced by "another self which has already sided with the world" (Merleau-Ponty, 216) in phenomenological terms. The French phenomenologist Maurice Merleau-Ponty (1962) describes the splitting that the subject of "sense-experience" in the following terms: "[e]ach time I experience a sensation, I feel that it concerns not my own being, the one for which I am responsible and for which I make decisions, but another self which has already sided with the world, which is already open to its certain aspects and synchronized with them" (cf. 216). Merleau-Ponty describes the "thickness of some primal acquisition" between the sensation and the intended subject of sensation. This primal acquisition is like a cortical layer for the human organism that receives the sensation; the layer protects the intended subject from the sensation and it also prevents the "experience from being clear to itself." The acquired layer is both a necessary shield for the modern subject and one that gets in the way of fully engaging with the sensation. For Merleau-Ponty, the sensation signals "a modality of a general existence, one already destined for a physical world and which runs through [the subject] without [the subject] being the cause of it." The sensation (painful for not) is directed towards a subject that is already conditioned by the physical world where rituals of gendering inflict sensations, but in order to delaminate these rituals the subject needs to attend to the "thickness" of the primal acquisition, to chip away at this accumulation that then could reveal how the sensation that is intended for the physical world runs through the subject without the subject being the cause of it. Mantel's descriptions labour at this chipping, always examining how the physical world that generates sensations and those sense-experiences run through the subject but is also rendered (il)legible to the subject in the wake of liminal experiences.

2.6 *Giving Up the Ghost:* a close analysis

In this section I will provide specific examples from *Giving up the Ghost* to show how affect in the wake of gendered exclusions in the past is accessed in the text to speak to the narrator's illness experience. The importance of these largely negative experiences in the memoirist's narrative is crucial because they speak to her experience of her body in a significant way that needs to be examined to better understand the illness experience in relation to what was for her for a very long time in her life a medically "contested disease." For instance, early on in the memoir, in a section titled "The Secret Garden", the narrator describes an incident from her childhood when she was bullied and assaulted by a "big boy" (73) in school. She comes home to her grandfather to complain and her grandfather promises to teach her how to fight a bully: "keep it easy, no need to make a fist. Try a big slap across the chops." Following this advice, the young narrator goes to school the following day and finds astounding success in regard to tackling the bully: "I do it. Tears spring from the ears of the big boy. He reels, clutching the diaphragm, away from the railings. Oh Miss, she hit me, she hit me!" (73). Her immediate reaction is that of amazement and absolute joy at the every likely possibility that she would not get bullied in future. She says, "I am amazed: less by my performance, than by his; his alarming wails, his bawls." But she also says this feeling of initial thrill soon subsides and gives way to an religiously inflected and deeply gendered compunction of having done something wrong, something that she aught not to have done. The narrator says that she does not believe boys, bullies are not, are not made to feel this sense of "beginning of compunction" in the event of an action they choose to take and distribution of the feeling of having done something wrong or acted in way that could have been otherwise is deeply gendered. "Shame, is somewhere among my feelings about this incident. I don't know who it belongs to: to me, or the boy I've beaten, or some ghostly, fading boy I still carry inside me," she says (73). This incident in school does not have much to do with her illness because she was not sick with any kind of illness as a child, but lays bare the gendered dynamic that is common to her illness experience as being bullied by medicine in no uncertain terms and being a bully's victim in middle school. Furthermore, she attributes the inculcation of this complicated "compunction" to a number of factors in her personal history. She is not sure if what she's experiencing is simply the beginning of compunction, or if it's the "awakening of a sense of sin, or is it the beginning of femininity" (73). She also cannot help but remember this incident and the concomitant feelings it arose in her young self from the fact that this took place at a time when she was only a year before she had to go to confession and "learn to examine [her] conscience."

In this seemingly insignificant incident, the narrator uses one incident to discuss how gendered experiences needs to be read from multiple perspectives: a girl child's affectionate memory of her grandfather, her bitter experiences in school, her growing up Catholic in England, and her question if the inculcation of the "compunction" itself is disproportionately distributed among little boys and girls—a disproportion that is enabled and endorsed by religion and society. In viewing an incident from her childhood in such terms, Mantel's narrator dwells on the category of "experience" itself, which in this analysis seems to be never self-evident or transparent category, as Das suggests. To track and record an experience at multiple sites in one's personal history that it emerges from is a task for this text and something that becomes a method for Mantel's narrator. This close reading of experience as a category wrests negative memories out of their potentially paralytic thralls and put them into action, mobilizes them to explain and dwell on the question of experience specifically in relation to an illness narrative. This illness narrative engages with the genre of the memoir by not just narrating memories but by working with them to put memories in dialogue with each other. This is the work of sustaining memories in this narrative, their "negative capability" (cf. Keats 1817; Holt 2004) of being in doubts, uncertainties, questions and chronic pain, without being either incapacitated by fact of a memory or suggesting memories to be merely an evidence of an injury in the past that can be easily harnessed for a positivist project that speaks to "fact or reason."[50] In this way, memories in *Giving* highlight the embodied and embedded nature of these memories from the narrator's experiences in her childhood and her illness, they, I suggest, have more to offer than we think they do. This "negative capability" (Keats 1817) is not limited by taking recourse to any "fact or reason"; it is a capability unique to creative and artistic processes that can think through "descriptions" that are often deemed superfluous from a rational-scientific point of view. In this regard, the importance attributed to descriptions overlaps with anthropological ruminations on description as a modality, but departs from anthropology's external gaze of describing other people's experience and locates it in the internal memoryscape of subjectivity remade through sensory experiences of illness and gendering. When anthropologists suggest that experience is "not a transparent category, for its essential feature of tracking it is much more difficult than many authors assume" (cf. Das, 2) they seem to suggest that conceptual pillars (such as race, class, gender, and sexuality) of our collective and individual experiences do not work in terms of an easily identifiable in relation to narratives that, in turn, could fully explain particular lives to us. Even our everyday vocabulary –when we say "a gendered experience"—tends to betray our very concerns because while the experience maybe definitely gendered it is never an easy answer in regards to how a particular experience is cast in those terms. In not pursuing a close examination of the processes of gendering in what Merleau-Ponty calls the "physical world" we risk succumbing to the injuries it inflicts on us and risk losing sight of a potentially agential way of resisting those wounded sensations. As concepts that are meant to allow us to think and not enable a paralysis in the activity of thinking, these categories cast long shadows on lives (institutions like the family, the state, or gender) generate sensations that we process (consciously and unconsciously) before they become a part of what we tend to call "our experience."[51] I borrow from

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[50] For a brilliant reading of John Keats concept of "negative capability" (1817), see psychoanalyst Wilfred Bion's use of the idea in *Second Thoughts* (1967). Also, see Terrence Holt's "Narrative Medicine and Negative Capability" (2004).

[51] I highlight this aspect of Merleau-Ponty's ideas on the "sense-experience" because it resonates with *Giving*'s account of how and to what end past experiences are narrated in the text, and the points in

accounts of descriptions because of their acknowledgment of what anthropologists call an opacity in everyday life of illnesses that when analyzed from the perspective of "models of thinking that glide over the surface of modes of attention and attachment in search of big systems located somewhere else are more and more like road blocks to proprioception than tunnels that yield understanding" (cf. Stewart, 75). What would it mean engage with the mode of description (in memory narratives) in its own terms and not through the lenses of what Keats would call "fact or reason"? This does not mean that *Giving Up the Ghost* does not participate in a dialogue with rational discourses at all; to the contrary, it performs a dialogue that is of importance to both rational-scientific discourse and creative projects such as a memoir because these dialogue in Mantel's text revitalize both memoir as a genre by highlighting the importance of a kind of remembering that is not haunted by possibility of forgetting of memory, on the one hand, and their descriptions of illness experiences could inform narrative approaches to medicine, on the other.

Thus far, I have elaborated how affect retrieval in a descriptive mode works this memoir, but here I want to trace how *Giving*'s nuanced attention to affect retrieval in memoir has something important to offer to a different collectivity as well, this is collectivity of the epistemology of medicine, and in engaging with this epistemological worldview the narrator experiences first-hand the text does not remain nostalgic in its visitations of the past. Retrieving the affective valence of memories is not in itself a negative act of working with losses that have happened but becomes an affirmative one. As we will see, the illness experience is deconstructed not in terms of an "event"—as medicine typically thinks illnesses to be—but represented on a smaller scale, incremental, insidious and accrued over time. We may think of these "smaller events" that are often not legible in terms of the interactions between the body-disease-health as imagined in biomedicine; they are smaller and require a different script other than biomedically elucidated scripts to be understood. The illness experience, of course, comes with a large number of factors that cannot be readily translated in terms of an "event" in the way medicine thinks of all illnesses as physiological or mental events. When we describe a disease as an "event" it construes a particular definition of this event and has an imagination of its time frame and what it could potentially do to the body.

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the memoir where exploring this "sense-experience" enables the narrator to understand what she finds in her memoryscapes.

In this formulation of an event we do not see the resonances of another idea of the event that would suggest that "[e]ach time we express what we have perceived of the world, we make a fold in the thickness, the way folds in the brain permit chemical communication among its surfaces" (cf. Merleau-Ponty qtd. in Marks, x). Perception is defined in this way in terms of a cognitive violence that works through dissonances—it's a fold in the *density of everyday* life that not so much takes a "slice of life" out of its continuity but a loop that is seemingly detached from its ends. This loop, this folding of continuity in our perception is not severed from the ends but becomes a block in relation to its ends. Perception needs this fold, this twist to draw an aggregate of the continuity, but it also needs to recognize that this aggregation is a cognitive necessity that often but not always forgets others ends that enable the fold. According to phenomenological terms, "the 'events' are shapes cut out by a finite observer from a spatio-temporal totality of the objective world" (Merleau-Ponty, 411). Folds, aggregated perceptions and making of events in human consciousness are indispensible, however; they are how we work and how we engage with the physical world. But this engagement is predicated on forgetting of a quality of seamlessness, a whole that is at odds with every fold, bend and curve that we recognize. For instance, if I were to say I had an "episode" of a panic attack to explain an intense physiological and emotional distress to a doctor, the language is understood in terms of an aggregated experience already in service of proper diagnosis that is typically attributed to patients who refer to this experience as an "episode." But if I were to describe my experience of a panic attack in terms of my understanding of its causes, histories and usual trajectories in the wake of its eruption then I can withhold a language that is already evented as an aberration, intensification, or irregularity but provides a new imagination, but will in all likelihood be considered incoherent and unruly. What does it mean to think of the sentience of "panic" as already been there in a way that does not make its episodic returns as a deviating instances or events and is enabled to question the very intensification of "health" and "illness"? This does not tantamount to flattening out of episodes per se, but viewing these so-called episodes as such in relation to each other. What would it mean to hold on to the thickness of the world and the folds that we need to engage with it through the lens of partiality in a memoir? Through partiality and its "weak theorizations" in *Giving* that attend to pasts, we can explore how experiences are formed and what are the implications of negotiating these experiences through the lens of a memoir.[52]

Ethnographers have defined the importance of a kind of theorization that "comes unstuck from its own line of thought to follow the objects it encounters, or becomes undone by its attention to things that don't just *add up* but take on a *life of their own as problems for thought*" (Stewart, 72; emphasis added). This is a kind of theorization that does not aim to "explain away" a phenomenon but thinks with it and tries to tease out the incipient theorizations the phenomenon itself. In fact, as opposed to a "strong" or "paranoid" theory (Sedgwick 1997) that "defends itself against the puncturing of its dream of a perfect parallelism between the analytic subject, her concept, and the world", a "weak theory" is more interested in following the object of analysis to be undone by it, it speculates why pointing out to concepts like "gender", "medicine", and "culture" cannot do justice to the narratives of chronic pain even though these narratives are interested and, in no uncertain terms, deeply informed by these concepts. Concepts do not explain embodied experiences in narratives because in the style of weak theorization, as Kathleen Stewart suggests, things "don't just add up" according to the dictates of big concepts.

A somewhat similar approach can be observed in the concept of "grounded theory" (Charmaz 2006). As Kathy Charmaz puts it, "grounded theorists collect data to develop theoretical analyses from the beginning of a project. We try to learn what occurs in the research settings we join and what our research participants' lives are like. We study how they explain their statements and actions, and ask what analytic sense we can make of them" (3). She adds, "We begin by being open to what is happening in the studied scenes and interview statements so that we might learn about our research participants' lives." A sociological approach that is less interested in what anthropologists calls the cultural poesis of ethnographic accounts but equally attentive to the voices in "studied scenes and interview statements", grounded theory seeks to restore and repair the phenomenon that has been virtually written off the script of analysis because of an overwhelming attention to analyzing it from the perspective of strong or paranoid theories; a perspective that is too attached to the idea of proving the veracity of its own insights and not interested in being surprised by what

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[52] See Kathleen Stewart's essay "Weak Theory in an Unfinished World" (2008) and Eve K. Sedgwick's essay on "paranoid" and "reparative" reading practices (2003).

it examines. This theorization is rigid, "hard", to use Hustvedt's (2013) term, and unable to cope with the "squishiness" (cf. Hustvedt 2013: 7) of the phenomenon itself. This formulation has gained uptake in the fields of qualitative analysis of illness and disability narratives (Charmaz 2006). Life writing narratives offer a significant area in testing such concepts because of the interfaces between lived experience and fallibility of memory they work with, and this gets much attention in *Giving up the Ghost*. In stylizing lived experiences through the narrative constructs of "a memoir", in relation to its fallibility and concomitant fictionality, *Giving* offers a particular *form of a patient's perspective* that, I suggest, is important to be read for itself; that is, the form of the narrative and not only the content of the partial nature of disclosure it elaborately pursues. It draws attention the immediate pain of having undiagnosed gynaecological condition but also asks us to witness that "[l]iving with serious illness and disability can catapult people into a separate reality—with its own rules, rhythms, and tempo. [Because] [t]ime changes—drastically. […] Good days and bad days lend new meanings to the present and future and shade memories of the past" (cf. Charmaz, 4). "Good days" and "bad days" are defined by the intensity and persistence of chronic pain, as Charmaz suggests, but they also give new meanings to pasts. Without essentializing suffering, I suggest, this is the point where an affective intelligence comes into play in Mantel's text. This intelligence allows us to see that the "past" is not fused with the pain-stricken self in the present but is interrogated in embodied and relational terms through the lens of pain and institutionalized injustices that produces the sentience. For instance, on being administered wrong medicine and being wrongly diagnosed for years, Mantel says, "The hormonal profile of the individual determines much of the manifest personality. If you skew the endocrine system, you lose pathways to the self. When the endocrine patterns changes it alters the way you think and feel. One shift in the pattern tends to trip another" (cf. 221). Thus, although in the case of hormonal changes, medicine can determine the changes through its technologies, the pain and even the reconstitution of the ways of thinking and feeling in case of hormonal changes remains tethered to certain aspects of practices of medicine in daily life that the institution itself is suspicious of or cannot afford to put into practice. Feeling pain through palpation and determining facial expression of the subject, as Vyshali Manivannan notes (36), are the only way to understand pain - and slow engagements with and every patient is often not justified due to cost-benefit measures or the climate of economic precarity within which medicine as an institution functions.

At a factual level, patients with historically contested diseases like fibromyalgia, for instance, have had to anticipate how and when the narratives of their bodies would be devalued because they preferred to "describe"—a reviled register of narration from a medical point of view—symptoms that cannot be subjected to the optics of machines and instruments. This is because fibromyalgia is a disease of the fascia (a thin sheath of fibrous tissue that attaches the muscles to organs) that cannot be subjected to optical invasion but is entirely "felt" by the patient—a feeling that can only be confirmed if, in the best case scenario, the physician is willing to listen to the patient's descriptions. Fibromyalgia patients, thus, have had to figure out ways to circumvent the dismissive response they typically received from a large number of doctors. I agree that it matters that fibromyalgia syndrome (FMS), endometriosis, and chronic fatigue syndrome are very different diseases with different symptoms and partly different historical occasions for their emergence; it also matters that while fibromyalgia and endometriosis produce chronic pain, chronic fatigue syndrome generates lassitude (cf. Greenhalgh, 9). But my point is there is something to be gained by viewing the experiences of these diseases in relation to how the sufferers have had to devise strategies of narrating their physical and mental states in order to be heard by medical experts. In producing these narrative strategies that would be deemed credible, Mantel's memoir exhibits and intense self-consciousness and mobilizes chronic pain to give new meanings to hitherto delegitimized pasts, and thereby participates in a similar narrative trajectories that sufferers of FMS and chronic fatigue syndrome have produced.

The issue of credibility around the sentience of gendered pain is replete in this memoir as it is common in narratives of other contested diseases like chronic fatigue syndrome and fibromyalgia (cf. Greenhalgh, 7).[53] What Mantel's memoir does is she does not simply relay medical violence toward women's pain, but she reworks this pain and examines how this pain—the other's disbelief on witnessing her pain—elaborates itself in

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[53] In an episode of *The Golden Girls* (23 September 1989), the character of Dorothy Zbornak, played by Bea Arthur, complains of what was then not known as "chronic fatigue syndrome", but her male doctor refuses to take her seriously.

diverse timeframes. She reads this suspicion towards women's bodily functions in relation to how her body was read when she was relatively healthy as an adolescent. She writes,

> A little girl, flat-chested, can't imagine her body will ever change. One day she becomes conscious of the brushing of her blouse against her skin. She puts her fingers there—I do—and feels enraged at the thought of what is to come. The whole process is beyond control. You have no choice in it. My body is getting the better of me, though people seem to feel I am responsible for what it does. My small blood vessels are unstable; I blush if anyone speaks to me, if anyone looks at me. I can't help this, but it seems to drive my mother and Jack into a frenzy of irritation." (*Giving*, 118)

Framing the illness experiences in adulthood through prior experiences that do not signal a history of the illnesses but a narrative of a changing body of a pubescent girl puts into forefront how it's not particularly or exclusively the illness experience in medicine is the only concern in the memoir; to the contrary, it is the exercise of reading medical neglect and a fundamental suspicion toward gendered pain in and beyond medicine and against a cultural amnesia that tends to forget other sites of the very same dynamic. What is then is the history of endometrial body when it belonged to a seemingly healthy girl? The attempt to trace a social history of illness is not a besides the point for an illness narrative because apart from providing a background to the illness, which is nevertheless always there in all illness narratives, it brings forth the notion of an intelligence of this memoir. Reflections on gendered pain and the theorizations they posit risk being elided because we tend to view such reflections in narratives on a scale between "raw emotions" and "cooked analysis." Pain and painful feelings, however, as Kelly Oliver (2016) notes, are never entirely "raw" but always already "cooked" in terms of the incipient criticism they carry, which is why the idea that the subject of pain cannot provide an "analytical" account of her stories is based on the assumptions that emotions themselves are not intelligent and someone who is "not experiencing" the emotions need to analyze the subject's emotions for her. The tendency to view the subject of pain and her narratives from the perspective that emotions in general and pain in particular are devoid of any particular mode of thinking is a problematic assumption. In understanding painful feelings as endowed with an own kind of intelligence we could potentially resist a culturally ingrained tendency to see narratives of embodiment as anti-intellectual and feelings as not capable of reflecting on the historical and material contexts that produce those feelings (Oliver 2016). The assumption that analysis is always devoid of emotion and illness narratives only relay pain is a specious one that is effectively exposed when we see how closely the narrator reads a single moment from her adolescence when her mother and her stepfather could not read her body for what it signified. Her small blood vessels are said to be unstable, perhaps due to her latent gynaecological condition, but her family mistakes this physical condition as her "blushing", as if she is inviting other people's attention in a way that is deemed inappropriate for someone of her age. The everydayness of the family's "frenzy of irritation" (118) does not become an event in and of itself because as a child she was not aware of the condition of her blood vessels, but she becomes aware of these aspects of her body as her disease becomes more pronounced over the years. These memories are not so much far out there in the past that needs to be excavated, but in a way, lie just below the all too familiar surface of a contested illness experience. The incident is not even a memory because it is only comes up in relation to how it is remembered: "[m]y body is getting the better of me, though people seem to feel I am responsible for what it does." It is as if the narrator relives her adolescence through this incident when she says her body "is" getting the better of her.

It's important to see how *Giving* works with the idea that memoirs can be curious, too, and not be simply hostage to its pasts. As I have mentioned before, for too long, as Huyssen suggests, we have thought of memory narratives as "prison house of the past" (8), as in, past-oriented—and implicitly "traumatized"—that the notion that memoirs can also shift its gaze to areas that they may deem necessary in the advent of its particular experience of the past has not been recognized. For *Giving*, the need to make this concerted effort to remember differently and using one's bodily pain creatively (both to alleviate pain and create an alternative epistemology of pain) has serious implications because all illnesses were not accorded the same prestige in literature—for instance, while tuberculosis in Thomas Mann's *The Magic Mountain* (1924) achieves "majestic depictions" and "profound reflections on life and death" (cf. Das, 210), in cases of undiagnosed illnesses, chronic pain, there is no particular script or a cultural imagination that could understand these unique modes of suffering.[54] Also, as Das writes, "Yet those writing about their own illness experiences are

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[54] I highlight this point not to discount any particular register of suffering and pain but to make a simple point that issue of endometriosis being a "contested illness" until the 1990s is closely tied to Mantel's style of identifying it in her memoir.

themselves cautious that their experience cannot be simply assimilated to the templates others have of what it is to suffer" (211); in this way, pain narratives work in interesting and counterintuitive ways with an anxiety of being always already influenced by other narratives that came before them.[55]

However, it's in Mantel's work that the contested aspect of the disease gets full attention because diagnostic categories and methods for determining endometriosis leave a lot of room of the physician's interpretation. Furthermore, the already gendered dynamic of the doctor-patient relationship (cf. Greenhalgh, 141) does not make it easy to convey the chronic pain in regards to a gynaecological condition (associated with severe social stigma) that is also related to the endocrine system and extreme mood swings. As a disease that affects cis-gendered women, endometriosis resists clinical definitions largely because its effects are diverse and related to multiple factors that have social implications. The weight gain caused by the onset of early and/or surgically induced menopause leads the disease to be experienced in overtly gendered terms because medicine does not view obesity with a social understanding of obesity and often attributes it as the patient's fault (cf. Rothblum 2009). Medical experts understand the disease in the following terms: "Endometriosis is an oestrogen dependent, benign inflammatory disease characterized by ectopic endometrial glands and stroma, which are often accompanied by fibrosis (Hickey 2014: 1). In other words, endometriosis is characterized by cellular movements in the endometrium—the lining of the uterus—to different parts of the pelvic region and causes scarring of the connective tissues in the endometrium. It affects women of reproductive age and is relatively common; the disease is also potentially debilitating (cf. Hickey, 1) and causes chronic pelvic pain. As Carolyn Carpan (2003) notes, "Endometrial tissue outside the uterus has no way of leaving

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[55] There are many ways of being ill and even more ways of representing illnesses: some narratives are angry, such as Sue Baier's *Bed Number Ten* (1989); some use illness as a critical metaphors for historical melancholy, John A. Williams's *The Man Who Cried I am: A Novel* (1967); and some are auto-ethnographic in relation to family narratives of illnesses vis-à-vis histories of migration: Richard Fung's *Sea in the Blood* (2000). But it is always difficult to talk about illnesses and conditions that are not recognized as such in a certain point in history, which is all the more compounded by the fact that not only are all illness narratives self-consciously constructed, but contested illnesses have no precedence to (dis)identify with but only an intuition of how to construct their illness experience/symptoms in their own terms.

the body, and thus, endometriosis results in internal bleeding, inflammation of the surrounding areas, and formation of scar tissue" (32). Largely influenced by medical and public scepticism of the chronic pain that this disease produces, endometriosis is particularly susceptible to being stigmatized on multiple levels in the course of its eruption and subsequent diagnosis, that is, both inside and outside the purview of medicine where instrumental use of rationality operates. The disease carried a highly stigmatized label of being a "career woman's disease" (Carpan, 32) because it was perceived that women who delayed having children were more susceptible to contracting it; although the cause of this disease is still unknown (cf. Hickey, 1) and women with this disease are in most cases unlikely to be able to have children (or have pre-term born or ectopic pregnancies). Not unlike other chronic illnesses like fibromyalgia and chronic fatigue syndrome (two diseases that have a very high percentage of women sufferers), medical neglect in the wake of endometriosis is deeply to tied to how the disease and the pain it produces are viewed in everyday life. To define this disease as an illness, which, as Arnold Weinstein (2010) suggests, is the particular experience of a disease, is not just to speak of how the disease is experienced in a social context but to understand that medicine itself is shaped by social implications of having particular conditions, conditions that are deemed "irrational" because of particular life choices that the sufferer and survivors make (cf. Barker 2010).[56] In order to challenge such a view of the disease in relation an instrumental logic that views the uterus and its functions as inevitably tied to child-bearing "cures" of a disease that medicine, for decades, tried to avoid defining, Mantel's opaque memoir that, in part, is about her childhood, her family, and also about her experience of iatrogenic distress and medical abuse chooses to what Zygmunt Bauman (2005) suggests as the crucial "need to ruminate" (317). Instrumental rationality of medicine, according to Baumann, takes us away from the time of rumination and reflection on why one is asked to behave in a particular way to take care of one's condition. It asks us to think of bodies—and parts of our bodies—as discrete entities that need to be managed for their functions and the social responsibility that comes along with these functions. Thus, one is required to take care of the uterus for child-bearing; lungs

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[56] See Arnold Weinstein's short lecture on the topic of "Why Literature and Medicine?" (19 Oct 2010): <https://www.youtube.com/watch?v=v3Pi2ebmrYM> Web. 27 Nov 2017. Also, see Kristin Barker's "The Social Construction of Illness: Medicalization and Contested Illness". In: *Handbook of Medical Sociology* (2010), pp. 147-162.

for not corrupting public morality (especially of the younger generation) by not smoking; and the shape and size of our body by ensuring that it is not "obese" and, thus, not only desirable according to normative standards of beauty but also perceived by medical practitioners as a proof of a body which is being taken care of on a regular basis.[57] Such an emphasis on the need for rumination is important because it forces us to think of what is lost in such an instrumentalization of rationality and when it could become lethal for the very bodies that it promises to be concerned about. Far from being a paralyzing logic that would read Bauman's argument to be antithetical towards a cooperation between multiple definitions of "health" that need to be taken into account, this intellectually provocative idea asks us to consider that which is inaudible in the clamour of the everyday mantras of the health industry, which is deeply gendered and ideologically inflected by instrumentalization of rationality. What kind of "health"—and whose health is and has been promoted in mainstream definitions of the industry? These ontological questions require clarification because of the way Mantel's memoir chooses to make its concerns clear. She asks why, as a child, was she not encouraged to think about "breathing" in order to be able to breathe when she is afflicted with chronic pain during her pubescent years: "The doctor says if I didn't think about breathing I'd be able to do it. Frankly, he is sick of being asked what's wrong with me. He calls me Little Miss Neverwell. I am angry. I don't like being given a name. It's too much power over me. Persons shouldn't name you. Rumpelstiltskin" (82).

The memoir, as we will see, is replete with passages like this where a comment or a memory from the past is ostensibly turned around in terms of its tone, focus, and language to suggest something in relation to everyday life, even comical, or experience in the clinic are read through power relations. The effect, however, is not necessarily as expected: we do not have a "serious" discussion of power relations imbricated in the doctor-patient relationship but more of a (comic) rebuttal to that relationship. For instance, in the above-quoted section,

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[57] Bauman summarizes this deeply ingrained cultural attitude in the following terms: "I can stop eating eggs, refrain from smoking, do physical exercises, keep my weight down; I can do so many other things. And while doing these right things and forcing myself to abstain from wrong ones, I have no time left to ruminate that the effectiveness of each thing I am doing, however foolproof it could be made, does not in the least detract from the uselessness of them all taken together. The case of instrumental rationality celebrates more triumphant battles—and in the din festivities the news of the lost war is inaudible" (317).

it is not that one thinks prior to breathing, but when one does due to a particular condition and what are the implications of being told not to do so? Also, what happens when one's breathlessness in the wake of having to think about breathing is infantilized with names such as the one the narrator gets from her doctor? These aren't just rhetorical questions or moral indictments for the narrative but, I suggest, provide a kind of affective literacy to the text, a literacy that tells us these seemingly less significant moments process the events of injury related to instrumental use of rationality ("if [you] didn't think of breathing [you] would be able to do it") that is always at odds with the subject of chronic pain. Does thinking of breathing patterns while being afflicted by pain provide a space of rumination—and if so, how can this space of rumination be retained?

Critics examining reparative features of literary texts (cf. McClain 2018) have highlighted the importance of "grief literacy" and how literature can provide this literacy for readers. Although the notion of "grief literacy" is tied to grief of all kinds that are evinced in literature, contested illness narratives, paradoxically, seem to provide a literacy that is not just limited to grieving illnesses that need to be recognized but understanding contested illnesses perform an intelligent work of speaking to institutionally validated knowledges. To appreciate the manifold demands that an unrecognized condition pose to the social imaginary we need to see narratives of stigmatized and contested diseases as vibrant imaginations that intuit through pain and changing bodily and mental transformations. Neither chronic pain nor bodily or mental changes can be seen as paralyzing because the stakes of recognizing these conditions in terms of their complicated life-worlds are simply too high for sufferers. That is to say, not only is the subject materially endowed with a greater access to her subjectivity and health in terms of having attention drawn to what happens when certain symptoms come without proper definitions, but when the social experiences of having those symptoms in a particular body is narrated these experiences affect prevalent definitions and unsettles what it means to be "healthy" at large.

By highlighting these dualities in relation to the politics of recognition of an illness and speaking of it from the profound *intelligence* of embodied pain, Mantel's text brings forth an affective literacy that is important to be recuperated. As a practice of dwelling on the category of experience from the subject's embedded locations, the memoir of endometriosis scrutinizes what it means to experience the *descent of instrumental rationality* *on a body in pain*. The need to engage with this conceptual descent of such a notion of rationality on gendered bodies is important because it relates to the effects on how these bodies are interpreted in and beyond medicine. *Giving* does this by attending to memory from the perspective of an ethnography, it goes back to scenes from the past to make those scenes stand out in relation to larger narrative of the memoir. While in a way this is, of course, typical of all memoirs, what is different about this in *Giving* is that the narrator provides an account of why these memories are important and need to be read in relation to her chronic condition; in this way, the memoir does something similar to that of an (auto)ethnography, which besides doing the important of describing cultural phenomena, does something equally significant: because ethnography itself is never just observation because the whole point, for a description, "is that as soon as you make the decision to describe something, with that comes a responsibility to account for what you claim to have observed" (cf. Miller 2017: 28). Although Daniel Miller, an anthropologist, is discussing the role of ethnography for anthropologists, it is important to notice that the recourse to memory in narratives of pain precisely attends to the moments of embodiment when the self was in no uncertain terms "othered," be it through being given an unwanted name and, thus, being silenced, or attending to death-like states in moments of illness ("giving up the ghost") from which the sick and gendered subject recovers through the act of writing. In many ways we may say Mantel's memoir is an autoethnography of her experiences, insofar as we understand that this is an ethnography with a very specific task at hand: to underscore the role of description that is denied in knowledge production and provide an affective literacy by situating "pain" and "pasts" in a productive dialogue with one another. Taking recourse to memories means understanding how gendered pain structures and sustains her personal memories relating to her family and that persistence of both in terms of unmaking the subject; this recourse also accounts for the creative features in the text that bodily pain works with. Consequently, the written word in Mantel's autoethnographic text means something different, i.e., from when the ethnographer deploys the rules of this particular genre of writing, because it refutes the confessional mode of communicating to an authority figure—the missionary or the imperial gaze to which ethnographic descriptions have historically disclosed themselves.[58] This is telling of how "autoethnography" functions in relation to a

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[58] According to G. C. Spivak, "if one looks at the history of post-Enlightenment theory, the major

horizontal axis, as if turning the stones and pebbles on a flat landscape upside down, as Mantel notes, where reaching out to a reader is crucial. Thus, engaging with the reader through a critical intimacy that can be partly identified with and forming a dialogue with a community of readers is of utmost importance for this memoirist's autoethnography.

In *Giving*, autoethnographic descriptions negotiate experiences through tropological and narratological mediations (cf. Hornung 2010); they make genres of truth in fiction through language and by inserting the role of narrator in coming to terms with her experiences at crucial points. Mediation requires are careful examination of what to represent, how to represent, and why that representation deservers the imagined reader's attention. The care for representation is not entirely a postmodernist obsession with the issue of representation itself, but requires an added layer of attention when writers—like Hilary Mantel and Siri Hustvedt, for instance— who consistently own up to their credentials as theorists of writing autobiographical work consider their life experiences that examine liminality in various contexts. The Barthesian idea of the "death of the author", as Hustvedt (2014) suggests, does not work for women writers because in the context of women's literature women's access to writing their life stories does not correspond to the privilege that white men of North-Western European origin have historically had. These writers of autobiography must not be "dead" because they never had a "life" as a writer in relation to the written word to begin with, and yet their works cannot be reduced their life stories but should take into account what these writers accomplish in their works (Hustvedt 2014). Similarly, when Mantel owns up to her credentials as a writer in her memoir, which is primarily her illness narrative but not entirely so, she is doing something akin to forming a genre of truth not in terms of "galloping confessions" of the experience of trauma or illness, but through an intellectual history of writing an autobiography from her set of experiences as a patient and an established writer (Ibid.). She writes,

> But this story can only be told once, and I need to get it right. Why does the act of writing generate so much anxiety? Margaret Atwood says, "The written word is so

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problem has been the problem of autobiography: how subjective structures can, in fact, give objective truth. During the same centuries, the Native Informant [was] treated as the objective evidence for the founding of the so-called sciences like ethnography, ethnolinguistics, comparative religion, and so on. So that, once again, the theoretical problems only relate to the person who knows. The person who *knows* has all of the problems of selfhood. The person who is *known*, somehow seems not to have a problematic self" (Spivak qtd. in Suleri, 343; emphasis in original).

> much like evidence – like something that can be used against you." I used to think that autobiography was a form of weakness, perhaps I still do. But I also think that, if you're weak, it's childish to pretend to be strong. (*Giving*, 6)

The narrator's voice is interwoven with the voice of the writer, it informs us that she feels a need to get her story right and, in so doing, she refers to the Canadian writer Margaret Atwood to examine the issue of an ideologically constructed "self" in reception of autobiographical writing. She arrives at a new perspective that she did not have, that is before adopting, even embracing, Atwood's notions. Finally, she transforms her own idea of thinking about autobiographical writing as a "form of weakness" in order to proceed with the task at hand: if one is weak it is insincere and childish to pretend to be strong. As critics have suggested, modernity has taught us to think of "pain" and management of pain in very limited terms (Scarry 1985; Manivannan 2017), and medicine and life writing—at least in some of their forms and practices—are not immune to these limitations. The notion that autobiographical writing is an expression of weakness (Gilmore 2001) relates to the idea that "great" works of literature must, to a large extent, be depersonalized, and male writers are able to produce this kind of depersonalization because "literature" (autobiographical or not) is already imagined as a terrain of emotions, feelings, and things that are not wholly "rational," so the presence of a male writer in the cultural unconscious serves to offset or counter this foray into the realm of what is deemed as "irrational" (Hustvedt 2012).[59] Similarly, autobiographical writing is partly about the private self, its histories and trajectories, so to expose the "weakness" of the autobiographical self—even as an established writer that Mantel was when she penned *Giving*—risks being ignored in terms of the content of the text because she is writing about gendered exclusions and also adopting the genre of a memoir to do so. While writing itself generates anxiety because the written word, as Mantel notes, can be used as evidence against the autobiographical self, the anxiety, however, is disproportionately distributed on the lines of gender among writers, if we follow Hustvedt's (2012) analysis of how women writers are imagined as not being able to "depersonalize" their concerns because their writing is viewed solely in terms of "raw emotions" (Oliver

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[59] See Siri Hustvedt's lecture (28 Jun 2012)- "Siri Hustvedt in Conversation with Paul Auster"- An evening at the Rare Books Room. <*https://www.youtube.com/watch?v=QvjEELisbyk* >Web. 28 Feb 2018

2016). Furthermore, reading *Giving Up the Ghost* as just an "illness narrative" with a limited understanding of illnesses as always fleshed out in legible and evented terms then covers over certain cultural attitudes that define "strength" and "weakness", "health" and "illness", etc. The problem is also compounded when we ascribe a particular physiological or mental condition that writers may talk about in their work as the only "object" of investigation for an illness narrative—for instance, an illness narrative would only concern itself with a narrative of a specific disease. That illness narratives can arrive at the object(s) of their investigation through different trajectories and, in fact, examine cultural constructions of what is perceived as "pathological" or legitimized as "normal", "weakness" and "strength", etc., through the "auto/biographical mediations" (Hornung 2010) they disclose and perform in their narratives get overlooked in our interpretations. The problem is, then, tied to an instrumental use of the concept of an "illness narrative" in critical discourse, i.e., in search of a legible and recognized disease it discusses, thus valorizing biomedically influenced event-oriented notion of a disease; a gendering of the emotional terrain of literature that is "corrected", as it were, by having an unquestioned bias towards male writers of autobiographies; a pathologization—"weakness"—of the genre of autobiography (which Mantel herself acknowledges on her part and criticizes as a cultural phenomenon); and, finally, a disavowal of the unique social theorizations (cf. Butler, 7-8) that women writers of autobiography produce. As Judith Butler (2005) suggests, "Indeed when the 'I' seeks to give an account of itself, an account that must include the conditions of its own emergence, it must, as a matter of necessity become a social theorist" (Butler qtd. in Hustvedt, 117). These theorizations are deeply imbricated with the autobiographical "I" of women's literature that discuss illness narratives, and in order to see their value for social purposes at large we need to engage with the affirmations of this specific and precarious autobiographical "I" in terms of the complicated narrative strategies it pursues.

2.7 Chronic pain between "radical dispersals" of structures of subjectivity and the "fact" of an experience

Thus far I have suggested the autobiographical "I's" narrative pursuits to give an account of itself intersects with autoethnographic strategies in terms of how it describes, how it positions itself, and the reasons it offers as to why the descriptions of mnemonic experiences are necessary to be revisited. Yet, it should be noted that descriptions are not simply focused on the fact of having described a phenomenon. In describing the narrative plays with signification and departs from its (auto)ethnographic inspirations. There is an inherent postmodern politics in these descriptions because in playing with what Linda Hutcheon (1986) suggests are “dispersals” of the “structures of subjectivity” (cf. Hutcheon qtd. in Banerjee, 39) in memory and by examining these dispersals in terms of the “small” scenes of everyday life, which then speaks to the incremental value of the smallness of quasi-events, suggests a practice of memory work. In a memoir that deliberately deals with partiality of memories and one which is much focused on mobilizing retrieved memories, we risk losing sight of a specific status of the narrative “I” if we examine this “I” from the point of postmodernist theories that underscore the valence of a “radical subjectivity” (cf. Suleri, 339), which risks enabling a pursuit of a kind of subjectivity in representation “which far too often resembles a “low-grade romanticism that cannot recognize its discursive status” (Suleri, 339). As Sara Suleri (2000) points out, “While lived experience can hardly be discounted as a critical resource […], neither should such data serve as the evacuating principle for both historical and theoretical contexts alike” (339). Speaking in the context of postcolonial criticism in the 1990s vis-à-vis postmodernist understandings that have repeatedly highlighted the importance of “ambivalence” (cf. Hutcheon qtd. in Banerjee, 39) towards positivist emancipatory goals, Suleri Goodyear’s reminder that theoretical discourses, too, tend to play with a “gleeful anti-intellectualism” (335) that is potentially dangerous is crucial. This anti-intellectualism is most pronounced when we tend to pit a postmodernist verve of thinking against, dare I say, the “fact” of an experience. This kind of a one-upmanship slides in to a problematic notion that subjects of chronic pain are so involved in the “fact” of pain that they are not able to discern ways in which they could not only ameliorate pain but also provide social theorizations of their experiences. Critics working in the field of postcolonial studies have offered rich analyses of the debate throughout the last few decades (Banerjee 2002; Durrant 2003; Varadharajan 1995) and much is to be learned for our purpose in the mobilization of memory in descriptive language. The question then is: how do we to address a sustainable politics of affect and what is found in memoryscapes that is sought by mobilizing memories- memories that are influenced by a specific experience of a rational-scientific view, which is a view that is not just shared by medicine alone; and, at the same time, respect the opacity of language without entirely instrumentalizing it or without getting trapped in a kind of self-scrutiny that threatens political and intellectual paralysis?

As Hutcheon (1986) suggests, even though postmodern writing cannot offer what Fredric Jameson longed for as a "'genuine historicity', that is, […] 'our social, historical and existential present and the past as a 'referent' [or] 'ultimate objects'", in its "deliberate" refusal to yield to the demands of providing a reliable referent that can form the blueprint for a emancipatory practices, it offers us an instructive understanding that the referent which postmodernism denies (against the pursuit of an "ultimate object") is, in final analysis, "discursively" (182) constructed—a construction that is often textually mediated in terms of its unruly character (cf. Weinstein 2010; Hornung 2010).[60] While I do not want to restate arguments for which much ink has already been shed, but the point on retaining a space of critique in which the referent of a literary work can be regenerative in terms of enabling new ways of thinking for social action is important to be reiterated. Sustainability of memory longs for a narrative of pain that is conducive to ameliorate pain in material terms and it also asks for a radically dispersed conceptualization of the "ultimate referent" of pain. In other words, if, as Huyssen (2000) suggests, "[t]o insist on a radical separation between 'real' and 'virtual' memory seems quixotic, if only because anything remembered—whether by lived or imagined memory—is itself virtual" (cf. 38), it is hard to choose between a narrative of an illness, like Mantel's, in terms of what it could "really" offers to technologies of amelioration and what it really does "not." In the context of illness narratives, the objectification and a pursuit of radical subjectivity is dangerous because it defeats the purpose of engaging with patients' perspectives, as Banerjee suggests, and from the perspective of literary criticism it tends to instrumentalize the gendered voice in—and of—autobiography as if this voice speaks only to be heard by rational-scientific discourse in accordance with its well-established terms. Thus, potentially discounting the social theorizations that this voice

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[60] The emphasis on a urgency in the context of medicine and its ability to "cure" too often slides an ideologically constructed notion of the "present" in which its historical lineaments are forgotten. Also, on this issue, see Fredric Jameson's concerns quoted in Linda Hutcheon's essay "The Politics of Postmodernism: Parody and History" (1986), p. 182.

inevitably provides at the moment of its construction of an "I".[61] Mantel's reflections on the quasi-evental substrate of chronic pain seem to challenge these terms of engaging with gendered pain. Also, as Hutcheon suggests, "The past as referent is not bracketed or effaced, […] it is incorporated and modified, given new and different life and meaning" (cf. 182). The creation of a new life and meaning in a postmodernist vein departs from the sentence of chronic pain—it is a line of flight that needs to be retained in our interpretations.

2.8 Coda

> The first drug I was given was called Fentazine. That would do the job, Dr. G thought. Do you know about akathisia? It is a condition that develops as a side-effect of anti-psychotic medication, and the cunning thing about it is that it looks, and it feels, exactly like madness. The patient paces. She is unable to stay still. She wears a look of agitation and terror. She wrings her hands; she says she is in hell (*Giving*, 181).

Too often the call for engagement with social histories of illnesses has been understood as a "petition" for sympathy from the humanitarian gaze (cf. Gilmore 2012: 83), which is an important emotion to be reckoned with in literature and medicine and something that we would not want to do away with because the humanitarian sensibility needs a sympathetic identification of some sorts for social action (cf. Ganguly, 36). However, while sympathy may, in fact, be the effect of illness narratives the labour of eliciting this sympathetic feeling is obscured and discounted if we do not explore how the text makes us encounter or arrive at the sympathetic feeling. The work of eliciting sympathy, then, could be a secondary effect of an illness narrative. The narrative itself, however, is intelligent and works through a process that aims to disrupt the structure of ego of the observer who readily sympathizes; we may understand this dynamic following Amartya Sen's (1977) formulation that social behaviour directed in relation to the affect of sympathy (and in response to what one perceives as one as solely demanding such an affect) is "egoistic" because "one is oneself pleased at other's pleasure and pained at other's pain, and the pursuit of one's own utility may thus be helped by sympathetic action" (326). Sympathy in this formulation keeps the structure of the ego of the individual who sympathizes intact; where as in case of what Sen calls "commitment", elicited social behaviour is "non-egoistic" (326) because the observer of a scene is not

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[61] I focus on the verb "choose" because I am also guided by humanist concerns that Sara Suleri discusses in her essay: a search and a preferred choice for a radical subjectivity has inadvertently or not led to a fetishization or an "objectification" (cf. 339) of the proper subject of critical discourse.

personally affected by what she witnesses and is thus not distressed, but nonetheless realizes something is "wrong and [she is] ready to do something to stop it." I dwell on these distinctions not simply because what such a distinction would do to the reader of an illness narrative in a memoir, but more significantly, what it means for our methodological practice. Also, Sen's distinction may not hold in the context of memoirs which, as I have suggested, provide an "emotional intelligence" in regards to discussing unrecognized conditions; memoirs like *Giving Up the Ghost*, perhaps, invite both a sympathetic ear because to write about pain is to hope that one would be heard (cf. Williamson 1998), and more significantly they also invite a kind of commitment that requires us to appreciate the narrative's commitment to read that which it asks us to sympathize with. That the narrative that seeks sympathy can also be committed to studying the object of its grief and pain is something that we may need to reckon with in our methodological practice when we think of how to examine descriptions and why is it necessary to talk about quasi-events—their smallness, their evanescence. Thus, we should ask, what would it mean to think of such a studied grieving in narratives in relation to conceptualizations that could potentially counter biomedicine's long shadow on social life? Illness narratives use our sympathy to an end; they may ask us to sympathize but they also require us carefully attend to their commitments to understanding social experiences of a diseases, which, in turn, seeks a similar commitment from us. The literary career of sympathy, which is a politically charged affect that can be traced back to Abolitionist literature and humanitarian narratives of suffering, is in this way reframed in memory work.[62] Commitment, in Sen's formulation, also helps us dismantle the structure of hubris that is inevitably enabled through an unproblematized recourse to sympathy from the point of view of the reader; it also speaks to a critical hubris, or more particularly certain argumentative drives that fails to account to for life-worlds of borderline experiences because they are more interested in proving themselves "right" and, by extensions, competing theories "wrong." (The debate between postmodernism and postcolonialism being a case in point.) This kind of theorization, however, is not commensurate with what theorists of affect, Eve K. Sedgwick (2003) and Kathleen Stewart (2008) envision, "weak theorization" to be. The debate around theorizations that stress the importance of the "radical dispersals" of the structures of subjectivity and the "fact" of a

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[62] See Debjani Ganguly's "Introduction" in *This Thing Called the World* (2016), p. 1-37.

historical experience (postcolonial, immigrant, or gendered) cannot be understood in terms of a complete polarization in illness narratives that discuss chronic pain. A commitment-based understanding then helps us to see how as interpreters we respond to this problematic polarization, that is, without taking recourse to depoliticization and sheer negativity in postmodern theory or enabling a kind of essentialism in relation to a moral tyranny of the "fact" of a historical experience that could potentially lead to constructions of master narratives, which subjects of chronic pain are not even interested in coming up with.[63] The latter can be challenged by postmodern emphasis on partiality of memory and inexhaustibility of language that resists instrumentalization of experience, as it "attempts to be historically aware, hybrid, and inclusive" (cf. Hutcheon, 193); and the postmodern tendency to abstract incremental and insidiously accrued pain in everyday life can be halted with grounded instances in which chronic pain of undiagnosed endometriosis can offer a new way to think of the very life-worlds of chronic pain.

Undiagnosed chronic pain adopts multiple registers in narration: it sifts through already evented episodes in time and finds something new in those episodes, it is also sometimes analytical in its tone and often it is as if the narrator performs a voiceover that directly speaks to her readers. This allows her to own up to her writerly credentials and assume an "expert's voice" as she gains more knowledge about her illness through her own research, but a somewhat coherent explanation is only achieved after the fact of the experience, which is explored in terms of the virtual quality of remembering and dissecting the past for a very specific use of mobilizing a particular experience. For instance, when Mantel's narrator describes the effects of the prescribed drugs to treat her pain on her vision, she writes,

> One day I went down to town to buy myself a nightdress. But because my vision was blurred, I misread the label and came back with size 16 instead of a size 10. 'Look at this monster garment!' I cried gaily to the nurses; I was having one of my less murderous days, and trying to lighten the tone. 'Look what I bought!'" (179).

The nurses do not believe the narrator that her vision was blurred due to the medication and asks, "Didn't you remember what size you were? Did you feel you didn't know?" The narrator continues, "But they wouldn't drop the topic. It was obviously characteristic of mad

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[63] See Linda Nicholson and Steven Seidman's *Social Postmodernism: Beyond Identity Politics* (1992), p. 9.

girls to buy big nightdresses. Every time I spoke I dug myself into a deeper hole" (179). This episode refers to two interrelated concerns in the text: credibility issues in medical practice, particularly when the patient is a woman and medicine's unsympathetic attitude towards obese bodies which the narrator experiences because of the way her body transforms due the wrong medication that she's prescribed over a long period of time. Significantly, it also connects to an episode with drug-induced severe motor restlessness called akathisia. This drug-induced state of akathisia, the nurses' disbelief in her blurry vision, and the punitive attitude of medicine do not emerge without a context, however; the text belabours on creating connections between this experience of medicine and Western cultural and material practices that, however remotely, enable medicine to assume its sacrosanct status in the cultural imaginary. The notion of undiagnosed pain in this regard is crucial because it provides a so-called "blank space" on which this medicine, now enabled by this imaginary, repudiates the narrative voice, a voice that we may think of in the Foucaultian vein of "subjugated knowledges" (1977).[64] The narrator locates these knowledges in curious ways: in a language of not just grievance against medical neglect but of an affirmative way of thinking about the subject of illness and her accounts. The undue punishment, as it were, that she receives from the nurses due to a blurry vision is reread in the light of the virtual nature of remembering, in other words, by "connecting the dots" between the blurred vision and the events that followed this incident. The narrator says, "I have been so mauled by medical procedures, so sabotaged and made over, so thin and so fat, that sometimes I feel that each morning it is necessary to write myself into being- even if the writing is aimless doodling that no one will ever read, or the diary that no one will see when I am dead" (222). And again, she writes,

> Akathisia is the worst thing I have ever experienced, the worst single defined episode of my entire life […]. No physical pain has ever matched that morning's uprush of killing fear, the hammering heart. You are impelled to move, to pace in a small room. You force yourself down into a chair, only to jump out of it. You choke; pressure rises inside your skull. (*Giving*, 181)

Losing her "sanity" while in the grip of a drug-induced state becomes a mirror for the illness narrative itself. To talk about this state in the past is to recount it, to seek sympathy from the reader in some way, but it also forms a study of a particular scene from the point of view of

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[64] For a discussion of "subjugated knowledges" in relation to patient's perspective, see Chapter Three: "Politicized Patients and the Dialectic of 'Loss' in Richard Fung's *Sea in the Blood* (2000)"

having experienced it- and accessing a kind an agency by writing about it. The narrative of this experience is discursively constructed, and medicine is one such site in which the discourse of gendering takes place, but it is significantly tied to other such sites where certain definitions—of "madness," for instance—are put into practice on an unquestioned basis. We see here how the narrator's experiences as a woman, an ill and obese woman, are radically dispersed across a spectrum in which medical neglect is a part. The notion of "care," particularly care work conditioned by social stigmas and mores, intersects with institutional definitions of care. The ability to communicate—form "narratives," as it were—is of not much help because, as she says, "Every time I spoke I dug myself into a deeper hole" (cf. 179). The more she seems enthusiastic about her new purchase the more the nurses think she's insane, while not recognizing the effect that the drug had had all along. The work of addressing what seems to be a cognitive apartheid (between the nurses' notion of care and the patient's need for care) at large cannot be addressed without situating the incremental forces that have a cumulative effect in this illness narrative. Again, the question is not having to choose between a instrumentalized definition of concepts like care and credibility in service of a curative ideal, without which medicine cannot be itself, or reading these experiences in the text as moral indictments against a rational-scientific view, but examining of how social theorizations formulated in this text could engage with prevalent definitions of the notion of care work and are potentially able to expand on the scope of definitions that are already in circulation.

The role of chronic pain and endometriosis being a "contested" disease in Western medicine for a long period of time can hardly be discounted in regards how a particular understanding of "chronic pain", paradoxically, facilitated in expanding the scope of prevalent definitions and practices, as we see in this memoir. This is so because there were no institutionally validated definitions or determinants of the disease, sufferers had to piece together experiences accrued due to having certain conditions at multiple, often intersecting, institutional sites. As Kristin Barker (2010) notes, "a disease does not exist, so to speak, until the social institution of biomedicine creates a representative diagnostic category" (150). As unrecognized sufferers and organic intellectuals of certain bodily and psychic conditions, narrators of contested diseases have had to perform a labour of mobilizing these experiences in relation to the particular protocols of the genres of narration they have chosen: gendered experiences for an equally gendered genre like autobiography, and nearly illegible quasi-events of an illness experiences to frame the complicated processes of accounting for memory in a memoir at the turn of the century. That pain has a "non-referential" character (Scarry 1985; Schwab 2012) and moves in multiple directions, emerges from particular sites, speaks in different registers of narration, but does not refer "to" something is important to be noted here. As Elaine Scarry (1985: 5) memorably noted, hunger, thirst, and happiness are affects that are "for" or "because" of something. These affects have a referent in the external world: we feel hungry for food, we are thirsty for a particular drink, and happy "because" of something; however, pain, while caused by a set of factors, is just there, it is what Mantel calls "a present-tense business" (2010: 41). There exists no direct referent of pain in the external world, but a stimulus that provides the sheer sentence of pain. The "is-ness" of pain requires us to ask what pain "wants" (cf. Brown, 43). Understood in this way, we are able to interpret the sites and scenes that the text depicts in a register that is not wholly instrumentalizing pain's fundamentally complicated referential language, but see how pain actually could form a political basis of our actions to come to terms with it. As Gabriele Schwab (2012) notes, "Pain can become unconscious, but it leaves traces, inscriptions, and, more importantly, it feeds our political unconscious" (19). Chronic pain's non-referentiality, then, resists an instrumentalization because it "feeds" our political actions and desires. This is a "co-embodied presence" of pain that intuits to be otherwise in relation to what it remembers, what it retrieves from memory, and what it retrieves in memory practice is new imaginations of narrating with pain.[65]

2.9 Summary

From the point of view of medical history, "contested illness narratives" (such as chronic fatigue syndrome, fibromyalgia, endometriosis, etc.) are those that have not been accommodated in medical definitions and addressed in practice with any ease. Experiences of these conditions have often been discredited because of a gender bias (Greenhalgh 2001). These narratives have, in turn, had to rely on a rich descriptive language and patients'

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[65] As Leigh Gilmore notes, "Chronic pain introduces the problem of persistent embodied otherness to self-understanding, and requires people to reframe "who I am" when pain is a fellow co-embodied presence that may persist as long as the human does. In this sense, posthumanism and chronic pain life writing can both be read as theorizing the agencies and energies, the lives and liveliness, of more-than-human assemblages of life" (92).

perspectives in order to challenge the lack of medical attention in regards to specific bodily and psychic conditions. Narratives of contested illnesses, thus, offer a fertile ground for representation of complicated experiences and the social implications of having those; but because these were historically “contested” as a disease, they risk getting read as narratives that simply petition to be included in rational-scientific discourse and be cured and restored according to its well-established terms.

I have tried to suggest that the “contested” aspect of endometriosis along with reflections on the experience of this disease in a memoir puts this narrative in the position of a dialectical engagement with narrator’s experiences. In this dialectical view of one’s physical and psychic experiences in the past, the role of description, and the incipient quotient of analysis in the memoir are put to use to deconstruct the experience of a changing character of the body, chronic pain, and how institutions engage with these. The result is events are viewed as something smaller because the experiences that are of significance to the narrator were not perceived as significant to be deemed as “events” by institutions (like family, medicine, rituals of childhood and gendering) that occasioned their emergence. Furthermore, the narrative’s techniques of engaging with what can be called “quasi-events” produces an emotional intelligence that needs to be recognized in its own right. The memoir achieves this by dwelling on the register of description, which is a mode of narration that is not taken seriously from a medical point of view. I have suggested examining the mode of “description” is important because it’s a mode through which subjects begin to make “sense” of their histories and experience. Of course, the importance of underscoring the issue of an “intelligence of emotions” (Nussbaum 2001) is hardly a new point to be made, but I have followed what this intelligence does to the narrative at large, what happens to the memoir written in 2003 in which it is deployed, and how it enables an ethnography of what is remembered and retrieved in memory. The postmodernist attention to the incremental force of the smallness of quasi-events cannot be overemphasized because it through a recourse to postmodernist verve that the memoir situates the structures of subjectivity of the narrative voice (and the writer’s) as radically dispersed along a spectrum on which various institutions of social life are positioned at different points; in doing so, the memoir defers arriving at the “ultimate referent” of chronic pain but nevertheless enables us to imagine what such a referent could be like, thus providing a political and ethical impetus to lessen gendered pain.

In the context of an instrumental use of life experiences in medicine studies that risks occurring if we do not engage with patients' perspective seriously, the role of literature, description as a register of analysis, life reviews and memoirs are sometimes viewed as means to an end. In tarrying with unique social theorizations that emerge when we explore the opacity of the subject of pain's experiences, I have examined how this "end" ("cure" in medical terms) by creating a space of rumination in a memoir this notion of an end is reimagined. I have tried to suggest that the memoir borrows from a language of (auto)ethnography in a way that is instructive for contemporary evidence-based medicine: it shows us how autoethnographic language is attentive to experiences that may never emerge or be recognized in terms an "event" of illness, for instance, or think of a direct experience of technologies of amelioration that negotiate biomedical practices in radically different terms. Instead, I suggest, contested illnesses- because they are "contested"- have always occupied the border zone that reveals themselves in terms of "quasi-events" attuned to descriptions of scenes of chronic pain; and in so doing, they could potentially transform institutionalized definitions and our understandings of bodily conditions. Also, event-oriented understandings of illness experience do not do justice to how a concept of illness is experienced particularly when there is a lack of scripts/definitions and diagnostic possibilities. This is reflected in a recent article published in the *Journal of American Medical Association*, where researchers suggest that there is a "high risk of bias, especially poor reporting of methods of randomization, […] small sample sizes, and confidence intervals" in research on endometriosis (cf. Brown and Farquhar 2015: 297). High risk of bias reflects a social problem, and it cannot be corrected without a large-scale and slow work of epistemological transformation among researchers and practitioners. Engagement with the unruly character of narratives in order to understand subjective experiences of the diseases is often discounted in meta-analysis (which is the highest tier of knowledge production in evidence-based medicine) by subsuming the unruly quality in terms of objectification of the patient's perspective. This is an objectification that can happen in theoretical discourse that are inflected by what critics have suggested to be "strong theories" as well as in qualitative research in medicine studies. In broadening medicine's definitions of undiagnosed and unknown diseases, Hilary Mantel's *Giving Up the Ghost* underscores the notion of exclusion from medical attention and care work (due to not having a medically recognized condition which can be easily understood in terms of a ‘yes’ or ‘no’) is predicated on a kind of “pathology” of scientific reason and institutions that validate it in everyday life. And finally, I suggest that texts like *Giving up the Ghost* needs to be read closely not just to recognize diseases like endometriosis but also to explore how descriptions can help us to dislodge certain views of bodies, registers of narration, diseases, and fixed curative ideals that we could do well without.

~Chapter Two~

"A talisman against the dark": embodied shame and figurative language in Dorothy Allison's *Bastard Out of Carolina* (1992)

3.1 Introduction: Negotiating shame between the "psychological" and the "somatic"

In this chapter I want to explore the concept of a "chronic condition" by examining it from the point of social stigmas around physical and mental conditions, and how stigmas enable and are enabled by material contexts in which they pervade. This is important because illnesses and conditions are directly affected by their attendant stigmas, they are also conditioned by the contexts within which social stigmas function. How do people talking about "chronic illnesses" such as PTSD, as evinced in US-American writer Dorothy Allison's narrative of what can be called "domestic trauma" of child abuse, when an element of taboo is associated with it? And, most importantly, how *do* they talk about stigmatized conditions even when they choose to break the silence, especially when life experiences are written about in the form of a novel? How might a closer examination of social stigmas and attendant affects of shame, dispossession, isolation, and a feeling of claustrophobia help us to understand the interrelations of physical and mental conditions and the narratives through which they are represented? My consideration of these questions is significantly influenced by recent studies in psychosomatic medicine that suggest research in the field needs to "bridge the division between the 'psychological' and 'somatic' treatments and gain important insights into the mind-brain relationship" (Beutel 2003: 773).[66] Shame and stigmatized conditions in this regard require a special examination because "shame" as an emotion is not just in our minds but deeply connected to how we feel it on our bodies, how our bodies contort and cringe when we are ashamed of something. This is why cultural critic Sara

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[66] See Manfred E. Beutel, et. al, "The Emerging Dialogue between Psychoanalysis and Neuroscience: Neuroimaging Perspectives" (2003). Also, see M. Beutel, et. al. "Mental Health and Suicidal Ideation Among 1st and 2nd Generation Migrants" (2016) for how self-destructive behavior mediates between somatic experiences and psychosocial states.

Ahmed (2003) suggests, in feeling shame, "I feel myself to be bad, and hence to expel the badness, I have to expel myself from myself (prolonged experiences of shame, unsurprisingly, can bring subjects perilously close to suicide" (Ahmed, 103). I want to examine how writing about shame and stigma of incest and physical abuse can be crucially related to creating strategies of survival. In making literature out of a history of shame, that is, a particular kind of shame that is incrementally inculcated through inheritances of generational poverty, sexual abuse in poor communities, and slow economic violence, Dorothy Allison's semi-autobiographical novel, I argue, endures and challenges socially precipitated shame. The connections between the ostensible split of the 'somatic' and the 'psychological' is pronounced in narratives of social class because the shame of being poor is reflected on the bodies we witness: we will get a glimpse of these bodies in Allison's literary universe but the experience of this embodied shame transforms into something else in their representation in literature in terms of an alchemical shift, which is why Allison's attention to making a literature out of these experiences (cf. "Believing", 166) is important to be examined.

The "embodied shame" and attendant stigma that I will explore in this chapter have a materiality, it also has a geography that is embedded in an ideologically inflected cultural imaginary. In order to tell a lived experience through its revisitations in a life writing text, however, we have to map this geography. The point is not see a direct or causal relation between the two, but see how these experiences and their revisitations in need to be contextualized in the broadest way possible. This is a kind of mapping, then, that needs to take place in relation to the histories of cultural spaces and the history of science (cf. Banerjee 2018: 8). This is particularly important to understand how this life narrative of embodied shame is influenced by the emergence and inclusion of "post-traumatic stress disorder" as a *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*) around the time *Bastard Out of Carolina* was published. That the literary text is not just a product of a particular set of sociohistorical context but also certain histories of developments in scientific discourse can be gauged through an analysis of *Bastard Out of Carolina.* As Alfred Hornung suggests, "there are many ways in which autobiographical narratives mediate between different disciplines of the humanities, the social and natural sciences, and medicine" (cf. Hornung, "Introduction," xii). Borrowing from this notion that at the heart of life narratives in all their forms is a dialogue between multiple discourses, I suggest, that a diagnosis of an illness or a psychic condition like post-traumatic reactions in the wake of incest and slow economic violence is, at least in part, a recognition of a particular set of social problems in scientific discourses. Thus, in instances where social stigmas serve to silence conditions operate, this diagnosis or a critical engagement can not only be a very difficult task but is itself imbricated with processes that entail stigmatization; it is here that a "slow engagement" is needed to see the effects of shame and stigmatization. This is evinced in an overemphasis on visible violences (at the expense of an exploration of the invisible violences that the novel also discusses) in critical material on *Bastard.* This is why an examination of what we colloquially, and dismissively, call "stereotypes" about individuals and places need to be examined in terms of how these stereotypes -in a self-fulfilling fashion for the subject who experiences it- can become genuinely violent for those individuals and communities.[67] How are these stereotypes dismantled in order to heal from their violence, and how does literature enable this healing by making us more "grief-literate" (cf. McClain 2018)? The focus on the implications of what it means to locate characters amidst violence where the tall order of social hierarchy can only be subverted by rhizomatic desires in language; the child narrator's complicated relationship with her much ridiculed friend, Shannon Pearl; and by highlighting this young adult narrator's feelings in relation to the women and men in her life; I suggest, Dorothy Allison takes recourse in figurative language to seek not so much to seek a resolution, but provides a poetics of endurance of a space at odds the dominant culture her work critiques. In so doing, she gives particular shape and texture to the materiality and daily life in Appalachian culture which speaks to conceptualization of "mind-body split" in multiple contemporary discourses.

Childhood trauma of sexual abuse is a chronic condition in which the incremental effects of social stigma operate in complicated ways. It is not just the case that the fact of incest and physical abuse is silenced, which it of course is, but what happens to this taboo once it is represented and its silence is "broken," so to speak, is of as much importance to understand how socially engineered traumas live an afterlife in relation to the stigmas that entail their suppression on a daily basis. By suggesting this, I am not equating silencing of

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[67] For a brilliant reading of the problems of circulation of stereotypes and how they affect literary interpretations, see Mita Banerjee's essay "Polymorphous Perversity and Contingency of Stereotypes in Bharati Mukherjee's *Leave It to Me*" (2004). Cf. *Sexualities in American Culture* (2004).

stigmatized conditions with the revelation of those conditions, but in order to make the promise of revelation and social justice more meaningful and genuinely restorative for the survivors, it is crucial to examine how stigmatized conditions do not just disappear through the act of their revelation when the revelation of such conditions is not socially, intellectually and politically supported. If, as Janice Williamson (1998) puts it, "[t]o cry is to address a listener. The [cry] goes not go unheard but unheeded; not only the story of woe but the desire to be heard warrants condemnation" (9), then the cry of a dispossessed subject's desire to be heard in the first place is an ethical demand that leaves the listener, often an unwilling one, shaken because the subject is not expected to cry and thereby desire at all. The cry of a beaten and sexually traumatized child disrupts some of the basic tenets of survival and wellbeing in society: conditions of parenting and the hetero-normative family as a socioeconomic unit. Thus, it is important to come to terms with the story of woe that the cry enunciates and the desire to be heeded against our perception of the stories that the cry brings forth. And especially in the case of a sexually abused child, whose cry is either silenced or recuperated in relation to the institution of the family, it is important to examine what kind of a comment the desire to be heard leaves on the larger structures that perpetuates the cry. As readers of incest and narratives of sexual trauma, particularly when the narrative brings forth a child narrator's perspective, it is important to understand how the afterlife of stigma and secrecy lives on in a curious way and leaves an impact in the way we choose to hear stories of abuse and trauma of children. And, indeed, it is a choice that the reader makes in relation to what part of the story—or more precisely the difficult knowledge that the story puts forth—that one tends to focus on when we bear witness to narratives of social stigma.

3.2 Allison's challenge: representing Appalachian culture in a semi-autobiography

Critical reception of *Bastard Out of Carolina* presents the some of the problems I have described above. I wish to highlight how reading the novel by focusing on the violence in isolation from the economic conditions within which this violence is perpetrated has had its devastating consequences in terms of further ignoring the material contexts in which the abuse transpires. This kind of an interpretation has also served to undermine the impact of the structurally inscribed relationship histories of Allison's rural and impoverished South Carolina shares with the popular imagination of very term "America." In this section, I want to give a historical overview of the space within with sexual abuse and the narrative of trauma transpires in Allison's novel and how that experience of abuse is reflected in figurative language. While the novel makes these connections laboriously and critics have taken these aspects of the novel into consideration as well, it seems engaging with abuse of the child in the novel without understanding it as part of socio-politically engineered abuse risks either having a limited understanding of sexual trauma manifests itself—"how can it happen?"—or, serves to see material contexts of poor white families in the rural South Carolina as an isolated and unproblematized space that justifies itself through acts of violence on women and children. *Bastard* is intimately aware of this problem, and Allison has commented on this issue in relation to her purpose and technique in her fictional work. After exploring the material context of Allison's novel, I will investigate how shame, stigma, and an abused sense of self are negotiated in figurative language in the novel. And negotiations of these aspects of the chronic nature of sexual abuse in figurative language processes a trauma that is unique to its treatment in place-based accounts, where trauma is often insidious, socially sanctioned, and not understood as an one-time event but accrues on a daily basis. What kind of an "autobiographical self" (Damasio 1999) is constructed in the process? How do such negotiations aim to construct a new subjectivity in and through language?

Vincent King has described the "kitchen-sink realism" or "gritty southern realism" of *Bastard* as deployed in a way that helps the narrative to familiarize and "[authenticate] what are presented as otherwise shocking or unbelievable truths: namely, the reality of childhood physical and sexual abuse" (cf. King 123-24). As Gillian Harkins suggests, "even as Allison's realist style is hailed a literary achievement, its window onto the horror of incest and the main character's personal journey toward survival seem to provide the real value of the text" (154).[68] In exploring the significance of survivor realism, we need to highlight what

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[68] What is important for Harkins is to situate the novel's form ("realism") and its content (often introspective and, broadly speaking, psychological realism in its ruminations in several scenes) in dialogue with each other in order to examine how they facilitate in developing the aspect of "survivor realism" (cf. 153). Harkins's project is to identify the form of "survivor realism" in relation to the political and economic changes in US-American public culture in the late-twentieth-century that witnessed the proliferation of incest narratives. In so doing, she focuses on how the survivor realist mode of incest narratives speaks to the neoliberal transformation of the US-American public culture. In other words, how incest narratives account for American familial sexual violence enabled by the consumption of "incest narratives" and the claustrophobically private space accorded to the American

precisely this mode seeks to survive; that is it say, how does it narrate itself in a semi-autobiographical mode, and works in tandem with storytelling traditions of a particular geography, and how does it renews itself in figurative language? I contend that in *Bastard out of Carolina* we not only see a history of surviving incest, but a history of surviving a particular geography, a geography of Appalachia and Appalachian culture where "courage, country, and cussedness are of core value" (cf. Cohen 2016). This narrative of survival is not to be confused with the prototypical "survival narrative" that is telling of a militant optimism of North American culture, but a survival through making literature from the experiences of a incremental economic violences that we need to focus on, specifically because these violences connect psychological states of trauma and somatic states that social abjection and poverty produce. Here, I take a cue from Harkins as I wish to pay equal attention to the "horrific and mundane" aspects of incest in order to underscore how familial sexual violence in *Bastard* emerges from a long history of structural violence that Allison's South Carolina shares with the US-American public culture as such. Also, while taking into account the form, the themes in relation to the autobiographical aspect of the novel is extremely relevant to a discussion of chronic nature of childhood sexual trauma, it is also important for my discussion to pay attention to the daily lives of the characters described in the novel, or how the space, rituals of daily life, and processes of stigmatization and taboo live through interpersonal relationship of characters. Appalachia, or the cultural region that stretches from southern part of the state of New York to the northern fringes of Alabama, shares a complicated relationship with dominant US-American culture and perhaps bears repeating. This mark of "difference" that the region shares with the dominant culture is, however, not easily gauged in terms of "rural" and "(sub)urban" divide(s). As Kathleen Stewart (1996), in her work on cultural histories of rural West Virginia's mining community, writes,

> In the United States, 'Appalachia' became one of these 'Other' places and filled the bourgeois imaginary with both dread and desire. In popular literature from the 1830s to the 1870s, the people from the hills were portrayed at once as tough pioneers ("our contemporary ancestors"), grotesque figures (vicious, bestial, extravagant, eccentric), and tricksters (wily, survivalist, con men who were as much victimizers as they were victims). […] During the Progressive Era from 1880 to 1920 difference came to be seen as cultural difference and "the other" became conceivable as a "a culture." […]

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family under neoliberalism.

> ‘Appalachia,’ like the inner city, became a symbolic pocket of poverty in an affluent society and an unassimilated region in an otherwise united region. (118)

Stewart’s analysis brings to bear a cultural and geopolitical region and not so much a place with a fixed set of coordinates, and while she is specifically interested in providing a narrative account of small town communities in West Virginia in her comprehensive work, her work helps us to understand the overall terrain that this cultural space shares with the culturally coded utopianism of the term “America.”[69] Through thick ethnographic descriptions and field notes collected at several localities that register a fundamental oddity in everyday life in relation to dominant American culture, Stewart focuses on how Appalachian culture has a life world that is predicated on contradictions, and contradictions that have been imposed on it through the cultural perceptions of the bourgeois imaginary. In fact, this aspect of contradiction is evident in the way the people are viewed through the lens of the dominant cultural logic. The figure of the “Appalachian,” or “hillbilly,” she writes, “remained tense and contradictory as it carried the weight of the ‘highs’ and the ‘lows’ of a bourgeois space of desire. Contradiction came to be seen as an essential characteristic of the culture itself” (119).[70] An Appalachian subject is, then, “not-quite” American in the national imaginary because neither can the dominant culture wholly absorb her presence as part of itself nor can she be entirely cast out of the grand narrative of a “national culture,” primarily because this narrative relies on marginalization of the culture to come into being through this “not-quite-ness.” This figure serves as a space in which a cultural script about Appalachia is inscribed and sustained. But while cultural and regional differences are inscribed and made through the presence of difference, it is not necessarily the case that they are sustained through an unproblematized narrative of difference. Regional identities, such as “Appalachians,” are read through lens of social class and economics as well. That the Appalachian cultural identity is viewed form the lens of class and generational poverty sticks to this identity is not accidental at all. As much of Allison’s non-fictional writing also show,

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[69] The notion of “America” as a utopian ideal of possibilities – or more colloquially the “land of opportunities”- is addressed in several immigrant narratives. Cf. See Jhumpa Lahiri’s *The Namesake* (2003). Kathleen Stewart’s ethnographic work examines the “other” side of this construction in locales that bear an ideological relationship with this notion of the “land of possibilities.”

[70] Stewart elaborates on the cultural perception of Appalachian identity in the following terms: “people in the hills were friendly and suspicious, talkative and taciturn, fatalist and individualist, religious and antireligious, pathologically dependent and utterly self-sufficient, pathetic and heroic, loving and violent, and above all capable of living with contradiction” (119).

generational poverty in relation to widely spread cultural aversion towards the poor goes hand in hand (cf. Adams 2004). With the federal government's War on Poverty in the 1960s and the presence of federally funded employment agencies in the region like the Appalachian Regional Commission (cf. Stewart, 118), although region had received some economic aid in some form, it has nonetheless become a "distinct area marred by the culture of poverty" (119). Appalachian culture has thus become at least in part synonymous with a culture of poverty in effect because of a collection of attitudes towards the region itself, which in turn mingles with pervasive national scripts of American individualism, an aversion towards poverty, and utopian ideal constructed through the term of "America" itself; in the bourgeois imaginary, the term stands for not a geopolitical space but an aspiration towards upward class mobility and a desire to move out of, if not just remain, in the ranks and privileges of the shrinking middle class. Appalachian culture's association with poverty and the abjected space that it occupies in relation to the national culture is telling of a curious process whereby "cultural difference" is not only produced but also maintained by conditioning this difference through ideologically inflected interpretations of "American" identity. We have here then a vicious cycle of production, preservation and consumption of this regional identity that bears heavily on representations of the identity itself.

We can see here how the concept of regional and cultural identity is experienced by those who are attributed this identity, which, in effect, secures a position of the "other" in relation to dominant culture. For a narrative of childhood sexual trauma and attendant shame and stigma coming from this context, we need to understand the different ways in which Appalachian identities have cast and recast in popular imagination. And while Allison is acutely aware of this problem and thus goes on to describe complicated and compelling inner lives of her characters in *Bastard*, it is not just the need to dismantle a stereotypes that pushes her work; to the contrary, it is the arduous task of making these lives the content of literature that is important for her. As she writes:

> That our stories maybe violent, distasteful, painful, stunning, and haunting, I do not doubt. *But our stories will be literature.* No one will be able to forget them, and though it will not always make us happy to read of the dark and dangerous places in our lives, the impact of our reality is the best we can ask of our literature. ("Believing" 166; emphasis in original)

Viewed from this perspective, *Bastard* is an ambitious project not just because it reveals the inner workings of class and cultural violence on a marginalized identity—"Appalachian," or in Allison's and Stewart's term "white trash"—which then unleashes horrific violence on the children and women in the community, but because it strives to transform structurally enabled violence and biographical details into literature. Although there are multiple ways to understand this move of transforming marginalized and life experiences into literature—as space where somatic and psychic experiences transforms the autobiographical self, I am specifically interested in exploring what this task of making literature does in response to the themes of *Bastard*. How to tell a story of a particular kind of shame, of being poor and abused, can be told to claim a space in the terrain of literature that has been denied to certain social groups? In this regard, we need to understand how this process is achieved, and how does the making of literature in this context speak to certain understanding of "reparative justice," as opposed to retributive justice that is institutionalized by the law and society. In distinction from retributive justice, or one which we know from the novel is always as odds with the community represented by the Boatwrights, reparative justice seeks genuine transformation and historicizes experiences in relation to how one precisely arrived at those experiences because it seeks to engage with broader sociopolitical conditions that make transgressions and violences occur in the first place. It is in this context that the use of figurative language is crucial because it allows Allison to circumscribe a set of problems without remaining tethered to the language of "kitchen-sink" realism that she, of course, uses, but cannot find the answers in regards to social justice for an Appalachian identity in. Furthermore, through figurative language Allison transforms violent pasts (and presents) into literature, which is why a close attention to spaces where realist details are transformed needs to be taken account; thus I investigate the use of figurative language in specific moments in the novel.

Allison's novel achieves the possibility of not only revealing the chronic nature of structural violence that enable her child narrator's sexual and mental abuse, but in so doing, i.e., by transforming these lives, cultural identities, and spaces that have been cast out of the grand narrative of American progress, equality, and myth of individual will to face adversity by pulling oneself by one's bootstraps, she is able to demand a kind of justice that we cannot imagine in practice or in the language of sheer realism. Herein lies the power of Allison's figurative language in *Bastard*. *Bastard*, then, as Ying-chiao Lin suggests, is a "text [that] has now the power to punish the abuser by laying bare his crime; the text becomes a court of law, the readers judges" (1). But what then is the precise nature of this crime, and how does Allison's literary ruminations complicate the notion of the kind of a critical adjudication that the reader can perform?

3.3 "Insidious Trauma" in *Bastard Out of Carolina* and the bourgeois consumption of incest

A few words needs to be said about the literary and critical climate of the 1980s and 1990s that facilitated the emergence of Allison's novel—a novel that self-consciously aimed at transforming "distasteful truths" into "mainstream literary tastes" (Harkins, 153). True to the genre of "survivor realism" or "minority realism" that emerged during this period in the literary scene, *Bastard* reflects a concerted attempt to form a conversation with the literary multiculturalism of the period that saw the emergence of voices from marginalized communities, most prominently those being of survivors of sexual assault who did not find an opportunity to narrate their stories in the earlier period when canonical literatures dominated circulation and readership. Yet this development in multiculturalist literature and narratives of minoritarian experiences did not emerge in a vacuum. Its emergence had been "prepared by the Civil Rights, Women's, and Gay Liberation movements of the 1960s and 1970s. It's also significant that these movements gathered strength from a radical questioning of federal authority to which the protests against the Vietnam War had given vent and which contributed to its conception as a 'national trauma'" (Ball 4). By demystifying and destabilizing institutional mechanisms, these protests fomented a cultural and political ethos that brought about a sea change in critical concerns within the academy as well. The dominance of canonical literature was questioned over the course of the two decades since the 1980s by underscoring hitherto neglected traumas of various kinds that minoritarian and multiculturalist literatures came to reflect upon. Thus "representation of difference" or "otherness" became the "topical catch phrase of a cultural agenda to make visible the wrongs of a society that reproduced the privilege" of white, heterosexual Christian men of property and "sustained the ideological and material conditions for the social and economic marginalization of women, people of color, and gays and lesbians" (cf. Ball 3). Although the new emphasis on marginalized experienced brought to the forefront a number of literary styles and themes that can be broadly called multiculturalist approach to literature and culture, it soon fell prey to a liberal pluralist agenda of "a positive embrace of depoliticized 'difference'" (cf. Harkins 153). This is so because critics—who mostly engaged with the literature of this period from the point of view of what has been contentiously called "identity politics"—failed to recuperate the radical potential of these texts by identifying structural transformations that literary and cultural productions demanded. In the context of narratives of sexual abuse and incest, which witnessed a proliferation in the literary market during this period, the "chronicity" of the conditions that enabled sexual trauma was maintained by not becoming the kind of reader or community of readers that narratives of incest envisioned and demanded. However, this phenomenon of de-radicalizing potentially subversive literature and cultural productions is neither accidental nor unique to the emergence of literature of incest and domestic traumas during the aforementioned decades. What has happened in the context of narratives of sexual abuse and incest is that the fundamental chronicity of these acts of violence has remained because the structural violence that precipitates these acts of abuse had not been addressed in a meaningful way (cf. Sandell 213). And significantly for my analysis of *Bastard*, the ideologically inflected interpretations of semi-autobiographical novels and memoirs that emerged in the wake of the emergence of narratives of "domestic trauma" enabled in depoliticizing the radically different nature of these narratives, which is to say, "incest trauma" has not been viewed in relation to cultural discourses of economic violence and medical discourses that had a profound impact on the thematic concerns of women's literature during this 1990s. I want to underscore that it is important to retain the radical potential of examining the literary text from these intersecting perspectives in order to get a glimpse of the vast intellectual terrain that Allison's novel maps for us through the various discourses it underscores.

In other words, the bourgeois consumption of these novels of horrific acts of violence and "distasteful truths" has ensured that the stories that novels like *Bastard* tell do not build the community that these novels themselves aspire to create. And by relegating violence, sexual abuse, and poverty as endemic to certain communities, by "enacting shock" in the act of reading these narratives, and by sustaining a problematic binary of "victim" and "perpetrator" limned with moral strictures that are foundational to the bourgeois family, readers of sexual abuse narratives have not been able to broaden the conversation around sexual abuse in working class communities in a meaningful way.[71] As Jillian Sandell writes,

> Thus, while the popular imaginary of the United States has proven largely unable to address or challenge oppression based on economic inequality, the widespread acclaim of Allison's *Bastard Out of Carolina* demonstrates that people have no such difficulty in consuming and enjoying stories about class in the marketplace. […] Indeed, capitalism has proven to be notoriously efficient in its ability to recuperate radical ideas and turn them into commodities to be consumed within the market economy. By turning the experience of class-based oppression into stories that are circulated in the marketplace, the act of articulation (rather than the issue itself) becomes the object of cultural consumption. (Sandell 213-14)

While certain experiences, particularly traumatic ones, need effective forms to express themselves, *Bastard*'s novelistic form has, on the one hand, been the perfect genre for its strategies of critiquing the social and political structures that it examines—namely, law, family, marginalization, and gendered violence—while speculating imagined futures; however, on the other hand, the novel's semi-autobiographical stature has also contributed to its consumption and a second form of marginalization in the hands of the reader as an isolated instance of an "individual's" life story. Yet, it is not particularly surprising to note why Allison chose the genre of a semi-autobiography in an emphatically novelistic mode to tell "the complicated, painful story of how [Ruth Anne 'Bone' Boatwright's] mama had, and had not, saved [her] as a girl" (cf. *Skin* 34), which also brings forth her dual challenge of not just writing an account of the history of abuse in her formative years but forming literature in the process of doing so because facts and an emphasis on realistic details cannot effectively convey this paradox. Often described as the principal *aporia* of the novel, this experience—of being "abandoned" by her mother, who, arguably, cannot but abandon her—has been explored in less critical terms than the trauma of physical and sexual abuse that Bone experiences at the hands of her stepfather, which forms the source of direct traumatogenic events in the novel. Here, it seems plausible to connect the lesser engagement with this theme of the novel with its de-radicalization within a literary market economy and circulation of the novel as an object of consumption, where consumption of a cultural product is often influenced by the absorption of "direct testimony" (cf. Vickroy 2015: 21) of survivors in the context of a culturally validated sentimentalization of direct testimonies. Such a cultural

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[71] I am grateful to Alena Kunkel for suggesting the notion of "performance of shock" in service of othering and de-radicalizing trauma narratives.

valorization of traumatogenic events has unwittingly or not led to a steady market and audience for survivors who can testify and "prove" their predicament; conversely, however, those traumas that are structurally precipitated, accrued through slow violence, and experienced in their most mundane and equally pernicious form in a hetero-patriarchal and classist society are understood, often even by the victims themselves, as hard to account for and thus harder to "prove." The plight of such traumatic events that occur on a daily basis in a classist society is that because such traumas are pervasive, intimately familiar, they often go unheeded. Hence, speaking of these conditions in a language that is not only able to situate violence in its mundane and realistic forms but also conceives alternatives through speculative and figurative languages of desire, that is, an affirmative desire to survive is something that we will see alternately emphasized in *Bastard out of Carolina.*

We see a tension of this sort between traumas that can be proven, so to speak, and problem of proof itself in the final scene of the novel when Bone's blood-soaked and raped body is not "proof" enough for her mother to leave Glen Waddell, Bone's stepfather and her rapist, even though she has just witnessed him raping Bone. What enables such a "choice" on the part of the mother? What triggers such a violent act from the stepfather? What sustains both- i.e., this particular kind of choice and the violence in this particular culture? Throughout the novel there are hints that Anney chooses to ignore Glen's assaults on Bone: at one point, we are told, she chooses to buy vitamin tablets for her when she cannot quite figure out why Bone seems to hurt herself all the time, while the reader gets the sense that Anney did not want to confront the difficult knowledge of being aware that her marriage to Glen, which is Anney's only hope for securing an entry into middle class ranks and privileges, is quite literally hurting her daughter. Bone recollects her mother telling her, "'[m]aybe you're thin-boned,' she guessed, and started buying me vitamins. I didn't know what to say to her" (111). And in the final scene when Anney walks in on Glen raping Bone and is escorts Bone to the hospital while fighting off Glen, Bone, at one point, says, "I grinned to feel the blood trickling down my neck. Look how hurt I was! Thank you, God" (289). The problem of "proving violence" is not so much dependent on the proof itself, or on the violated body that bears the testimony of rape, but on a desire to acknowledge and a desire to pay heed to precisely where the violence stems from. In other words, it lies in the desire to pursue the end of such violences through genuine transformations. Thus, economic violence that pervade in narratives of generational poverty in rural communities; traumas that occur in the wake of invisibilization of social class in North American culture (cf. Brown, 43); and, in short, traumas of we may understand of an "insidious" (Root qtd. in Grogan, 1) variety are not only difficult to represent but difficult for readers to assimilate in their repertoire of cultural knowledge because they are too susceptible to being assimilated into more manageable scripts like "incest trauma." Here, I, of course, do not wish to valorize these traumas as "more" traumatic than the actual trauma of incest or physical abuse, but I wish to underscore the mechanism through which radical potential of literature, as Sandell suggests, are retrieved only to be turned into commodities of consumption in a classist society. As Sandell notes, "the act of articulation rather than the issue itself" (214) is emphasized, even in critical discourse, for an ideological purpose. One way to challenge this process of "consumption of incest narratives" is to contextualize it in relation to multiple cultural and critical discourses. We need to see how these stories are, however remotely, related to social and scientific discourses and their dialogues—and what happens to them in life writing narrative. As Judith Herman, a clinical psychologist writes, "We are beginning to understand that rape, battery, and incest are human rights violations; they are political crimes in the same sense that lynching is a political crime, that is, they serve to perpetuate an unjust social order through terror" (Herman 1992: 14). Insidious traumas that can reveal the way institutions like family, marriage, and patriarchal norms and values enable instances of trauma and cause a kind of vulnerability of being ever more silenced and invisibilized. Thus, by taking into account the insidious traumas of generational poverty, we may ask, how may we resist the vicious circle of narration and consumption of insidious traumas by engaging with narratives of child sexual abuse in a productive way? Making literature out of violences in this context, or conferring the status of "literature" to everyday experiences is then not only a project of drawing attention to spaces and experiences that were never recognized as carrying the potential of literature in their own right, but it is also a dialogic project of actualizing the potential of literature, of the role of figurative language of literature in underscoring how those very spaces and experiences are endured needs to be underscored in this regard.

Following Maria Root's (1996) definition of "insidious trauma", Christine Grogan writes, "the idea of 'insidious trauma' refers to the traumatogenic effects of oppression that, although not always blatantly violent, threaten the well-being of the person who suffers them" (1). She elaborates a crucial distinction between insidious traumas and the concept of trauma that is widely circulated in theory and popular understanding in the following terms: "contrary to current medical definitions of psychological trauma and posttraumatic stress disorder, most of the traumatic experiences of women and those economically deprived and racially othered, are not time-limited, singular 'events.' Rather, many traumas affecting these groups are current, cumulative, and quite common" (cf. Grogan 2). By moving away from the concept of "event" of a trauma, Grogan demonstrates an everyday-ness of trauma that is experienced by certain groups that cannot we account for in the language and established paradigms of trauma theory (2). Furthermore, she is able to attend to cultural and environmental factors as the source of individuated pathology by examining the relation of trauma in everyday life and in structural factors. Understanding insidious trauma of sexual abuse in Allison's novel, then, requires a shift in approaches because *Bastard,* through its interleafing of realist and figurative language, is interested in examining the environmental factors that contribute to sexual and familial violence as much as it is invested in representing the repercussions and persistence of borderline experiences in a literary account. This apprenticeship reflects a labour- it is not exactly a therapy through the literary but a labour to make literature from a certain set of experiences that is perceived in problematic terms in the context of mainstream imagination of Appalachian social life.

Reading *Bastard* as a working class novel that self-consciously participates in the project of denaturalizing whiteness and a historically marked culture may help us in breaking this vicious circle in which narratives of child sexual abuse is greatly susceptible to be consumed without being contextualized, or is contextualized in a way that only serves to relegate those instances of abuse in perpetuating essentialist notions of a community. However, the project of denaturalizing whiteness is contingent on several factors that need to be addressed to identify a method for this project. In this context, making visible the insidious ways in which traumas work, that is, as mechanisms of a classist society, and how they shape people's life, or open up worlds that have been concealed for ideological reasons is crucial to be observed. Yet this opening up of spaces like Appalachian culture in order to make visible unfamiliar communal conditions is not easily achieved, and cultural productions like Allison's semiautobiographical novel is reliant on and, in turn, respond to certain prevalent discourses. The emergence of *Bastard* in 1992 is, thus, in not accidental to the inclusion of concept of posttraumatic stress disorder (PTSD) in the *Diagnostic and Statistical Manual of Mental Disorders IV* (*DSM*) in 1980 (cf. Harkins, 82). This was an important historical significance because the addition of PTSD in the *DSM-IV*'s lexicon was, in effect, an acknowledgment of the traumatic legacies of the Vietnam veterans. As Gillian Harkins writes:

> Only after the Vietnam War did a full codification of PTSD emerge (1980), and over the course of the 1980s and 1990s the Holocaust became more central to the ideology of PTSD (Leys 15). Between Vietnam and Holocaust, however, a third major coordinate of trauma culture appeared in the horizon: incest as a form of child sex abuse. (82)

The trauma incurred through military ventures outside the borders of the United States is deeply imbricated with domestic trauma of incest narratives that emerged in the period, which then finds a voice after the *DSM-IV*'s inclusion of the term. While the encounter with PTSD as a phenomenon in the wake of the Vietnam War had a historical precedent in the US-American experience of the Holocaust, domestic traumas such as incest as a form of child sex abuse borrowed from the language of PTSD in order to reflect upon how these traumatic experiences were not that far removed from the society that ascribed names and definitions to it. Instead, the same society facilitated in harbouring material conditions that enabled forms of trauma (in private spaces) within its national borders. Furthermore, the upsurge of feminist and queer publishing houses in the United States and Canada during the aforementioned decades (cf. Williams 2003) along with the emergence of incest as a topic of discussion in popular media—through discussion on "incest" on daytime talk shows—delineated a female experience of PTSD in relation to the private sphere, a realm of everyday life which, paradoxically, was not readily associated with PTSD until the proliferation of incest narratives. Although the connection between PTSD and so-called "incest narratives," which offered a rather different understanding of the public understanding of domestic trauma, was largely enabled by the popular print and the televisual medium, it was also to the credit of writers of the period who chose autobiography as a genre to express themselves. In doing so, writers like Allison were able to interrogate both overarching definitions of "trauma" that the *DSM-IV* subscribed to and, in turn, showed how literature in general can reveal certain facets of everyday life under violence that cannot be grasped without narratives, largely because those facets cannot always be put into the language of institutionalized definitions. While on the one hand the inclusion of PTSD in the *DSM-IV* resonated with survivors of domestic violence and abuse over the decades, on the other hand, their representations of having survived insidious trauma went unheeded because, as Jamaica Kincaid suggests, there was a "[m]oral panic about the end of childhood innocence at the end of the [twentieth] century: [t]he "child-molesting Gothic story" distracted Americans from more structural social problems such as poverty, lack of educational opportunity, and failure to provide basic services for children (cf. Kincaid qtd. in Harkins, xvi). Allison's engagement with "white trash" identity and histories of rural South Carolina in the 1950s and 1960s—following intellectuals like Toni Morrison's and bell hooks's comments—has participated in the task of "call[ing] for whites to revaluate themselves and their identities self-consciously, eschewing a vision of whiteness as the 'norm' for a more realistic and fair-minded understanding of whiteness as a specific, racially-marked group existing in relation to many other such groups" (cf. Wray and Newitz 1997: 5).

Allison, who considers Toni Morrison, Alice Walker, James Baldwin, and Zora Neale Hurston, among others, as major influences on her literary career (cf. Grogan, 146), has commented on the impact that Morrison's 1970 novel *The Bluest Eye* (1970) has had on her in the following terms: "[b]esides James Baldwin, nothing ever hit me as hard as Toni Morrison' *The Bluest Eye*… it was about incest, about that terror, and it was about suicide" (Allison qtd. in Grogan, 146). Allison goes on to suggest that the novel resonated with her because of the "'speech,' 'rhythms,' 'language,' and, most familiarly, the emphasis on the working class." She says, "[i]t didn't read to me black; it read to me working class" (146). In finding a story of her own in Pecola Breedlove's everyday life in Lorain, Ohio, in her shame of being raped by her father, and in her introjection of the dominant Euro-American beauty ideal—"the bluest eye"—that Pecola herself could never exemplify, Allison's refracted approach to her story in relation to Morrison's text facilitated her to understand the foundational double bind of this text: that is, the mother's "abandonment" of her daughter in this specific context (cf. *Skin*, 54). However, in terms of the connections and cultural histories that it draws upon, her focus on the working-class life in order to uphold her childhood in South Carolina and transform that into literature is also a challenging task because of what Wendy Brown has called the "invisibility and inarticulateness of class" (61) in the US-American context. It is an inarticulateness that is not only widely accepted but also put into practice in what Brown calls "identity politics."[72] What fuels this harmful invisibility and inarticulateness of class in a classist society is the fact that there is a widespread hatred for the poor; as Annalee Newitz and Matt Wray write, "Americans love to hate the poor. Lately, it seems there is no group of poor folks they like to hate more than the white trash" (1).[73] They go on to suggest the economic crises that fuel this hatred, and how a neoliberal order of "inclusion" at the cost of genuine transformation sustains this sentiment of hatred and a concomitant fear of losing the white subject's historically accrued privileges. Newitz and Wray write:

> As the economy and unemployment figures in the U.S. worsen, more whites are losing jobs to downsizing and corporate restructuring, or taking pay cuts. While it used to be that whites gained job security at the expense of other racial groups, whiteness in itself no longer seems a sure path to a good income. Hence, one might argue, mass-marketed books and TV sitcoms about poor white trash are one way the dominant culture acknowledges that whites are the victims of poverty these days, too. (Newitz and Wray, 7-8)

While these comments help us to get a glimpse of how a climate of economic precarity operate in contemporary North American culture in general, the question of consumption of mass-marketed books and TV sitcoms about poor white trash communities, however, brings in an interesting angle: that is, how urban(ized) and middle class white (and non-white) communities consume cultural productions of those based outside suburban spaces, often in rural communities or inner cities, places where there are limited resources to support the local economy because of jobs have either been off-shored for cheaper labour or there were little to begin with. Such a "consumption" of the poor through mass-mediated images, especially the poor whites who are located outside urban areas and who have in the bourgeois imaginary somehow not availed the opportunities offered to them because "they" failed to

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[72] As Brown writes, "In contrast with Marxist critique of a social whole and Marxist vision of total transformation, to what extent do identity politics require a standard internal to existing society against which to pitch their claims, a standard that not only preserves capitalism from critique, but sustains the invisibility and inarticulateness of class—not accidentally but endemically? Could we have stumbled upon one reason why class is invariably named but rarely theorized or developed in the multiculturalist mantra, 'race, class, gender, sexuality'?" (61)

[73] Allison speaks of this notion of a cultural aversion towards the poor in her lecture titled "Mean Stories and Stubborn Girls" (*The Tanner Lectures on Human Values,* 2001). She says, "It is no advantage to realize that as a culture we have the same schizophrenic notion—that Americans fear and hate the poor even as we drape over them an idealized veil of awe and sentimental fantasy (310-11).

live up to ideals of bourgeois individualized will, or are perceived as not worthy of being recognized in relation to those ideals to begin with, is widely circulated. Arguably, however, this process of consumption is even necessary for urbanized communities because it generates an anxiety in terms of what could happen to them if they disappear from the ranks of the middle class (or do not yield to the demands of capitalist ideals of production) and thereby extremely efficient to maintain the status quo: we may understand this phenomenon as weaponization of poverty against the poor. With such an understanding of how representations of poor white communities and Appalachian regional culture in general are generated and consumed by mainstream America because the abjection of "white trash" serves as a foil for the myth of a "healthy" national culture, *Bastard* highlights a trenchant critique of one of the most under-theorized mantra of identity politics: social class (Brown 1995: 61). These notions of "white trash" identity and its circulation in cultural discourses resonate with Brown's points on the problematization of identity politics as well. Although Brown's discussion is not related to multicultural literature and cultural productions and is meant as a critique of prevalent critical approaches to those texts, her point that identity politics, because of its over-investment in identity's given constructs, naturalizes and even "preserves capitalism from critique" (61) is important. It seems ignoring complicated and often intersecting aspects of identity risks betraying the project of criticism that envisions a "total transformation" and privileging any one aspect of identity, which, according to Brown, often happens to be social class in multiculturalist critical approaches, over others retains the status quo. It seems to me Allison, too, is influenced by such a rigorous understanding of intersectional facets of identity, and her aesthetics concerns in the novel bears testimony to her determination of not valorising any one aspect of her identity over others but providing as much of a holistic view as possible. In the following section, I would like to examine how she achieves this by focusing on the making of her child narrator's subjectivity in the wake of traumatogenic events and code switching of registers—between the speculative/figurative and realist modes—that enable her to construct the narrator's emergent subjectivity beyond pathological terms of conceptualizing abreaction of sexual trauma.

3.4 Insidious trauma, the "autobiographical self", and repair work

I want to discuss how *Bastard* negotiates politically charged emotions like shame in relation to a literary account of trauma for the purposes of a possible therapeutics. It bears highlighting that this mode of addressing the emotion, or the notion of engaging with therapeutic possibilities in the wake of shame, as critics have suggested, is significantly different from what we understand of the term in a clinical context (cf. Balaev 2012; Vickroy 2015). The notion of therapy in *Bastard* is neither purging of emotions nor is it a release of affects of trauma that puts the subject in a passive position of generating previously suppressed affects; to the contrary, literary accounts of trauma in general, as evinced in the figure of the child narrator of *Bastard*, attest to a kind of therapeutics that belabours its own shattered story of traumatic event *in relation* to its contexts. Shame and the therapeutics that it deploys to negotiate this pain is "not simply a *cause* of action, but often itself a kind of action" (cf. Asad 31; emphasis in original). In the novel, the perspective of the child narrator, Bone, is used to make sense of the brutal violence that she suffers. Through Bone, Allison not only writes about her childhood experiences but, in making her past pain as a kind of action, she depathologizes the affects in the wake of trauma. For instance, in the novel we find a social history of class from a point of view of a child narrator, which, not unlike a child's perspective, is always curious to learn her own context. This sense of curiosity is a resource for Allison's narrative because it allows us to see a radically defamiliarized social context that is repeatedly questioned—not unlike a child typically does with her incessant, "why?" Thus, critical lenses emerging out of the multiculturalist approach, such as "social class," fall somewhat short because these variables of experience are not seen as discrete labels from Bone Boatwright's point of view, particularly when she is seen to try to make sense of the social implications and lived experiences in relation to this concept. Thus, while the novel narrates violences of different kinds, it arrives at this violence through a concerted attempt to examine the politics and poetics of daily lives: the novel begins with an epigraph that is a quote from James Baldwin's 1972 essay *No Name in the Street.* Baldwin writes, "[p]eople pay for what they do, and still more, for what they have allowed themselves to become. And they pay for it simply: by the lives they lead" (Baldwin qtd. in Allison, epigraph). The use of this quote prepares the reader for a holistic vision, or an overarching view of lives and what they threaten to, or indeed, do "become." There is a tension here in the way these two terms are used—"lives they lead" suggests a somewhat fixed set of conditions, whereas what people "become" through their actions suggest a dynamic process in which the conditions of their lives transform them in ways that cannot be fully anticipated. This unpredictable (or perhaps "too predictable") exchange of a set of social and political relations and their transformative potential is rendered all the more complicated because what people do to others. Not unlike Baldwin, Allison, as evinced in *Bastard*, is careful not to introduce the concept of a "choice" here or "punishment"; instead, very little is said in terms of how people arrive at their own actions. We may say Allison's effort to make literature from the lives in an Appalachian community dwells and expands on this structurally enabled silence around how an individual's action transforms her into someone else. The subject's arrival at her actions through lived experience of a concept like choice, then, is of as much importance as is what she finally chooses to do. What people do in the face of adversity is focus here, which is rendered all the more transparent from the child narrator's point of view even when the reasons for the violences that she experiences are not intelligible to herself. In retrospect, Allison's novel dwells on spaces of profound sadness of the sentiment elicited in the idea of *how* people pay for what they do, by being what they become through their actions. There is no transcendental notion of choice or a deification of the law in terms of a possibility of a punishment here but a descent into the ordinary and extraordinary experiences of the child narrator in Appalachian culture.

Allison's semi-autobiography of white trash identity registers the violence that perpetuates a classist society. Her novel is thus an investigation of the daily lives of a "white trash" community and how these lives are perceived by the mainstream society in a way that reveals why and how the perception is formed in the first place, how it circulates, and ways in which it eventually returns to affect the actions of members of the community. Perhaps, herein lies kind of "therapy", a kind of studied grieving and processing of the past that is also about what Antonio Damasio calls "a laying down and remodelling of the anticipated future" through mediations of the "autobiographical self" (cf. 224).[74] This kind of a therapy in

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[74] Also, see Alfred Hornung's *Auto/biography and Mediation* (2010). Hornung situates the autobiographical self and its narratives in relation to multiple discourses generated in material cultures. He writes, "Auto/biographical narratives display an ever-increasing range of media in which lives or parts of lives are presented: print media, performance, film and video, radio and tapes, or the Internet. Many autobiographies combine different media for intermedial effects, such as the inclusion of photography into texts, voice and music on the radio or tapes, sound and images in filmic auto/biography, or music and dance in self-performances. Autobiographical multi-media performances dissolve the boundaries between genres and technologies of signification. ("Introduction", xii)

autobiographical literature finds a "solace" in writing.[75] The therapy occurs in relation to not a triumphalist representation of affects, or wishes to display a heroic agency that valorizes a romanticized notion of resistance, but in describing events that tell us how certain spaces and conditions are endured by subjects. I will return to the concept of dwelling in figurative language in this regard in the following sections of this chapter. In order to examine what "white trash is all about" (cf. *Skin* xiii), Allison writes:

> I show you my aunts in their drunken rages, my uncles in their meanness. And that's exactly who we are said to be. That's what white trash is all about. We're supposed to be standing in our yards with our broken-down cars and our dirty babies. Some of that stuff is true. But to write about it I had to find a way to pull the readers in and show you those people as larger than that contemptible myth (xiii).[76]

Allison seems to pose the question of what it means to form narratives to rework and subvert prevalent myths and stereotypes of about a poor white community. The project of destabilizing the potentially violent myths that Allison undertakes in *Bastard Out of Carolina* is crucial to explore the ways in which subjective becomings are viewed in the novel, particularly because they are shown as a part of the formative experiences of the child narrator. In fact, the making of this character's perspective in the wake of traumatogenic

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[75] See Mita Banerjee's concept of "solace in autobiography" in *Medical Humanities in American Studies* (2018), p. 9. Also, Talal Asad's "Agency and Pain: An Exploration" (2000).

[76] Allison goes on to suggest, "And show you *why* those men drink, *why* those women hate themselves and get old and can't protect themselves or their children. Show you human beings instead of fold-up, mean, cardboard figures" (xiii). Allison's project of giving a face to the nameless and faceless groups of men and women who, as she says, are always stigmatized as "no-good," "lazy," and "shiftless" is powerful because it leaves us with a lasting impression: in showing *why* those men drink, and *why* those women hate themselves and get old, we, I think, are pushed to imagine how subject positions shape the contour of subjectivity's encounters with, as Oliver suggests, infinity, meaning and historicity. In Oliver's terms, oppression "withhold[s] social support for sublimation, on the one hand, and foreclose[s] forgiveness for the revolt essential to singularity and thereby individuality, on the other" (180). What Oliver calls "sublimation" resonates with the psychoanalytic notion of "release" of strangulated affects in crucial ways: a triggering of sublimation, however, is only able to when the internalized foreign objects or those affects of trauma and oppression are able to transform into, literally, nothing—after they become a part of "sequential time" of history—which is precisely what sublimation does. It makes these affects disappear, indeed, magically. Citing Hannah Arendt, Oliver describes, forgiveness as the "magical formula that would break the spell" (cf. Arendt qtd. in Oliver, 180).

events is the work of producing an important counter-perception to the "contemptible myths" that Allison discusses and a point of view that reads the conditions of its own emergence; in so doing, it provides a map of the social world which it navigates in a way that unsettles the reader's understanding of the given sociality. There are several instances of this kind of an attempt at transformation in the novel. For instance, in 1955, Greenville, South Carolina, Bone tells us, "was the most beautiful place in the world" (17). It is through observations like this that we can come close to appreciating the scale of Allison's project that mediates between given conditions of lives, or what we could call the "somatic", and the becomings made possible or foreclosed to those lives in terms of psychic influences of environmental factors. Thus, we could ask, what does it mean to appreciate viewing Greenville as the most beautiful place in the world, as Bone tells us to think of it? And similarly, how does this perception give an alternative perception to what mainstream society thinks of as "rural" Appalachian culture?

Showing the members of Bone's family, her aunts and uncles, in their drunkenness and meanness is both an acknowledgment of the marginalization of these lives and a way of witnessing the their subjective becomings, realized or not, which suggests that these characters exert some sense of agency by forming relationships, by merely hoping to have better lives as we see in the context of Anney Boatwright's life story, by quarrelling and fighting among themselves, and, most problematically, even by hurting themselves and their own. Thus, it is when we understand how this community lives that we can come close to interpreting *why* these characters end up hurting themselves and others. The relationship between these two facets of the narrative, that is, living and exerting some form of agency through action is a complicated one, and one that is rendered all the more compelling because of the way it traverses the "rough edges" of traumatic experiences in Allison's novel (cf. Cvetkovich, 35).[77] To return to the issue of negotiating *Bastard*'s narrative of shame, stigma, and socioeconomic violences faced by the Boatwright community, the question, then, is: how to account for scenes of affective release (cf. Oliver, 180) in the novel in a way that helps us to productively understand the conditions of emergence of these affects and what happens in their aftermath—an interpretation that does not turn into a verificationist trope of those very

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[77] See Ann Cvetkovich's *An Archive of Feelings: Trauma, Sexuality, and Lesbian Public Culture* (2003), p. 35.

conditions but enables us to understand the lived and marginalized experiences of violence as simultaneously reimagined and transgressed in figurative language.

Through an analysis of multiple narratives around everyday trauma that the child narrator's point of view brings to forth, Ann Cvetkovich (2003) argues that in regards to privately held traumas that were not recognized as traumatic because "domestic traumas" remained mired in cultural histories of disavowal, these "silenced traumas" had an effect in establishing a prevalent public culture (10). She writes,

> My claim that trauma raises questions about what counts as an archive is thus connected to a further claim that trauma also raises questions about what counts as a public culture. My goal is to suggest how affect, including the affects associated with trauma, serves as a foundation for the formation of public cultures. (10)

Affects related to trauma are constitutive of public culture, and they enable us to question what is perceived as "public culture." Such affects are indexical of how private griefs refract beyond private spaces and challenge our conceptions of what constitutes archives, records, and repositories of where the stories of trauma may have been narrated in peculiar forms, which then allows us to read circulation of certain narratives or silences around some others in a productive way to better understand what constitutes as "public culture." Theorized in this way, Cvetkovich is able to interpret Allison's task as necessarily opening up a world of multilayered characters experiencing a range of emotions that come to play because these characters occupy an unrepresented but not necessarily unfamiliar space in relation to dominant public culture. Elements of biographical details that Allison draws from become more significant for analysis because they are not just details that help in fleshing out the characters and communities in the narrative but work as a resource for storytelling and a kind of therapy; as Cvetkovich writes, "Trauma cultures are actually doing the work of therapy" (10). Examining everyday lives around trauma (as a creative project) is meant to show "people as larger than the contemptible myth [of white trash identity]"—it's a work that is both literary and therapeutic. It is so because such a project connects inner lives with realities in a way that dismantles these dualities but also speculates how those dualities and disconnections are put into effect in the form of prevalent "public cultures", as in how such conditions form cultural inscriptions generated through discourses and across spaces where insidious traumas are experienced and accumulated. But the question of *how* trauma cultures are doing the work of therapy remains somewhat unproblematized in Cvetkovich's formulation. While I agree with the presence of a therapeutic aspect in the narratives of trauma, I am also concerned if representations of trauma can be readily interpreted as "therapeutic" with dominant paradigms of trauma that we bring to interpret them. In other words, what do we mean by "therapy" when literary accounts of childhood trauma and social shame, as we see in *Bastard*, do more than just abreact and relive the experiences of violent pasts to provide depathologized views of lives?

The definition of therapy in literary accounts, as Michelle Balaev (2012) argues, is not undertaken in the mode of simple recalling of past events, or silences around them, but "lurches the protagonist into a profound inquisitive state, in which meaning of the experience and the process of conceptualizing the self and the world are meticulously evaluated" (164). According to Balaev's concept of "place theory," or one that is uniquely associated with literary accounts of trauma, "[t]his expression of the self is socially contingent and connected to a place of inhabitation and meaning, not binarily dependent on a linear re-enactment of a traumatic experience" (162). Balaev's theorization of the posttraumatic iterations in literary accounts departs from the dominant abreactive model in crucial ways because in literary trauma we do not just witness the "shattered" self of the protagonist; to the contrary, we have a trope of a shattered history in novels from which protagonists either attempt to reconstitute their sense of self or fail to do so, but this trope of a traumatic past is negotiated in the novel. Thus, how can such negotiations be understood as passive abreaction of suppressed feelings due to trauma—and what do we lose in our interpretations of literary texts when we risk doing so? While the abreactive model incapacitates the victim because the "unassimilated" and, thus, "not known" (cf. Caruth qtd. in Balaev, 151) character of the event of trauma (that is, when it occurred in the first instance) returns to haunt the subject belatedly and repeatedly, the place-based model of trauma in literary accounts gives more agency to the protagonist of survivor realisms because literary accounts provide a therapeutic possibility. Also, the profoundly inquisitive state that Balaev refers to leads to a depathologized understanding of abreaction that is closely tied to the place, time and various cultural factors that can have a healing effect. The child narrator's perspective provides an instance of this inquisitive state in *Bastard*; as I have indicated above, Bone's (in)ability to make sense of her story is a part of an "inquisitiveness" that is ushered in because of her encounter with childhood abuse, but they also become something akin to therapy in her accounts.

In *Bastard*, these subtleties are also represented through the intertwined motif of (il)legitimacy, shame due to being an "illegitimate" child to an unwed mother, legality and how these are not just concepts or institutions but they generate "affects of trauma," Cvetkovich notes, that organize the given form of sociality in the Boatwright community. Bone tells us of her mother's anguish when her birth certificate describes her as "illegitimate" by legal powers vested in "the state of South Carolina" (3), which has a very little in common with the locality of Greenville County that we later come to know in greater detail and one that the narrator remembers in affectionate terms. Soon after a car accident Bone is born while her mother, who was in the car during the accident, remains unconscious for three days. Her shame on learning that her child's birth certificate certifies her as a "bastard" is overwhelming and also inflected by a notion of having failed and a desperate need to make amends: "Mama always said it would never have happened if she'd been awake," Bone tells us (3). We also learn that she makes several attempts to change Bone's legal status at the local courthouse and, finally, when she is unsuccessful after a year of waiting, the scene and her reaction is described in deeply emotional terms. The narrative tells us "It was the same, identical to the other one. Across the bottom in oversized red-inked block letters it read, 'ILLEGITIMATE'" (4). Anney's reaction on finding out that a change in the legal status of her child is not possible is described in the following terms: "Mama drew breath like an old woman with pleurisy, and flushed pink from her neck to her hairline. 'I don't want it like this,' she blurted" (4). We see Anney's shame of not being able to provide Bone with a socially recognized identity, which pushes Anney to purse respectability throughout the novel, and she also repeatedly takes recourse to legal structures in order to ensure that the law recognizes Bone. At the end of the chapter, when the local courthouse burns down, the Boatwrights and the community at large are seen to have a strange but profoundly compelling reaction to the accident: they laughed, grinned, looked at each other in amusement at the sight of "the smoke billowing up downtown" (16). The first chapter ends with a celebratory moment amidst the destruction of the courthouse. I highlight this scene and the way Allison arrives at the ending of the first chapter because it portrays a crucial aspect of Allison's project. Not only do we explicitly see the dynamics of the relationship that the Boatwrights share with legality as such, but we also get a glimpse of how these structures of society cast a long shadow on this community at large, which, in turn, affects the emotional lives of the characters and even influences their rituals of daily life. As Bone's uncle, Earle, says, "The law never done us no good. Might as well get on without it" (5). Yet, this historical precipitation of an attitude towards the law is not shared by all members of Bone's family, especially Anney, and, as we will see, to some extent by Bone's stepfather, Glen Waddell. Bone's grandmother did not care about the law as well, but her mother did (3). Bone tells us,

> Mama hated to be called trash, hated the memory of every day she'd ever spent bent over other people's peanuts and strawberry plants while they stood tall and looked at her like she was a rock on the ground. The stamp on that birth certificate burned her like the stamp she knew they'd tried to put on her. *No-good, lazy, shiftless.* She'd work her hands to claws, her back to a shovel shape, her mouth to a bent and awkward smile—anything to deny what Greenville County wanted to name her. Now a soft-talking black-eyed man had done it for them—set a mark on her and hers. It was all she could do to pull herself up eight days after I was born and go back to work waiting tables with a tight mouth and swollen eyes. (3-4)

It is important to consider these socially sanctioned shame in relation to the law and structures of everyday life experiences of each of these characters because it is by focusing on these spaces that Allison is able to humanize these characters and deconstruct the myth of white trash identity. In order to comprehend how people in this community live their lives and how they transform in complicated ways by the fact of living their lives, Allison is able to reclaim these lives as the stuff of literature. In the process there is a concomitant task of ideological unravelling of the conditions of production of these lives and their psychic worlds. By highlighting the struggles between living and becoming, the Allison's child narrator shows us the friction between what Kelly Oliver (2004) has called "subject-position" and "subjectivity"; as Oliver writes, "The subject is a dynamic yet stable structure that results from the interaction between the subject position's finitude, being, and history and subjectivity's infinity, meaning, and historicity" (xv). While approaching the narrator's community through the lens of the contemptible myth allows the narrative to delve into subjects conditioned by finitude, being, and history, it is by focusing on the formative experiences and point of view of the child narrator, Bone, such as shame and stigma as a condition of subjectivity, and a dynamic attempt on Bone's part to make sense of her own experience, that the narratives shifts the attention towards subjective becomings through the individual's relationship with institutions that ascribe subject-positions. In the process of locating the influence of the law and legality on the mental life of some of its characters, this novel is able to show how the law is experienced and how it is lived on an everyday basis among the Boatwrights, how these characters identify with the law from their subjective positions. As Anney seeks legal recognition of her daughter, she takes a course of action in the novel to ensure that the law recognizes Bone's parentage; in other words, her relationship with the law and the institution as such paves the way she arrives at her actions and influences Bone's life. Similarly, there are characters like Earle and Bone's grandmother who do not identify with the law at all and get on with their lives in a different way. In analyzing this work closely it is important to understand that *Bastard*, even though the novel is deeply invested in deconstructing "white trash" identity, it is an act of love in the sense of "critical intimacy" for her community, and this is reflected in the way the child narrator thinks of her aunts and uncles and the greater family.[78] As she says, "I worshipped my uncles—Earle, Beau, and Nevil. They were all big men with wide shoulders, broken teeth, and sunken features. […] Their eyes were narrow under sun-bleached eyebrows, and their hands were forever working a blade or a piece of wood, or oiling some little machine part or other" (22). In navigating the terrain of Allison's critical intimacy through the lens of love and a tenderness in the way in which she looks and imagines her characters, I want to tease out the role of positive affects that emerge while processing shame and stigma because these negative emotions, even when they are delineated through particular instances in the text and often intersect with positive one: the shame of being poor, growing up poor, is interspersed with an adoration for the adults, uncles and aunts, in the family. The community established through these familial relationships is collectively a victim of the "contemptible myth" which Allison is set to dismantle, and a way to do this is to show the humanity of each of these characters and most particularly the child narrator's relationships to those around her. This is why shame and social stigma of poverty or physical trauma is never one thing in the novel; in

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[78] See G. C. Spivak on the idea that "critical intimacy", what is more popularly known as "deconstruction", as an act of love. According to Spivak, "You can only deconstruct what you love. Because you are doing it from the inside, with real intimacy. You're kind of turning it around. It's that kind of critique.*"* <*https://lareviewofbooks.org/article/critical-intimacy-interview-gayatri-chakravorty-spivak/#!*> Web. 29 Jan 2018.

order to understand the pervasive character of a stigmatized life we need to attend to how it intersects with several other emotions, as in the above quoted passage, love and adoration, which then goes on to show the character in the novel are "human beings instead of fold-up, mean, cardboard figures" (cf. *Skin*, xiii).

While critical emphasis on the novel's depiction of violence has yielded rich scholarship, the question of examining an incrementally accrued "embodied shame" to better understand the community that Allison is interested in has not been sufficiently explored. This line of inquiry is important because it allows us to see the communal psychology of the characters Allison is representing and biographical details she is processing in the course of the novel. For instance, how does this novel deploy "embodied shame" to legitimize this emotion in all its complications? How do practices of healing through narration work in regards to representing embodied shame? The politics of influences in the novel and even the fundamentally liberatory task of storytelling to process the feeling of shame in an affirmative way have not been sufficiently explored.[79] Consequently, it is important to note that *Bastard Out of Carolina* begins with a dedication to Allison's mother. The dedication reads, "For Mama, Ruth Gibson Allison, 1935–1990."[80] As readers, we know that Bone's mother "chooses" to give her up after witnessing her stepfather raping her. This event becomes the central paradox in the novel, which is a source of shame for the child narrator and for the mother as well. Bone is seen to come to terms and comprehend this event at the end of the novel when she's left with her lesbian aunt and, finally, given a copy of her birth certificate that recognizes her as a "legitimate" child of her parents and the subject of the law. The birth certificate, we learn, is her mother's final gift to her. The biographical details of Allison's formative years of being a survivor of her stepfather's abuse, comes to play in this aspect of the novel. And although Allison does not explicitly talk about how her mother reacted to these violent experiences in her past in her non-fictional writing, she is clearly

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[79] By this I mean both biographical and intellectual influences that Allison acknowledges in her non-fictional writing in regards to her fiction, particularly *Bastard*.

[80] Although I'm reluctant to overemphasize the role of paratextual materials like dedications and ekphrastic quotations from other writers that have influenced Allison authorial politics in this novel, I find it useful to focus on these elements in the text to specific uses of "embodied shame" that have fallen under the critical radar, so to speak.

empathetic to her mother's plight as a poor woman who had very few options regarding how to look after her two children as a single parent. In her essay, "A Question of Class" (1994), Allison writes,

> But what may be the central fact of my life is that I was born in 1949 in Greenville, South Carolina, the bastard daughter of a white woman from a desperately poor family, a girl who had left the seventh grade the year before, worked as a waitress, and was just a month past fifteen when she had me. That fact, the inescapable impact of being born in a condition of poverty that this society finds *shameful, contemptible, and somehow deserved*, has had dominion over me to such an extent that I have spent my life trying to overcome or deny it. I have learned with great difficulty that the vast majority of people believe that poverty is a voluntary condition. (15; emphasis added)

Allison's revisits these themes in much of her fictional and non-fictional work (Adams, 82). She uses words like "overcoming", "denying", and having "learned with great difficulty" about certain pervasive myths about poverty in the U.S. In providing her own experience of the life-world that poverty and its myths construct, she must return to dwell on this theme in her literary meditations. She understands poverty, growing up poor as a "bastard daughter of a white woman from a desperately poor family" as the "central fact of [her] life." Thus, we may ask, how is this autobiographical text engaging in a work of repair, reconstitution and, surely, a kind of therapy through language and place-based narratives by processing certain foundational themes that are common in Allison's oeuvre? The labour of returning to engaging with place-based traumas needs to be examined by situating this literary narrative of trauma in relation to what Antonio Damasio (1999) has called the "autobiographical self", a self which mediates between "extended consciousness" and "core consciousness" (196).[81] The autobiographical self, as Damasio suggests, "hinges on the consistent reactivation and display of selected sets of autobiographical memories. This self then initiates a dialogue

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[81] In Antonio Damasio's formulation, "proto self" is what all mammals have, while the core self is wholly neurological, and the extended self is more human and prone to refashioning itself in relation to language and futurity (219). Proto self is consciousness that cannot be registered—it's like the beating pulse, or involuntary characteristics of the organism. However, all these selves have neurological basis in Damasio's conception of the mind (cf. 219).

between the "core consciousness" and what he calls "extended consciousness" (196).[82] He describes the latter in following terms:

> In extended consciousness, the sense of self arises in the consistent, reiterated display of some of our personal memories, the *objects of our personal pasts,* those that can easily substantiate our identity, moment by moment, and our personhood. (196; emphasis in original)

The autobiographical self in this formulation is modelled around a tension; it mediates between the "fleeting feeling of knowing", or what Damasio calls "core consciousness," constructed anew with each heartbeat and pulse and the external world (196). This feeling pushes the consciousness to go beyond the physiology of the human organism. It is what establishes "personhood" through its foray into an exteriority, an exteriority that substantiates itself through the ramifications of "having a pulse" in each passing moment. Extended consciousness can travel back in time and it is able to reflect on the images of some of its personal memories—significantly, extended consciousness is not just reflexive but also reflective.[83] This means the extended consciousness attached to the autobiographical self is not simply reflexive due to the sheer physiology of the core consciousness—it can reflect to a degree.

In this regard, the role of figurative language is of importance in Allison's text because this language transgresses the limitations of kitchen-sink realism through its iterations between reflection and reflexivity. Allison's autobiographical narrator maybe understood as "the end product not just of [her] innate biases and actual life experiences, but of the reworking of memories of those experiences under the influence of those factors" (cf. Damasio 224). The reworking of memories of experiences under the influence of the factors that created those memories can be enabled by an interleafing of the language of realism and figurative language. Whereas Allison's kitchen-sink realism address the factors that created those memories, in her project of making literature out of those memories she takes recourse to a different register of narration. Also, the recourse to "memories" under the influences of the very place-based factors that led to the experience of having those memories is not a

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[82] In core consciousness, "the sense of self arises in the subtle, fleeting feeling of knowing, constructed anew in each pulse" (cf. 196).

[83] I am grateful to Catherine Halbach for explaining this concept to me.

linear re-enactment of the processes of accruing those memories (Balaev 2012) but, significantly, a reworking. Reworking suggests an on-going labour for the autobiographical narrator, a constant processing of the details of the place-based memories in relation to everyday life and practices of that place. Through a close reflection of the place and communal experiences in the place this autobiographical narrator, then, brings to light certain "strangulated affects" that requires to be released in the time of narration (cf. Flatley 55).[84] These affects need time to be addressed and processed through a style of slow attention of descriptions that is typically generated in a place-based narrative—this would be a kind of narrative that can refer to specific instances and contexts in the past that led to the sudden internalization of what lives on as "internal foreign bodies" in the psyche (cf. Flatley 53). In Damasio's terms, then, the autobiographical self's capacity for reflection can enter into a dialogue in the aid of releasing these internal foreign bodies, so to speak. This can be achieved through a close examination of the place-based nature of events, and in relation to "the objects of our personal pasts, those that can easily substantiate our identity, moment by moment, and our personhood" (cf. Damasio 196; emphasis in original). Allison's narrative actualizes certain features of the novel by using figurative language. First, she achieves the task of "therapy" through literature, which I understand as a kind of healing which is framed in relation to the place-based character of insidious trauma. Second, she attends to the material conditions of Bone's childhood in a way that speaks to the mediation between the subject of insidious trauma and the extended consciousness (in terms of Damasio's formulation) of the child narrator. Allison's traumatized child narrator, thus, is also able to tell us, "In 1955, Greenville, South Carolina, was the most beautiful place in the world" [17]. Finally, she engages in the work of repair of those very conditions in a distinctly literary vein; she does this by spelling social and personal experiences of shame, abjection, and fear in order to heal from these experiences. If storytelling, in part, is meant to release a repressed affect generated in the past, recalling those affects and bearing witness to those in writing is a way of what Jonathan Flatley (2008) calls "bringing those affects into language" that "allows

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[84] These strangulated affects are, as Jonathan Flatley suggests, those that can refer to a shock, they can be traumatic, or could be certain censored memories that could not be processed in the past because they overcame the defenses of the ego too abruptly (cf. Caruth 1996). Cf. See Cathy Caruth *Trauma and Testimony* (1996).

them to age (and to thereby prevent them from repeating themselves) by putting them into sequential time" (55).[85] Thus, it is imperative we ask how are these strangulated affects released in a narrative that has a definite therapeutic aspect to it—and how might our interpretative strategies account for this repair work? Given that the notion of a "release" is a positive one, and a much ignored process in the critical literature on *Bastard*, I want to underscore its possibilities in the rest of my analysis.[86] What kinds of anxiety are released in the novel, and what are these anxieties indexical of in their broadest form?

Borrowing from Jillian Sandell's work, I have highlighted, how the "bourgeois consumption of incest" has been enabled by the "act articulation [of incest] (rather than the issue itself) becomes the object of cultural consumption" (213-14). In this regard, we need to think of the release of affects and repair work undertaken in the course of the novel as not solely in terms of descriptions of violent scenes- the "facts" of incest and generational poverty in the novel- but the foundational violences and anxieties that the characters live through on an everyday level, and those that the descriptions of visible and intensified scenes of violences speak to as well. The repair work that the novel attends to addresses those anxieties in their mundane, (in)visibly violent, and pernicious forms. I am thinking of the narrator's mother Anney's pursuit of an idea of a heteronormative family that unleashes visible violence on her family and herself. In this regard, we may ask, how does the repair work- and release of affects in the novel- in the wake of visible violence enable us to engage

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[85] Since affects of trauma are internalized in an abrupt way (as a shock to the senses) when the defenses of the ego are suddenly overcome and the "outside" of consciousness enters the "inside" without any form of mediation (Caruth 1996), affects in the wake of trauma remain as "strangulated affects," or those "'internal foreign bodies' within the psyche" (cf. Flatley 53). These affects do not get to become a part of sequential time, the time of chronological human experience, but threaten to erupt occasionally and in unexpected ways as "[s]trange pains, linguistic disturbances, nervous tics, and seemingly unmotivated emotional reactions." The release of the strangulated affect is possible (cf. Freud qtd. in Flatley 53) and they can be "disattached much later," but unless released, they "persist unchanged by the passage of time" (53).

[86] In this regard, it is important to take the novel's critique of the law and legality and the institution of the bourgeois, heteropatriarchal family seriously because valorizing negative affects in the novel overdetermines the traumatic aspect of Bone's experiences and risks, at least in part, promoting the multiple ideological sites (such as the family, retributive justice and the law, and social structures in general) that the novel criticizes as "cure for the harm" that these institutions enable for marginalized communities (cf. See Ball qtd. in Kilby, 182).

with violences that are slow, pervasive, and incremental and thus harder to be integrated in the reader's knowledge of the cultural repertoire, but one which the novel's repair work responds to as well? At the end of the novel, Bone's mother is told to walk in when Bone's stepfather, Glen Waddell, is raping her. But even then her mother decides to give her up after providing her a copy of her birth certificate—one without the word "bastard" written on it. Finally, Bone is seen to be somewhat happy in her Aunt Raylene's company, who, we're given to assume, becomes the Bone's custodian. Finally, Bone says, "I was who I was going to be, someone like her, like Mama, a Boatwright woman. I wrapped my fingers in Raylene's and watched the night close in around us" (cf. 309). Bone's and Raylene's moment of togetherness works as a critique of the heteropatriarchal family unit in a classist society. At the end, we see that the wellbeing of a child is not dependent on the Oedipal family structure of the father, mother and their biological children, which Anney, owing to the limited range of choices she has, seeks to establish and sustain throughout *Bastard*. As a foil to Anney, Raylene is consistently described in masculine terms in the novel—she is a woman who made unconventional life choices and lives on her own. By the end of the novel, Raylene is positioned as a maternal figure to Bone, and, indeed, there is a political commentary in this act of semi-autobiographical substitution in the novel. If, as Ann Laura Stoler (1995) writes, "The family, as Foucault warns us, should not be seen as a haven from the sexualities of a dangerous outside world, but as the site of their production" (112), this substitution and dismantling of the polarization between Anney as a "feminine" presence and Raylene as "less" so, which the novel builds up to account for the given sociality and only to dismantle the binary in the end, needs to be viewed as a re-imagination of the notion of the family in at least two ways. First, the "family" is resignified in terms of the intimacy and solace that Bone finds in Raylene's company after Glen rapes her and her mother "abandons" her. And second, the notion of a "family" is questioned in terms of the anxieties (read, invisible violences) of insidious exclusion of certain sexualities and life-choices that it is founded upon. Bone interprets both women's influences to be a part of her when she decides to be a "Boatwright woman" when she grows up. The site of the heteronormative family- even in terms of the pursuit of one, as Anney does- is seen as a site of production of violences and anxieties of exclusion of multiple sexual practices. These are violences that are invisible but pervasive. However, in Bone's newfound definition of a "Boatwright woman" that is able to accommodate multiple faces of femininity, that is, of the "masculine" Raylene and "feminine" Anney, she suggests her family and kinship with Raylene is effectively repaired and purged from the anxieties and sexualities of a having monolithic faces of a "femininity" and "motherhood", both of which Raylene does not conform to. In *Bastard*, these anxieties are finally released and reworked in the end by producing desires and solidarities that cannot be acknowledged within this paradigm of the heteronormative family. In fact, when these anxieties are released and narrated they subvert our understanding of the family and points to the social transformations that are necessary for queer solidarities and kinship- such as Raylene's and Bone's- to take place. The novel's ending is crucial because as much as Bone embraces Raylene's presence in her life, she tells us she also wants to become someone like her mother and other Boatwright women (cf. 309). In finding a way to assimilate the built-up and polarized positions that Raylene and Anney pose in Bone's experiences by the end of the novel, Bone's desire to be like someone like her mother and her familial intimacy with Raylene after being abandoned by her mother displaces the critique of the novel on a systemic abuse that the model of the bourgeois heteronormative family perpetuates in relation to Appalachian culture. Allison has commented on the ending in regards to her intersectional approach in her work and in the analytical framework that she borrows from. In "A Question of Class" (1994), Allison writes,

> [O]ften I felt a need to collapse my sexual history into what I was willing to share of my class background, to pretend that my life both as a lesbian and as a working-class escapee was constructed by the patriarchy. Or conversely, to ignore how much my life was shaped by growing up poor and talk only about what incest did to my identity as a woman and as a lesbian. The difficulty is that I can't ascribe everything that has been problematic about my life simply and easily to the patriarchy, or to incest, or even to the invisible and much-denied class structure of our society. […] The only way I found to resist that homogenized view of the world was to make myself part of something larger than myself.

Viewing the Boatwright community and by extension Bone's experiences as emerging from a group identity that has been systematically encouraged to destroy itself complicates the picture even more (cf. *Skin,* xiii). It also connects to the idea how we cannot always think of freedom, responsibility, well-being as closely tied to an always willing agent—an "I"—who can or is allowed to emancipate herself by merely wanting to be free of oppression, oppression that works from an imagined outside that situates this subject. It is because the incremental violence experienced by “white trash” identity is closely tied to a self-understanding that is predicated on destroying oneself, of being interpellated by this self-conception, that the insidious ways in which this identity category harms those who inhabit it on a daily basis is not recognized if we address *Bastard* as a novel that provides a neat critique of either class or sexual violence, or the formative experiences of a lesbian woman. Rather, the messiness with which a child experiences these constructs and categories is reflected in Allison’s hesitance to ascribe her experiences to her class background, or to patriarchy, and in her reflection on a kind of pervasive incapacitation in the face of violence. Added to this is a kind of fatigue against realization of one’s freedom is suggested in the notion of the community’s participation in its own destruction (cf. *Skin*, xiii).[87]

The discrete lenses of Allison’s experiences as an incest survivor from a marginalized community do not help her anymore because these analytical frames of reference betray the local textures of everyday life in relation to which her intersectional experiences are sustained and experienced. As she says, she avoids a potential paralysis, however, by taking recourse to “something larger” than herself, and her desire to recast her experiences in relation to other experiences that she has very little in common with is also a way of breaking the construct that could ensue from conceiving “white trash” identity in pathological and paralytic terms of a category that enables its own condition, or wholly positivist terms of an “identity” that needs to be unproblematically upheld in narratives. Always transversal in her approach to her “own” story, Allison’s treatment of affects in the wake of childhood trauma, their therapeutic releases in literary narratives belabours the conditions under which negatives affects are generated, which then reflects on the affirmative possibilities and implications of their emergence in figurative language. In final analysis, then, a narration of childhood trauma in this literary account is not a mere repetition of previously suppressed affects that emerge in the same way they were initially registered; their emergence requires a different register of narration. As potentially depathologized emotions that could enter

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[87] This is also the self-destructive behavior that research in psychosomatic medicine is interested in exploring (cf. Beutel 2016)- and this social psychology can only be understood more fully through a dialogue between life narrative (like Allison’s) and the interdisciplinary discourses it generates in relation to the life sciences (cf. Hornung 2010; 2015).

sequential time after being enabled by social and environmental factors, they leave a social commentary in the picture they draw for us. Release of internalized foreign bodies in the psyche require a willing narrator, a narrator who would like to put "pain" and "words" in dialogue with one another, but in contexts where this willingness to emancipate oneself is under attack and social support is few and far between, this release becomes more difficult. Figurative language recognizes this difficulty.

3.5 Shannon Pearl, figurative language, and (dis)identification

The novel needs to be read in relation to its complicated portrayal of Bone as an abused child and her brief friendship with Shannon Pearl, and there is much to be said in Bone's feelings of attachment and aversion to Shannon. A child with the dermatological condition of albinism, Shannon appears in the novel in chapter eleven and by the end of chapter thirteen (approximately fifty pages) she dies in a fire accident at a barbecue party that her parents' hosts. A language of affection and concern mixed with intermittent that Bone uses to describe her friendship with Shannon, the way this usage along with the fact of Shannon being bullied by other children and, ultimately, her death, enables Bone to process her own fears and sense of shame seems crucial to me. In Shannon's life and death and in her life-long sense of shame, Bone's finds a mirror of her own self that enables her to process her story. There is in the fifty pages that deal with Shannon what I want to call an "affective spillage" from being overwhelmed by shame and fear; this is evinced in the visceral language that is used to describe Shannon. The allegory of shame and disgust in relation to Shannon's physicality, and Bone's self-disgust and concomitant anger at being sexually abused by Glen Waddell, which is initially incomprehensible for her, that we see in the chapters dealing with Shannon is a crucial one because it allows Bone to abstract and distance her pain and use an emotional intelligence, often figurative language, to process her grief. I will suggest Shannon's "ashamed body" is where Bone's autobiographical self is mapped out. Bone, the child narrator, comes to negotiate her sense of shame in Shanon's- in her brief, and at times awkward, friendship with her she also finds a companionship that is *raison d'être* of her autobiographical self.

Shannon's stigmatized skin condition becomes an occasion for Bone to relate to Shannon's predicament of being bullied because of her physicality. Bone finds herself wanting to spend time with Shannon, but she is simultaneously repelled by her physical appearance (156). We are told that even an adult in the community says the following about Shannon's appearance: "I don't care. The Lord didn't intend me to get nauseous in the middle of Sunday services. That child is a shock to the digestion." Bone's conflicting feelings towards Shannon is reflected when we learn that whenever Shannon would sit between her mother's legs or "chewed licorice strings her daddy held our for her," Bone would "purely [hate] her"; however, when other people would call her "Lard Eyes" or "Cootie train," she felt a "fierce and protective love, as if she were more [her] sister than Reese" (156). Furthermore, Bone, too, describes her as "wholly monstrous" (155) and a "lurching hunched figure shining with sweat and smug satisfaction" when she is pampered with treats by her parents. But in the same breadth, Bone's perspective of her is reflected internally, as she says, "[t]here had to be something wrong with me, I was sure, the way I went form awe to disgust where Shannon was concerned" (155-56). And yet again, when she sees her cousins calling her names, Bone says, "All right, she was a little monster, but she was my friend, and the kind of monster I could understand" (200).

Along with a strong (dis)identification with Shannon's physicality, Bone arrives a simple knowledge about her after she realizes that all the stories that Shannon liked to tell her were always about "decapitations, mutilations, murder, and mayhem" (157). After listening to Shannon's stories for a while, Bone corrects her own misconception of having imagined that Shannon would be saintly at heart just because she was remarkably unprepossessing. She says, "Shannon Pearl simply and completely hated everyone who had ever hurt her, and spent most of her time brooding on punishments either she or God would visit on them" (157). The reference to a powerful "she" in her imagination, as opposed to a powerless self, and God, suggests Shannon seeks recourse to a moral order of retribution and recompense in the event of being hurt. Throughout the episodes that help Bone to understand Shannon as a person, Bone refers to her as "Shannon Pearl" and not simply by her first name; by using her full name there is an attempt to read her from a distance, which is also partly due to the disgust and torment that she causes Bone. In Bone's final analysis of her friend, she tells us, "The fire that burnt in her eyes was the fire of outrage. Had she been stronger or smarter, Shannon Pearl would have been dangerous. But half-blind, sickly and ostracized, she was not much of threat to anyone" (158).

This (dis)indentification of Bone's own shame of her sexually abused body is subtly confounded when she meets a Shannon who is said to be "Six inches shorter [than herself]," had "white skin, white hair, and pale pink eyes of an albino, though her mama insisted [she] was no such thing" (155). Bone not only notices her friend's physical difference compared to herself—she was six inches shorter than Bone, for instance—but also realizes her parents loved her nonetheless. Later on, she notices Roseanne Pearl's (Shannon's mother) determination to make her daughter's hair curly to make her look pretty: "Egg and cornmeal, that'll do the trick. We gonna put curls in this hair, darling, or my name ain't Roseanne Pearl" (156). Bone becomes a keen reader of Shannon's body and multiple perspectives from which that body is read and addressed by others, so while she notices her parents surely love her she also notices how her friends and cousins bully her because of her physical difference. In turning her own self-shame into identifying the stigma that Shannon's body is attached to, Bone finds a way to "turn" with her shame of sexual and physical abuse to a different topography where shame, stigma, and disgust dominate, which allows her to read those carefully even when she is not fully aware of how that topography of shame might speak to her plight. In Shannon's story, Bone finds not only her shame, but also the love and support that she receives from some people in her life to come to terms with shame. These factors are not only the parental affection that Shannon does receive, but also her own resilience in the face of being bullied. We learn from Bone that Shannon had the habit of cleaning her glasses when her bullies humiliated her, or "whenever she needed a quiet moment to regain her composure, or more often, just to put everything around her at a distance" (155). Without her glasses, Shannon could avoid to clearly see the children around her that hurt her so much.

In shame, the subject's movement back into itself is simultaneously a turning away from itself (cf. Ahmed 104). In shame, "the subject may have nowhere to turn" (104). Speaking of the physicality of this particular affect, Ahmed shows how visceral the feeling of shame is, how it "works on and through bodies" (103), and how shame "also involves deforming and re-forming bodily and social experiences, as bodies 'turn away' from others who witness the shame," or could be in a position to witness their shame. The turning necessitated by shame, Ahmed suggests, "is painful" and involves "a specific kind of pain." In the kind of inward turning entailed by shame, there lies a possibility of a tropological inauguration of a new subjectivity at the precise moment of this turning which is deeply influenced by a specific kind of pain that shame causes in various contexts, but also sublimated in the act of turning with pain. Bone turns to Shannon to understand (in her own way) how her stigmatized body works in the multiple spaces it occupies; Shannon turns away from her bullies (by deciding not to look at them, that is, by taking off her glasses), sometimes Shannon turns to Bone and her parents so seek solace. In so doing, Shannon and Bone do become companions who could turn to each other, so to speak, but their friendship is lacerated by this specific kind of pain—of "reading the other as bad," of a "bad feeling" (Ahmed, 104)—because each of them are in the position to witness the other's shameful pain of either having an albino body or being a victim of sexual abuse (although Bone never confides to Shannon about her sexual and physical abuse at home, but that does not preclude her from anticipating Shannon's insight into her life). This dynamic is compounded with the cultural and historical factors that explicitly come to the forefront when the two get into a bitter fight while on their way to a gospel show on the other side of Lake Greenwood.

The bad feeling of shame and its quiet proclivity to read the other as "bad" in this context are not about just about two young girls who come close to each other because of the stigmas that afflict them, but also because their relationship cuts across and is circumscribed by a context where stigmas pervade in complicated ways, and social stigmas and shame come to determine (and often over determine) interrelationships between individuals and communities. The narrative describes this stigmatized interaction and the affects they generate by identifying the historical context where the bad feeling crucial to Shannon's and Bone's relationship emerge and they have a bitter fight. We are told,

> Shannon turned and stared at me with a peculiar angry expression. "He don't handle colored. An't no money in handling colored." At this I froze, realizing that such a church off such a dirt road had to be just that—a colored church. And I knew what that meant. Of course I did. Still I heard myself whisper, "That an't one good voice. That's a churchful." (170)

It is the day when Bone takes a trip to a gospel show with the Pearl family. Mr. Pearl, who organizes shows for performers of gospel songs, we learn, prefers to have white clients. But when Bone comes to know this from Shannon (after she suggests her that she should ask her father to talk to the church members who were performing in a church in their vicinity), she refuses to do so. Shannon knows that her father believes there "An't no money in handling colored." To Bone, however, this knowledge is a rude awakening because she had always perceived how the Pearls, though seemingly polite to her, patronized her family and her community at large, in the same way Glen Waddell's middle-class father and brothers looked down upon the Boatwrights. Bone processes Shannon's (and by extension her family's) attitude towards African American gospel singers inside the church is the same way her Aunt Madeline mentioned the word "trash" (170). She says, "The way Shannon said 'nigger' tore at me, the tone pitched exactly like the echoing sound of Aunt Madeline sneering 'trash' when she thought I wasn't close enough to hear" (170). As the scene unfolds with the girls fighting, we remember in the backdrop the gospel music of the church had never ceased: "I was crying, I realized, the tears running down my face while behind us the choir never stopped singing. The woman's voice still rolled over the cottonwoods: "*was blind but now I see…*" (171).

We never see this community of African American gospel singers, but we know from Bone that there was a "churchful" of these performers. Their voice forms a part of the altercation between Bone and Shannon in literal and symbolic terms. This portrayal of an "African American presence" (cf. Morrison 1988) in *Bastard* (and much of American literature, as Morrison has suggested) forms the founding shame of a national culture that can neither wholly absorb non-normative presences nor can it cast those out of the cultural space that it marks as its "own." The intra- and intercommunal (and even individual) relationships that are formed in this space thus must negotiate this founding disavowal of the presence and lives of marginalized communities. It is, thus, no coincidence that Bone's quick recognition of the similarity of "tone" in which her Aunt Madeline refers to word "trash" and Shannon's visceral hatred towards the African American gospel singers, when she says, "My daddy don't handle niggers" (170), connects diverse histories of shamed, dispossessed, and stigmatized identities in US-American culture. Through the altercation with Shannon, Bone's returns to a sense of being, indeed, abandoned by her friend, which is exacerbated when they briefly reconcile just before Shannon's death. Thus, Bone's hurtful words to Shannon during this scene—when she says, "I swallowed my tears and made myself speak very quietly. 'You're God's own ugly child and you're gonna be an ugly woman. A lonely, ugly old woman" (171)—seem to be response to protect her own vulnerability in the aftermath of being "abandoned" by Shannon with her use of words. Later on, after Shannon's death, Bone will admit, "Shannon's death haunted me. Suddenly, I didn't feel so grown up anymore" (204). This haunting connects the way Bone witnesses Shannon's death, by being "fascinated" with the way Shannon unwittingly stages her own death.

Before Shannon dies, and when Bone and Shannon are not in touch with each other due to their fight, Bone tells us, "I would suddenly find myself as fascinated with my reclusive old aunt as I had ever been with gospel music" (180). Feelings of being fascinated by characters and even her own initial perception of people are interspersed in Bone's narrative. In fact, we may say, Bone likes to remain in fascination (a term she chooses to describe her newfound familiarity with her Aunt Raylene's solitary life) with a series of things and characters in the novel. In part, markers of her own coming-of-age narrative and partly to do with way how Bone abreacts her own emotions after her stepfather hurts her, Bone's narrative of fascinations are plenty and come one after the other. In fact, it is through this language of fascination that Bone learns to spill her grief and pain in non-pathological terms. A kind of therapy happens in the process that can only be accounted for when we see the objects of her fascination as a part of continuum of her coming-of-age narrative because of the way Bone's fascinated (even when she is repulsed) gaze sticks to these objects. Although her feelings of fascination and disgust in relation to her own shame is intensified in during her friendship Shannon Pearl, they neither emerge with Shannon's appearance in the novel nor end with her death. Bone's love for Gospel music, the "Sunrise Gospel Hour" (137) on the radio; her experiments with her queer sexuality through masturbation and fantasy; her curiosity about her younger sister, Reese, when she realizes that Reese, too, enjoys fantasizing about being in imaginary situations like herself; Aunt Raylene's unconventional lifestyle in the context of the Boatwright community; and finally, her mother's complicated presence in Bone's life are intermittently read through a lens of fascination in the novel.

When Bone discovers an old hook that was used for trawling and dragging (186) large amounts of fish on fishing boats at Raylene's place, she decides to steal it and uses it to sexually stimulate herself; before she does this, Bone finds herself strangely drawn towards this heavy metallic object. She says, "The hooks got in my dreams too, dripping blood and river mud. […] I wanted one of those hooks, wanted it for my own, that cold sharp metal where I could put out my hand and touch it at any time" (187). Fascination for Bone is not simply a transitory and flippant emotional activity; this aspect of fascination is the way she interprets and come to term with in the event of her personal shame. Fascination is a mode of becoming to which Bone takes recourse; she reflects the same fascination when, as I have mentioned above, she tells us she found Greenville, South Carolina, to be the most beautiful place in the world as a child (17). She reads Shannon's life, her habits, and her last moment through the mode of, yet again—fascination. It seems Bone cannot help but watch her accidentally kill herself while remaining spellbound to this spectacle. She says:

> I heard the lighter-fluid can sputter and suck air. I saw the flame run right up to it and go out. Then it came back with a boom. The can exploded and the fire ballooned out in a great rolling ball. Shannon didn't even scream. Her mouth was wide open, and she just breathed the flames in. Her glasses went opaque, her eyes vanished, and all around her skull her fine hair stood up in a crown of burning glory. Her dress whooshed and billowed into orange-yellow smoky flames. […] I saw Shannon Pearl disappear from this world. (200-01)

Bone appears to be in a trance like state at this moment, as she says, "[a]fterward, people kept asking me what happened" (200). It is important to note that while Bone does not seem to recognize fully that Shannon is about to die as result of putting a large amount of lighter fluid on the burning coals that were placed for the barbecue, she nonetheless describes her act of watching the whole sequence of events from the vantage position of a third person observer. The last line ends the episode even though the onlooker Bone did not know that Shannon was about to die, but arrives at this knowledge in retrospect—yet when she writes about it, it takes her to the moment when she says she "saw" Shannon disappear from the world. The "I" here is placed at the crossroads of becoming someone else other than what Bone was before this event, she remains glued to the scene like a spectator at a site of car crash, even without realizing how this moment transforms her in the process. Such moments at which two or more time frames and two (or more) subjectivities come in the same frame are replete in Bone's narrative. For instance, while sexually stimulating herself with the large hook that she steals from Raylene's place, Bone says, "The chain moved under the sheet. I was locked away and safe. What I really was could not be touched. What I really wanted was not yet imagined. Somewhere far away a child was screaming, but right then, it was not me" (193). Fascination, thus, is a part of Bone's becoming. The sound of the chain attached to the hook as it emerges from the bed sheet, clink of the metal, is a comforting and sexually stimulating for me. It is also a sound that promises her that she's "locked away and safe." It is an emotion that she repeatedly encounters as she turns away from her own sense of shame and pain. She describes this hook, one that she carefully hides up in the "rafters over the washing machine" (194), as a "*talisman against the dark and anything that waited in the dark*" (cf. 194; emphasis mine). The hook, we learn, made her feel "taller just to know it was there, made [her] feel as if [she] had suddenly become magically older, stronger, almost dangerous." In being fascinated and engrossed with certain characters, objects, or the feelings they evoke in her, she is able to alleviate her pain and realize a maturity. Significantly, this maturity and an engagement with her fascination happen through a figurative language that is abstract, removed, and intimately aware of her psychological and bodily states. By using figurative language she is able to spill and spell her emotional state in a way that the language of realism cannot perhaps entirely convey. Bone's recourse to figurative language also shows her need for something to believe in—"a talisman"—against the darkness she perceives around her, so in using this talisman to arouse herself, she highlights her need to believe in her body. After Glen sexually assaults her for the first time, Bone wakes up in the morning to wonder, "how [she] could have bruised [herself] if it had been a dream" (48). "I kept squeezing my thighs together, feeling the soreness," she says (48). Her utter confusion in regards to what Glen does to her body while they waited outside the hospital where Anney is admitted to deliver Glen's child leaves her shaken in regards to how to view her body, how to "believe" it, and whether to believe it at all. Finding a source of belief, her now brutalized body, which can give a pleasure that feels "safe" (cf. 193) is, thus, important for her because this sensation of pleasure, in a way, gives her body back to her. "Every link on the chain [attached to the hook] was magic in my hand," Bone says (193).

In regards to "seeing", as opposed to feeling, however, this reclamation of her sense of self from what she sees is requires a different kind of labour of retrieval. Shannon's death is described as both happening right in front of her and leaves her with a reconstituted self in the act of watching this death and writing about it. The paradox of witnessing and experiencing is reminiscent of Maurice Blanchot's (1986) notion of "writing of the disaster." Blanchot suggests, the disaster does not "touch anyone in particular; "I" am not threatened by it, but spared, left aside. It is in this way that I am threatened" (1). Although I have borrowed from critics who have criticized the strand of trauma theory that conceptualizes trauma as an one-time event and somewhat insufficient to understand the role of literary representations of place-based and insidious traumas (cf. Balaev 2012), Blanchot's notions, however, are instructive for our purposes to explore the use figurative language and the repair work of writing in Allison's novel in the sense that Bone sees Shannon's disaster as totally separate from hers but not quite. As Blanchot memorably writes, "the disaster ruins everything; all the while leaving everything intact" (cf. 1). And then again, "When the disaster comes upon us, it does not come, the disaster is its imminence" (1). The experience of the disaster is its imminence. This experience of the disaster is reliant on thinking of the disaster as "most separate" (1) from oneself and one that can still be engaged with in the written word. This potential for a kind of passivity in relation to the disaster can be checked in the process of writing. In Blanchot, however, the disaster is exalted in gendered and heroic terms: it's something that looks and ignores the subject-bystander from afar, looks askance her, spares her, and casts this subject aside as detritus in the course of its action. How does this "missed encounter" with the disaster become instructive for autobiographical self in Bone's narrative? If this encounter with the disaster is an object of the personal past, how is it negotiated through "consistent reactivation and display of selected sets of autobiographical memories" (cf. Damasio, 196)? Bone's "fascinated" gaze at the sight (and site) of Shannon's death and her recourse to figurative language to narrate it requires to be understood through the process that this sight triggers in Bone and how she arrives at this scene. The disaster in *Bastard Out of Carolina* is not simply Bone's rape and physical abuse, and it is also not the dramatically described and observed death of Shannon Pearl, but one that facilitates Bone's arrival at this scene of intensification of the disaster, that is to say, Bone as a victim of sexual abuse and a child of a poor community in a classist society witnessing Shannon's death. The intensification that lies in the moments that lead to Shannon's death cannot really be gauged unless we see the continuity of the disaster in terms of its mundane, (in)visible, and everyday faces, which is the slow economic violence on Appalachian subjects that striates communal and intimate relationships and friendships. Shannon's death is a disaster, but it is also "not a disaster"—it is an insignificance that needs to be carefully examined in language precisely because it will be forgotten without this close examination. Shannon's disaster "will" leave everything in her and Bone's society "intact" (1), in Blanchot's terms, because this child's life in this context is insignificant. Bone says, "Her dress whooshed and billowed into orange-yellow smoky flames. […] I saw Shannon Pearl disappear from this world" (cf. 200-01). In her fascinated gaze, then, Shannon's death, her "accidental" self-immolation, which reads much like a desired suicide, and Bone bearing witness to this act needs to be seen in a spectrum in the context of a community in Greenville, South Carolina, that cannot protect its children against the different kinds of disaster that await them every day—sexual and physical abuse, slow and (in)visible violences, and incremental traumas being the most frequent ones. This is suggested in no uncertain terms because Shannon's death, while an accident, happens soon after her cousin ruthlessly bullies her. We learn he said to Shannon, "'You fat old thing. […] You musta eat nothing but pork since you was born. Turned you into the hog you are.' He laughed and ran on. Shannon pulled off her glasses and started cleaning them on her skirt" (199). Thus, Shannon's disaster—her embodied shame, pain, and stigma—is intricately related to Bone's, and what paves this relation is Bone's unflinching attention to engage with the disaster itself.

3.6 The disaster in a continuum: "fantasies" and the child in pain

In a 1997 Canadian film, directed by Thom Fitzgerald, *The Hanging Garden*, that describes experiences of a queer adolescence in rural Nova Scotia, we see the protagonist, Sweet William (played by Chris Leavins), return to his family home after a long absence. The sixteen-year-old Sweet William, we learn, had run away because of not being accepted by his Catholic and homophobic family, but mostly because of his physically abusive father. The occasion for Sweet William's return is his sister Rosemary's marriage to their bisexual childhood friend, Fletcher. Rosemary had always stood by Sweet William's decision to leave for the city and still very much loves her brother. Sweet William was an obese child; we also learn that just before he left his family, his otherwise affectionate mother had taken him to a sex worker to "cure" him of his homosexuality. This happened after his grandmother found him and Fletcher having sex in their garden. During his short stay, Sweet William, now a handsome, slender, and well-adjusted gay man living in the city, repeatedly encounters the vision of his own corpse hanging in his family's garden. The hanging corpse of an obese teenager punctuates Sweet William's stay at his family home and his thoughts of his adolescence, which, in turn, reminds the viewers that for the protagonist and his family members (who also see this corpse) the disaster "was" in no uncertain terms around the corner.

In her work on the queerness of children in relation to the prescriptions of normative childhood that are imposed on all children, Kathryn Bond Stockton (2009) has described the phenomenon of “growing sideways,” as opposed to “growing up,” to better understand the emotional topography of the queer child’s narrative in response the perpetual uncertainty and fear that situates this child. Bond Stockton does not ontologize this figure, but suggests that there is a queerness in every child—she’s interested in “children’s queerness” (3)—that suggests, “[c]hildren grow sideways as well as up […] in part because they cannot, according to our concepts, advance to adulthood until we say it’s time” (6). And it is the queer child that shows “that the figure of the child does not fit children—doesn’t fit the pleasures and terrors we recall” (6). For Sweet William, growing sideways, as Stockton suggests, takes a literal form in terms of overeating and becoming obese because obesity, as he tells his mother during this visit, protected him from having to participate in sports, date women, or hang out with his friends. But growing sideways in less literal terms is also a response to the profound anxiety due to the conflict between cultural scriptures of what a child “is,” what she could do to “grow up” in accordance to the available scripts of childhood, and where her fascinations take her, which is, unsurprisingly, often away from the terrain that heteropatriarchal home draws out. I mention this film in relation to the phenomenon of “growing sideways” because if growing sideways is essentially a response to the conflicting cultural prescriptions of what a child “is” or when she could “grow up,” the notion of the queer child’s fascination, or desires and tendencies that she must abandon to “grow up,” and the registers of narration that attend to this fascination need to be conceptualized as affective investments that emerge in a continuum, especially because there is a political unconscious to this continuity. What connects those objects that are invested with fascination of children who grow sideways (as well as up)? How do those objects stick to each other—and what makes them stick?

In narratives of sexual and physical abuse, women and children who experience this abuse often do so because “subjugated group[s] [when] powerless to change the larger society turn on” the most vulnerable among them (cf. Wong qtd. in Rodi-Risberg, 85). This holds true of Allison’s novel because Glen Waddell becomes increasingly violent toward Bone soon after his he realizes that he can never have a child with Anney (their own biological child dies while Anney is in labour), and when he gradually fails to live up to the standards of middle class respectability that his father and brothers ascribe to and compels him to adopt. Thus, sexual violence against women and children from disadvantaged groups is a “collective abuse committed by a racist, misogynist [and classist] society rather than by a single individual aggressor” (85) and needs to be read as a “social criticism,” as Marinella Rodi-Risberg (2015) suggests. Locating investments of fascination help us to extrapolate beyond those sites of investment and ideological vectors that make abused children turn to those sites in the first place – what kinds of strategies of survival are constructed at these sites? In other words, because narratives of sexual abuse in the context of minority groups are always a response to systemic abuse of power relations it is imperative to identify how children growing sideways encounter and resist hierarchical abuse of power with their laterally spreading, indeed rhizomatic, fascinations and desires. In *The Hanging Garden*, Sweet William runs away from his family and goes to live in the city, which is literally a horizontal axis of departure, and thereby resists the desire to hang himself from a tree in the garden. The vision and a presentiment of several characters in the film of a corpse as a vertical image that underscores hierarchical abuse of power he experienced until he left (and views more closely when he returns). The latter image, of course, is always around and informs his newfound selfhood. At the end of film, Sweet William leaves again, but this time he leaves with his son, Violet, whom he had unknowingly fathered with the sex worker, someone his mother took him to to “cure” his homosexuality. When Violet asks Sweet William if they are running away at the end of the film, he says, “no, we’re just leaving.”

In *Bastard Out of Carolina*, Bone’s fascinations come one after another, there a sequence to these attachments; whether it’s the gospel music hour on the radio, the metallic hook she uses to masturbate, Aunt Raylene’s personality and her lifestyle, and, perhaps most importantly, her attention to her mother’s vulnerability, beauty, and her labouring body as a Boatwright woman. Throughout the novel, Bone is, indeed, fascinated with her mother. She notices her mother’s reactions to everything in a very interesting way. The way she gets angry when the clerk at the courthouse gave her yet another copy of Bone’s birth certificate with the word “illegitimate” printed on it. When Anney’s first husband and Reese’s father, Lyle, dies, Bone describes her mother’s grief in the following terms: “No one knew that she cried in the night for Lyle and her lost happiness, that under that biscuit crust exterior she was all butter and grief and hunger, that more than anything else in the world she wanted someone strong to love her like she loved her girls” (10). And later when Anney starts to date Glen, Bone notices show Anney "seemed to like" when Glen carried Reese and Bone out of the diner where Anney worked "with all the truckers watching" them leave. She says, "I'd see her look over as he went out with us, see her face soften and shine. Maybe that was love [for Glen], that look. I couldn't tell" (34). There is tenderness in Bone's perception of her mother in the way she looks and thinks about her. The day when Anney is forced to undertake sex work because Glen is unemployed and the children had gone hungry for days, Bone remembers her mother's preparing herself to meet a client. She says,

> Mama was pulling her hose carefully up her legs when I ran in to stand beside her, too scared and excited not to stay close. She paused to hug me briefly. 'Go call and have your Uncle Earle come by here to pick you up when he gets off. […]' I ran out of the kitchen, where the phone was, but didn't call. Instead, I hung back in the doorway and watched her reflection in the mirror down the hall. (73-4)

"Scary but wonderful" (73), Bone notes, Anney did not "seem to be afraid of anything," as she rebukes Glen for not being able put food on the table before leaving the house to presumably undertake sex work to feed her children. Bone's language of fascination enables her to become a keen observer, of course, but it is this through this language, or more precisely through its sequential attachments to sites and objects, that Bone arrives at her own moral conviction and a sense of being wronged and hurt. She grows up and she grows sideways in relation to the language of fascination in order to heal from the demands of "growing up" in her context. Thus, while she remains a fascinated observer with her mother's beauty and her vulnerability, she also notices Glen's violence inducing hands in the same way. In a way, Glen's hands are what her mother longed for in her longing for an ideal family, a provider, and father figure to her daughters in order to escape into the ranks of the middle class by marrying Glen; at a literal level, however, Glen's hands assume to be the macro-signifier of violence for Bone as they end up hurting her in every possible way. A caring fascination for her mother's body, particularly her fading beauty because it was common among Boatwright women to age prematurely due to too much work to provide for their (often several) children (cf. *Skin*, xiii), is simultaneously suffused with a revulsion and fear of Glen Waddell's hands. Bone describes those hands in the following terms:

> People talked about Glen's temper and his hands. He didn't drink, didn't mess around, didn't even talk dirty, but the air around him seemed to hum with vibration and his hands were enormous (35). […] Reese and I made jokes about them when he

> wasn't around—gorilla hands, monkey paws, paddlefish, beaver tails. Sometimes I worried if he knew the things we said. My dreams were full of long fingers, hands that reached around the doorframes and crept over the edge of the mattress, fear in me like a river, like the ice-dark blue of his eyes (70).

Glen's hands assume significance in relation to Bone's sexual and physical trauma, but they also occupy a significant space in Bone's narrative even before they begin to hurt her. Bone notices how strangely his hands envelope Anney's body when they hug, and this is when Anney and Glen were dating. "When he hugged her, he would lay his hands on her back so that he covered it from neck to waist, pulling her as tight to him as he could," she says (35). Glen is repeatedly described as boyish and immature, like most Boatwright men (although Glen is not a Boatwright) were, but his strange affection for Anney is inflected by his desire to have a family and secure a role of an authority figure in a family at any cost. He is seen to prey on Anney's vulnerabilities and needs. While I do not want to go into the details of the infantilized descriptions of Glen's masculinity too much, largely because most critics have analyzed these aspects of his personality and his violent nature in great detail, I find Bone's attention to Glen's hand in their traumatizing details useful because it brings home the idea that the notion of the "disaster" for Bone needs to be seen in contiguity with the objects and sites of fascination that she joyfully relates to and observes (such as her mother's body). The disaster, then, is always around the corner for Bone, too, just like it is for Sweet William when he comes back to his family to attend Rosemary's wedding. How might we understand Bone's objects and sites of joyous fascination (her mother's body and her affected reactions, for instance) as striated with anxious concerns and disastrous apprehensions that necessitate her to (re)turn to those objects and sites in the novel?

Shame forces children to turn to withdraw into a mental life that needs to be interpreted in relation to the specific character of the disaster in the novel. The disaster is a cumulative process for Bone—it is not just the events, it is place-based in relation to a lived history of a specific geography. The disaster culminates in the act of rape at the end of the novel. Because it is always treated as a process in the novel at the edge of semantic and cognitive legibility (through the notion of how Bone witnesses Shannon's death, for instance); however, its connections with language need to be underscored. The disaster that Glen hands cause Bone is always related to larger disasters that position people, especially in disadvantaged communities, and how members of that community treat the most vulnerable amongst them. The disaster is realized from the start with Anney being literally unconscious due to a car accident when Bone is born. Related to this symbolic abdication of responsibility that needs to be situated in relation to demands of being a Boatwright woman, the disaster arrives again when Anney never really comes to Bone's rescue after Glen beats her up in the washroom. We are told, Anney asked Bone, "Oh, girl. Oh, honey. Baby, what did you do? What did you do" (cf. 107) after Glen physically assaults her. These instances of not being saved by Anney are seen to have had accrued meaning in the past; however, they become something else on being narrated, on being released in narrative time.

Language is crucial to the kind of therapy that takes place in the narrative in this way because it stays with the past in a way of being attached to those place-based events. While language, of course, speaks to the past events, through figurations they take us somewhere else- they depart from staying unprocessed- we may understand this as a kind of alchemical shift brought forth by narratives. For instance, we get a glimpse of the mental topography of the child narrator in the way she fantasizes about being watched by other girls, who are just like herself, but able to form a community of spectators to witness her plight. "My fantasies got more violent and more complicated as Daddy Glen continued to beat me with the same two or three belts he'd set aside for me," she says (cf. 112). Bone's fantasies indeed become more complicated as she imagines "some girl" watching the physical violence being perpetrated on her:

> When he beat me, I screamed and kicked and cried like the baby I was. But sometimes when I was safe and alone, I would imagine the ones who watched. Someone had to watch—some girl I admired who barely knew I existed, some girl from church or down the street, or one of my cousins, or even somebody I had seen on television. Sometimes the whole group of them would be trapped into watching. They couldn't help or get away. They had to watch. In my imagination I was proud and defiant. (112)

Allison's provides the connections between pleasure and pain from the point of view of a young adult who is being beaten and experiencing fantasies in the wake of traumatogenic events. She shows how Bone's imagination becomes a resource to live with the persistence of physical and psychological abuse; along with fantasies of being watched, her coming of age through masturbation while fantasizing about a possible spectator, sometimes a community of spectators, is also imbricated with a conviction in her own innocence. A conviction of being wronged and hurt is generated and this feeling shapes her emergent subjectivity from the point of her subject-position (Oliver 2004). In language, I suggest, Bone asserts her sensual awareness of her own violated body, a heroism of her imagination (although she mentions that there was no "heroism" [113] in the actual act of being beaten) that is "covered with snot and misery" (113) because of being beaten, and also a moral conviction on being wronged and a desire to be heeded. In this spectral economy of being intensely aware of being watched, Bone seeks to "defy" Daddy Glen with the help of the community of spectators that she imagines watching her back. As she says, she felt "pride" in being able to imagine the figure of "someone [who] had to watch." Bone's feelings about these fantasies are strangely double-edged: she says,

> I loved those fantasies, even though I was sure they were a terrible thing. They had to be; they were self-centered and they made me have shuddering orgasms. In them, I was very special. I was triumphant, important. I was not ashamed. (113)

While critical literature on *Bastard Out of Carolina* has evaluated Bone's sexual and sensual maturity amidst structural violence, the inauguration of a conviction of being wronged in relation to a corporeal sense of self, however, needs to be underscored. In her fantasies, Bone is "important"; she feels triumphant and "not ashamed." Putting these fantasies into words enables them to depart from the pathology that violence and abuse condemns the traumatized feeling to remain stuck in terms of "internal foreign bodies." Instead, by claiming these fantasies in split terms, as "a terrible thing" and "triumphant" at the same time, Allison's novel presents a compelling features of literary accounts of trauma that needs to be recognized. What gets in the way of this recognition is a particular model of understanding trauma in narration that seems get in the way of coming to terms with these fantasies. Michelle Balaev speaks of this problem in relation to literary narratives; referring to psychiatrist Colin Ross's notions on the problems posed by the "abreactive model," she writes, "healing from trauma depends more upon addressing the current feelings and behaviours of the individual and less upon the memory of the event or abreaction" (cf. Balaev, 34). She defines trauma as "a person's emotional response to an overwhelming event that disrupts previous ideas of an individual's sense of self and the standards by which one evaluates society" (Balaev, 150). It is not that the abreactive model of trauma is not useful, but that they can only offer a limited understanding of the phenomenon at work in literary narratives where there is a conscious aesthetic meditation on past experiences. Thus, specifically in relation to "the trauma novel" (154), there are multiple ways in which characters choose to negotiate trauma, which is often but not always a triumphalist release of previously suppressed emotions. Balaev criticizes the abreactive model because of its focus on the "self" as a "fixed entity that then fragments" (162) in the process of abreaction. Contrary to this model, the contemporary trauma novel, she suggests, is "not binarily dependent on a linear re-enactment of a traumatic experience" (162). According to this pluralist conception of articulations of trauma in literary narratives, trauma needs to be understood in terms of the words and silences that it brings forth. Although wounded in the past, the protagonist's subjectivity is seen as a "fluid process" that is tied to the contingencies places and genres of representation that ushers in new knowledges and new realities. Reiterations of trauma in this model is neither pathologically tied to a time-limited understanding of abreaction nor is it reliant on the "self" as stable locus that is conceptualized against the influences of place and social conditions. As Laurie Vickroy (2015) also notes, "[l]iterary renditions of trauma offer important insights into this phenomenon by allegorizing the therapeutic process of putting traumatic experience into words" (15). Interpreted in this way, I find it useful to focus on the use of figurative language, or what we may understand as enduring mental life around traumatic events in *Bastard*, suggests the problems posed by strangulated affects in sections that I have highlighted above. An exploration of figurative language is also important because it gives us an idea of how embodied shame is negotiated. The scenes of figurative use of language that I highlighted give an account of how the past is experienced and actively reworked. Language inflected with fascination and pain reaches out sideways and tangentially, so to speak, to a community of listeners, and sites of love, curiosity, and fascination while resisting hierarchically sanctioned violence and abuse.

2.6 Conclusion: significance of interdisciplinary dialogue for trauma narratives

> Censorship is never over for those who have experienced it. It is a brand on the imagination that affects the individual who has suffered it, forever.[88]

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[88] See <*https://www.theguardian.com/books/2014/jul/14/nadine-gordimer-a-life-in-quotes*>. Web. 27 Jan 2018.

Nadine Gordimer, "Censorship and its Aftermath", 1990

> Stories open the door to the darkened room. Language can carry us past the horror to the sense of purpose in a life that refuses to surrender to that darkness.
>
> Dorothy Allison, *Bastard*, "Afterword"

Narratives of lived experience of places and borderline experiences are performances of intellectual labour. They are constructed by the reflexive and reflective capacities of the autobiographical self (Damasio 1999) through its mnemonic visitations, and maybe even real-life visits to the places in the case of auto-ethnographic projects like *Bastard*.[89] These are projects that "open door to the darkened room" of silence and ignorance of many varieties. The intellectual labour of writing these narratives and finding a therapeutic value in the written word is only fulfilled when we engage with life narratives of borderline experiences meaningfully and from as many perspectives as they demand. For me, these perspectives have been literary criticism, ethnographic account of Appalachian culture, critical theory, history of scientific development in terms of cultural movements around the inclusion of PTSD in *DSM-IV*, and, finally, the new perspectives, definitions of chronic conditions, and an enlightenment value that the novel itself provides. I have tried to suggest *Bastard*'s reflections on its uses of multiple registers of narration –from "kitchen-sink realism" to the language of figuration—traverses a wide array of concerns. From its need to share, its hope to be heard, and remake oneself and communities of readers, narratives like *Bastard Out of Carolina*, then, is a profound significance. An important way to make the significance of such a narrative evident is to engage with it from diverse points of view. This would mean making workings of the literary text evident for not just literary studies but also a part of a curriculum for other qualitative analysis that are invested in investigating studies in "mind-body split" and narrative healing.

In this regard, it is important to remember Allison's text was censored for teaching in an English course in a high school in Salem, Maine. It was "removed because the language and subject matter of 'incest' and 'rape' was [deemed] 'inappropriate' for fifteen-year-

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[89] Dorothy Allison studied anthropology as at the undergraduate and graduate levels and was well-versed in ethnography before she wrote her debut novel *Bastard Out of Carolina* (cf. Behar 2009).

olds."[90] In her "Afterword" to the 2012 edition of *Bastard*, she mentions Toni Morrison's *The Bluest Eye* (1970) and Harper Lee's *To Kill a Mockingbird* (1960) while discussing how high school boards in the states of Maine, Ohio, and California have censored these novels on different occasions and on different grounds. The problem of censorship, of course, relates to the Puritan origin of US-American sexual and cultural selves (Hornung 2004: 1) and it cannot be easily wished away. But the problem of censorship for trauma narratives, particularly those that come with an element of stigma attached to them—rape and incest, for instance—can be challenged by making conversations around these "domestic traumas" as broad as possible. This would mean examining these violences in regards to how they resonate with several disciplinary lenses that aim to establish conversations around healing through narratives and qualitative analysis of many varieties. This would also challenge a different kind of paralyzing trauma that is unleashed on the writer's imagination—a trauma on creativity—one that Nadine Gordimer calls the "brand on the imagination" that stays forever. Close reading is particularly important in this regard because as projects of intellectual labour, trauma narratives in literary and cultural productions are self-conscious documents in the sense that they know very well how their pain will be perceived, interpreted, and viewed in critical reception (Das 2013).

Not engaging with the novel at all due to censorship at the level of high school education is a structural problem that is perhaps largely beyond the scope of critical intervention, but engaging with it only in terms of narrow approaches that serve to focus on the notion of "trauma" as a one-time event and heavily dependent on the its temporal aspect, that is, without its geographical and insidious implications are not productive in regards to the specific character of the traumatic experience in *Bastard*. Also, the overemphasis on visible violences at the expense and disavowal of invisible violences like sustained economic deprivation of a particular region that enables the afterlife of shame and stigma does not speak to the thematic concerns of the novel. Such a problematic emphasis also does not speak to the labor of spelling this trauma in a language that we need to hold on to. The tense of suffering in figurative language, I have tried to suggest, is always unique and demands an attention and engagement that has much to offer to diverse collectivities. This focus on the child narrator's use of language is to make new modes of thinking possible and to "carry us

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[90] See <*http://www.deletecensorship.org/bastard_out_of_carolina.html*>. *Web.* 27 Jan 2018

past the horror," as Allison writes (cf. 318). Getting past the horror and putting a light in a dark room are acts that define the violated subject's conatus—the innate and organismal proclivity to strive and persevere in the face of adversity—and it's expressed in the careful way through which figurative language attends to experiences that are difficult to be represented in sequential time. Moreover, it is in language that pain can be diffused, sublimated, and processed to arrive at what critics have called the "solace of autobiography" (cf. Banerjee, 9). Turning to "something larger than myself," as Allison writes in "A Question of Class", is a way to put the pain to rest. In her "Afterword" to the latest edition of the novel, Allison discusses the question of censorship of several novels that deals with similar issues marginalization and oppression. But most often these novels bear a strong element of historically precipitated shame and stigma, that is, shame in regards to a primary event in the work, which then speaks to US-American cultural history.[91] The censorship that these novels have faced in the U.S. is one of the major impediments against social and critical engagements with the very thematic concerns of this novel. In order to counter this, Allison suggests, free and open distribution of novels that have been censored, but she's also extremely generous to understand why parents may not want their children to learn uncomfortable truths and stories that make "no sense"—"Why would anyone beat a child? Why would anyone rape a child?" (319). A dialogue around these novels, such as the ones Allison mentions, needs to ensure that the communities that novels like *Bastard* want to build through readership are in fact realized and readership is most crucial to that realization.

For informed readers and critics, this readership needs to recognize narratives of "domestic traumas" have broader implications and resonate with conditions beyond the private spaces where they're typically experienced. Domestic traumas are, as clinical psychologist Judith Herman notes, "human rights violations" and "serve to perpetuate an unjust social order through terror" (cf. 14). Following Herman, I have tried to make the relationship between privately experienced violences—largely invisible ones—such as the notion of "embodied shame" in Allison's novel explicit; this shame requires to be tracked from various perspectives. Ethnographic and cultural histories of Appalachia offer a glimpse

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[91] While Morrison's novel has been banned in towns in Ohio, which is where the author grew up and the state in which the novel is set, and a town in Colorado, Lee's novel often faces severe criticism for parents for its depiction of the US-American history of racism.

into how embodied shame is a historically sedimented on bodies in relation to the geography of Appalachia. The disasters that await women and children in this geopolitical region show their mundane character through everyday experiences, which makes them all the more horrific. This is the everyday character of trauma specific of narratives of social abjection like *Bastard*; I have explored its place-based nature in terms of how these traumas are circulated and how they are inscribed on bodies marked by economic violence. Being insidious and invisible to dominant perspectives, in Allison's literary universe these traumas need to be tracked in relation to the marks they leave on bodies. These marks are, of course, lesions on the brain, but they are also the sore thighs of a child after her stepfather sexually assaults her (cf. *Bastard*, 48). They are experiences that require the child narrator seek escape in fantasy, but they those fantasies and are also sites of survival because they allow her to "grow sideways" and thereby resist hierarchically sanctioned violence (cf. Bond Stockton 2009). The tension between the need to mature and heal in non-normative ways by subverting inherited and inhabited violence is evinced in the bastardization of multiple registers of narration in this novel. Figurative language is at once a sign of this tension and a wish to come to terms with it through literature.

~Chapter three~

Politicized Patients and the Dialectic of "Loss" in Richard Fung's *Sea in the Blood* (2000)

4.1 Introduction: reflective pain and its material contexts

Carla Rodrigo: "Such a Shame."
Max Klein: "Yeah."
Max: "It was gonna be gentrified and rebuilt but then the recession hit."
Carla: "The country's falling apart."
Max: "Yeah, the United States is finished, but you and me, we're in peak condition."

There is a scene in Peter Weir's 1993 film *Fearless* where a character played by Jeff Bridges, Max Klein, is shown to be driving across what he initially describes as "beautiful, downtown Oakland" and gets into the above mentioned exchange with his friend Carla Rodrigo, played by Rosie Perez. The banter between the seemingly insouciant group of two enjoying a ride across the downtown area captures wide shots of beautiful murals and stately buildings that locals of the area, as they are, would barely notice while going on with their lives in the city on any given day. Carla bursts into a hearty giggle after Max's casual observation and the two drive away. Later in the film, they enter a supermarket to buy gifts on a Christmas Eve for the people in their lives who are now dead: Carla's son, who died in a plane crash that happened earlier on in the film and one that both Max and Carla survived, and Max's father who had passed away many years back. The film is about people with what has been contentiously called "post-traumatic stress disorder" (PTSD) and how it impacts upon individual lives and, in allegorical terms, what the experience of PTSD does to social understanding of the self and society. While these two characters are seen to be grappling with the effects of PTSD, along with their respective families, the film provides an acutely aware reading of not just the socio-political contexts of these characters but of the category of "post-traumatic stress" and interrogates the question of what kind of a disorder PTSD reveals itself to be when mapped on its material context. There is a lot to be said about these complicated issues in relation to this particular movie and others from the 1990s that discuss cultural saturation of trauma narratives in the period, but I only mention this movie and Max's and Carla's burnt-out reflections because of the film's particular kind of attention to trauma. The film asks what becomes of trauma and the post-traumatic as concepts when traumatized subjects mobilize their individual experiences, that is, be it surviving a plane crash and left acutely numb and detached from social life itself, or using transgenerationally received historical traumas that give a particular form and shape to the material bases of mnemonic experiences as we will see in Canadian video artist Richard Fung's *Sea in the Blood* (2000). The common thread here that is worth considering is: does trauma's engagement with an essential quest for what I will provisionally call "freedom" from a kind of culturally precipitated trauma taps into a collective political consciousness that is not otherwise registered? Does the lack of "freedom" from trauma enter into a significant but often neglected dialogue with freedom of crises that are yet to be named, crises that are too mundane but nonetheless experienced at an intimate and affective level?

Whether it is freedom from personal histories inflected by socially stigmatized illnesses and mental conditions, or freedom from conditions from which traumatized subjectivities emerge, trauma's negotiations with freedom (i.e., not only from trauma but also historico-material conditions that precipitated encounters with repetition of trauma) have not been sufficiently explored.[92] Traumatized subjectivities emerge from their own fragmented narratives in profoundly ambivalent ways; in fact, we may say trauma narratives such as the one that I have referred to here is ambivalent because just as there is "dissociation" from the event of trauma (the ostensible desire to enjoy the beautiful downtown Oakland), there is also an implicit and compulsory repetition of trauma in the narratives I will discuss later. What is important for our purpose is to examine how this dialectic enabled by traumatic experiences

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[92] Admittedly, the connections here are tacit, subtle, and complex, but I want to suggest that the risks implicit in making these connections are worth considering, in thinking about the contexts in which trauma narratives have been "contextualized" are worth thinking about because these contexts have fundamentally given back a revitalized concept of trauma itself. Also, I use the term "freedom" advisedly because just as Max's and Carla's post-traumatic reflections ground trauma in everyday life in Oakland, California, the concept of "freedom" from post-traumatic pain needs to be engaged with in relation to the everydayness and not as wholly a transcendental category. This is particularly important to understand how traumatized subjects engage with such a conceptualization of "freedom" and create a dialectical relationship in relation to it.

speaks to its social and material contexts. Borrowing from Damasio work, we may say, here is a reflective aspect of engagements with traumatic pasts, which is particularly important to examine when survivors reflect through engagements that put for complex narrative strategies. Both these features of trauma—Max's and Carla's "peak condition" in the wake of a plane crash that is simultaneously able to identify the backdrop of a gentrified neighbourhood—animates a dialectical tension that grounds trauma in conversation with the materiality that it finds itself in. Trauma, thus, is indexical of broader questions even though it compulsorily attends through repetitions the moment of its inception. At the same time, trauma, besides being an irrevocable injury, a wound, entails a process of interpretation in relation to not just what it is ("post-traumatic stress disorder") but what it becomes or what it does in relation to contingent factors. While Weir's film offers a perspective of the mode of the post-traumatic in the context of American cultural life, Canadian video artist Richard Fung's *Sea in the Blood* is similar only insofar as this video shows a peculiar deployment of historical traumas of diaspora to recuperate narratives that are rarely recognized as "traumatic" in their own right. If, as Kirby Farrell (1998) suggests, people "use trauma as an enabling fiction, an explanatory tool to manage unquiet minds in an overwhelming world" (5), then it is important to take seriously the various *uses of trauma in narratives*—and what precisely is at stake when trauma is used for particular political and formal purposes in Fung's narrative of patients' perspective? As Cathy Caruth suggests, because to be traumatized is to be "possessed by an image or event" (1995: 5) the story of trauma is "inescapably bound to a referential return" (1996: 7). Following Caruth, it is important to consider the conditions that influence on-going experiences of traumatized subjects and to examine how trauma's referential return portends to put forth a different set of significations with which it tells a story.

This chapter, however, is not entirely about "trauma" in any of its institutional avatars (literary, historical, psychological, for instance). It is also not about what is referred to as PTSD; indeed, it is about an interrelationship between the two that when mapped against its broader contexts (as we see in the scene from *Fearless*) tells us how this interrelationship affected by a dialectical exchange. Our engagements with narratives of patients' perspective and those of caregivers and immediate family are better informed if we observe the discourses that shape this exchange. Thus, it is worth dwelling upon cultural discourses of suffering, for instance, the "post-traumatic", and the human need to overcome it, which shape the contours of experiencing and narrating illnesses in the text I will examine. In order to have a better understanding of various engagements with trauma, how they are established, and what they secure, we need to examine the intersections between the narratives of illness experience, contingent historical factors, and aesthetic practices through which narratives are formed. It remains to be seen how this dialectical exchange is worked out in Richard Fung's *Sea in the Blood.* Significantly, from the point of life writing studies, Fung's video shows the experiences of Richard Fung, the director and the narrator of the video, who is neither the afflicted with thalassemia (a congenital disease) nor an HIV-positive individual, but someone who has lived closed to these illnesses with respect to his sister and his partner. While all inherited, insidious, and mediated traumas are in no uncertain terms traumatic, it's important to highlight the distribution of complicated subject-positions when we engage with "patient's perspective" in a life writing text like *Sea in the Blood.* I ask, how does the dialectic between illness experiences of HIV and thalassemia and historical factors that shape their engagements—in the form of Fung's "autoethnography" of his pasts and his "medical ethnography" of two family members—offer a way to examine patients' perspective in this video narrative?

4.2 Movements, journeys, and returns: a dialectical engagement in *Sea in the Blood*

In summarizing the story of this video I want to underscore the role of movements and journeys in the video and connect it to the issue of representation of chronic illnesses in a memory narrative, and precisely what this representation achieves and implies in and beyond *Sea in the Blood*. Fung's *Sea in the Blood* is a complex video narrative that discusses issues of chronic illnesses like thalassemia and HIV, interpersonal relationships in the aftermath of these illnesses, and traumatic histories from the perspectives of Richard the narrator, his mother, Rita Fung, his sisters, Arlene and Nan, and his partner, Tim. The video evolves around Richard's and Nan's childhood, particularly Nan's life after being diagnosed with thalassemia as a child and her death many years later. The video also discusses transnational histories of migration in relation to the Fung family's journey from Trinidad to Canada. Although *Sea in the Blood* refers to movements to and from different places, these travel narratives help in framing a larger picture within which experiences of chronic illnesses are portrayed, which is to say, chronic illnesses are viewed in relation to diasporic histories. The video refers to the family's trip from Trinidad to Ireland to obtain a diagnosis and treatment for Nan, Richard's absence during Nan's death (while he is said to be visiting different countries in Europe and Asia), and even the state visit of the British monarch to Trinidad just before the country's independence in 1962, one that is recorded on a homemade video by the Fung family. These are different kinds of journeys that are recorded in the video but, as we will see, they are not entirely unrelated. These descriptions help the narrative to juxtapose its stories of lives in relation to illnesses and movements, even the ones that were subconsciously desired at a point in time but happened much later. We learn from Tim's part in the video that Richard did not want to fly back home from Europe when he was informed that Nan was dying. "But Nan has always been sick," he says in a tone of protest that sounds like it is intended to convince himself more than anyone else. The concomitant guilt and shame associated with not returning to Nan, to the heteropatriarchal structures that offers familial love whilst in pursuit of homosexual love outside the boundaries of "home" stages a return to a scene from their childhood. Earlier on, Nan is said to have confided in Richard that she regrets realizing that she can never have a boyfriend, but Richard's thought of not being able to tell Nan then how much he wanted a boyfriend rolls across the screen in the form of a subtitle that suggests a painful secrecy around guilt and shame that the narrator still cannot quite mention in the voiceover. Not returning to Canada when Nan was dying is deeply connected with an earlier desire to make a journey elsewhere (outside home) to find love and intimacy; at the same time, thinking through these dynamics in relation to the footage where he discusses these issues makes the viewer realize that Richard is working through certain affective legacies that are in a process, a process that semantic tools like the voiceover and subtitles in the video cannot fully convey.

We also have in the video the family's journey to places because the trip was much-needed to get medical treatment for Nan; we have a young Richard leaving home and his sheltered life to be with his partner in foreign destinations; and we also see communities living in places where they have lived because of historical conditions not of their own making. There are multiple push and pull factors of these travels and journeys that are not explicitly stated in the video but addressed in relation to the discourse of the critical illness narrative generated in the video. The references to places like Trinidad, Ireland (where Richard attended high school and Arlene went to medical school), and Canada evoke specific histories of Asian Indentured labour, postcolonial Dublin, and the making of multiethnic Toronto that somehow remain as a vestige of the past and a quasi-present frame of reference in *Sea in the Blood.* The presence of these seemingly older histories in a video that is focussed on discussing "personal" narratives of illnesses and what it is to live with illnesses from the perspectives of family members and immediate caregivers seem not at all incongruous in relation to its own concerns but rather peculiarly seamless in the way the historically inflected pasts are incorporated in the video. At one point, Richard suggests how his trips not only takes him away from Nan's deathbed but closer to places where he has his own memories and how those memories potentially carry him to a new future with Tim, whose illness eventually comes to replicate Nan's life. Thus, just as there are journeys from one place to another, there is also a feeling of arrivals of earlier histories that emerge in different places and time periods through a motif of cyclicality that takes us ahead but not to a completely unfamiliar sense of future.

> We'd come back to New Delhi to find a letter waiting. Nan's condition is worse. We make it back to Europe but, I don't know why, I don't go home. Not yet. Instead we go to Ireland. I show Tim my old high school in Dublin. Arlene calls. Nan is dying, she says. And I know she meant it.

If Richard's decision to not to return home despite being informed by his mother that Nan's was sick and his eventual absence on the day Nan died forms what Monika Kin Gagnon (2009) has called the "emotional koan" of the video, then, the seemingly straightforward understanding of illness narrative seems paradoxical because the video is not so much about illnesses but their presences and implications in different people's memory, most prominently in Richard's. The video goes on to deal with the notion of movement in more literal ways in the context of its own constructed footages. The beginning and the closing shots are the same scene of Richard and Tim swimming in an orange-hued water along with a scintillating score by Phil Strong and Laurel MacDonald; through this footage the video remains punctuated with what critics have called the "symbolics of blood" (Lawless 2012). We see what seems like Richard and Tim swimming in an orange-tinted underwater footage, while each takes turn in swimming through the inverted 'V' of the other's spread legs. As Julianne Pidduck notes, "with their faces and bodies almost brushing the camera as they glide upward to the surface. Tinted with ambers and reds and shot through with rays of light, this footage is speed altered to accentuate a dreamlike fluidity of motion" (cf. 453). This footage of two homosexual men's (potentially ailing) body as it easily moves ahead in water that shimmers with a peculiar tint of blood is supremely suggestive of a complicated set of questions that I find productive to think about: namely, what is the precise nature of the relationship that this body shares with time itself, with movements, particularly when the blood-red tint of the water is connected to (blood) relationships across the slow passage of time (as observed from under the water); forms of kinship across generations and outside the biological family; and, by extension, to blood-related diseases such as thalassemia and HIV? Do these questions seem to come up with a different set of signification altogether in Fung's work? Admittedly, I cannot do just all these interrelated questions in my analysis, but I find it important to think through them as I proceed in my analysis. Furthermore, if the footage seems to be interrogating the relationship that these bodies have with time and movements, we may say, in giving an account of what it is like to grow up while living close to illnesses, and what it means for queer subjects to have a historical understanding of illnesses, Fung seems to draw on complicated techniques that have both formal, political, and ethical implications.[93] Formally, the stylized footage such as these makes the viewer realize the complicated ways in which ideas are put into dialogue with one another through images; whereas politically, the emplacement of images and textual matter in a video where image, sound, and subtitles are always purposefully misaligned seems to suggest the difficulties of recuperating specific histories of illness while legitimizing experiences that medicalization of race and sexuality elides. From the point of ethics of medical ethnography of other people's painful experiences and illnesses, Fung video suggests a need for a kind of engagement that the very subjects of illnesses he discusses need to be the intended audience of his medical ethnography of others, which demands a reciprocal view of engagement from Fung in the way these characters live with their chronic conditions.

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[93] See Paula Treichler's introductory chapter in *How to have a Theory in an Epidemic* (1999) on the multiple significations of the male homosexual body in the context of AIDS pandemic. Treichler writes, "'AIDS' cannot be separated from stories about the illness that has nothing to do with the clinical condition […] because AIDS is derived from "a text that does not exist: the body of the male homosexual. People want—need—to read this text that they have gone so far to write it themselves" (19).

We learn from the video that the family has lost a child to thalassemia before Richard was born; Nan, who is diagnosed free of cost by a doctor in Ireland, is said to have had beta-thalassemia major and begins to live with the illness as a child. Long after Nan's death, we learn from an e-mail exchange between Arlene and Richard that there is a possibility of Nan being perceived as a "medical curiosity" by her doctors because thalassemia was not known to be an illness afflicting people of Asian extraction. In these footages, as e-mail scripts roll across the screen, the idea of a movement is inflated on multiple levels: the scripts do not linger on the screen for a long time, not unlike afterthoughts that cannot quite discern their presences that would enable them to participate in the politics of the questions, intuitions, and apprehensions that precede them in the video. Furthermore, the genre of the e-mail signify a mode of communication between two people who are now separated by distance and time, but, at the same time, its presence as an archived correspondence displayed on screen suggests a kind of interpretation is made possible in retrospect that could not have happened earlier. The query if Nan had ever been treated as a medical curiosity is never known for certain because neither Arlene nor Richard has any answer for it, but the presentiment that it could have been the case seems to be carried forth in the narrative when in the video Richard reflects on Tim's association with historic Montreal AIDS summit in 1989 and his own infection with HIV later in life. Thalassemia is, of course, not a disease with the same social history as AIDS, and even though it is not stigmatized in the same way as HIV is, the possibility of medicalization of race intersects with medicalization of sexuality because of the crisis of credibility that scientific knowledge has faced since the 1980s in the wake of the AIDS epidemic.[94] Significantly, *Sea in the Blood* draws on these tacit connections through its strategies of misalignment and movements and puts injuries in the past in direct relation with the present and future-oriented purposes; it actively wonders how might the past help us understand the contingencies of the present. This particular aspect of the video has been called the "queer auto-ethnographic form" in Fung's work (Muñoz 1995) because auto-ethnography imitates the constitutive conditions of queer subjectivity and remains in dialogue with queering as a practice. Others working with the similar hypothesis of the queer auto-ethnographic form has explored multiple temporalities of "loss" that are addressed

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[94] Cf. See the "Introduction" of Steven Epstein's *Impure Science* (1996).

through Fung's deliberate misalignment strategies: Fung's "voiceover and use of subtitles shift his position in relation to these images so that the past self inhabits the present, even while the present self speaks to the past" (cf. Cho, 427). Through this process, shifting positions of selfhood are effectively deployed to put forth a historicized reading of the different timeframes. Through an interrogation of the past and present with the lens of an agency that the queer auto-ethnographic form enables, *Sea in the Blood* becomes "not an expression of a melancholic attachment to the objects lost, but rather a commitment to transformations of objects lost and then found" (431).[95] If, by situating loss outside the logic of something that "has happened", Fung's video is able to displace loss in relation to a future that is to come, it is important to understand how a proleptic sense of suffering in relation to this loss spills over to read bodies, memories, referential returns of traumas in the vein of a life writing narrative. This, I suggest, happens in the space of the meantime. The proleptic suffering or an anticipation of loss in Fung's autoethnography is also, as we will see, not a passive state of experience of loss but one which produces narratives of other's experiences of illnesses and those living close to illnesses, much like Richard himself. In other words, Fung's life writing is inextricably connected to other people's lives, so his "autoethnography" is also an ethnography at certain points in *Sea in the Blood*. Also, on the one hand, the notion of prolepsis is partly contained in "chronic" health and mental conditions: since there is no cure for thalassemia and AIDS yet, these are chronic illnesses, which is to say people live with these illnesses and eventually succumb to their conditions or they do not, but they are nonetheless influenced by the possibility of their condition terminating. The possibility of these conditions terminating is a thought-experience that lies at the horizon for subjects of these illnesses. On the other hand, video also problematizes the notion of the chronic through its historical focus, which is to say, neither thalassemia nor HIV was considered "chronic" when these illnesses entered the public discourse in the West.

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[95] Objects such as family photographs, older visual technologies, 8mm home-movie footage, and even the emotions that are allowed to surface while interviewing Rita, Arlene, and Tim; these are emotions that are rarely addressed but was always registered by Richard's family members. The commitment, as Lily Cho (2008) suggests, is realized through an understanding that queer diasporic subjects, or subjects who are constituted through a sense of dislocation from the notion of "home and desire outside the heteronormative home" (431), are able to and often do transpose "loss" as a modality of experience in ways that suggest "loss [itself] is not so straightforward, that it moves in all kinds of directions, that it is not one thing" (427).

Nan's condition was not diagnosed easily because, as I have mentioned above, it was not known that thalassemia could affect people of Asian extraction, and contracting HIV was considered to be a death sentence for gay men in the 1980 and 1990s because very little was known about the disease in that period. The belated recognition that these are chronic illnesses, and that people can lead a fairly normal, albeit compromised, life even after contracting HIV or that thalassemia does not only affect people from the Mediterranean region, which, as per the video, was the perception of the doctors and specialists when Nan was diagnosed, is in itself revealing of multiple social and temporal landscapes that *Sea in the Blood* navigates. In so doing, while the video does give meaning to the notion of proleptic pain, transformative and coalitional politics of "anticipation of injury," failings of health, I want to suggest it recasts the *meantime* in ways that highlight the intersections of Fung's autoethnography and his ethnography of other's illnesses and diverse experiences of living with illnesses.

The meantime, the time that is brought forth by techno-scientific advancement in dialogue (and often at odds) with political activism as evinced in the history of AIDS epidemic carries a transformative possibility; the meantime is also aware of its own contingencies beyond loss while it refuses to be a space of sheer paranoia of anticipation prior to the injury. It is a place of negotiations where new knowledges emerge, and they do so strictly in relation to their embedded and situated locations in the meantime. In the meantime—the time between different journeys that the video refers to; the display time of subtitles carrying crucial cues to Richard's narrative but those that are available to the audience for a short while before they disappear; and Nan's and Tim's chronic time periods in their lives—seem to underscore something that an austere emphasis on "loss" or the narrator's proleptic suffering belies. The meantime in this narrative takes its audience to places and timeframes where subjugated knowledges in their affective and inchoate forms reside—it makes use of traumas from its points of arrival at experiences, and is reflected upon through the embedded agencies of stories. The scope of viewing the "I" as "not-I" and as an identity that is "potentially in motion", as evinced in the focus on the meantime, is perhaps most powerfully explicated than in the form of queer-auto-ethnography. The way this genre facilitates the emergence of the "politicized patient" is somewhat covered over due to an overemphasis on "loss" and if we do not examine the metaphor of the meantime and transitory spaces in Fung's video production.[96] I will argue the emergence of the politicized patient with her narratives of historical losses is one such point that punctuates the passage of the meantime in Fung's *Sea in the Blood* through its stylizations.

The video suggests the problem of chronic medical condition through its meditations on the culturally precipitated discourses that shape the interrelationships between psychic and somatic experiences of illnesses, that is, both for sufferers and those who live close to illnesses. It does this by engaging with the meantime of its narrative; the video contributes to our understanding of contemporary contexts in which culture, illnesses, and politics intersect.[97] By drawing attention to the meantime, the transit period in the course of movements of different kinds that I have described above, the video enables a reflection of how to account for illnesses, personal and historical traumas and, of course, losses in the context of what we can broadly call a climate of traumatic pain, or what David Morris has called "the culture of pain" (Morris 1991). The video invites us to think of the narratives it highlights within a broader context of the notion of loss, perhaps even losses of a different variety, that is, the inability of the political left to organize alternatives to dominant imaginaries of a future while exploring the characteristics of what Wendy Brown has called the "wounded attachments" (Brown 1995) of the left in general and those of identity politics in particular. This is not to suggest that wounded attachments to identity's situated constructs are something we need to simply forget for any kind of "collective goal," but perhaps we need to examine how these attachments are explored in narratives, and if interpretative strategies can hold on to their tenuous and textual mediations between experiences of illnesses for sufferers and narrators alike. The historically precipitated attachments to woundedness as evinced in narratives of medicalization of race and sexuality

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[96] See Judith Butler's "Afterword: After Loss, What Then?" (2003: 463-473) for an analysis of why historical losses need to be critically engaged in order to break through a potential intellectual impasse.

[97] I am influenced by Eric Cazdyn's *The Already Dead* (2012) in this context. In his introduction, Cazdyn writes: "The paradigmatic condition illustrating the already dead is that of the medical patient who has been diagnosed with a terminal disease only to live through medical advances that then turn the terminal illness into a chronic one. The disease remains life threatening, still incurable, even though it is managed and controlled, perhaps indefinitely. The patient is now afforded a meantime that functions like a hole in time, an escape route to somewhere else and a trap door to where he began (4-5).

require us to think of losses in distinction from their character of "woundedness" by focussing on scenarios that are embedded in the very sites of pain. There is something to be gained by tarrying with these scenes in the video because they help us to understand those various forms in which woundedness thrive and the kind of attachments they strike with history. In these attachments, then, there might be a potential for "embedded agencies" (cf. Schwab 29) that narratives like *Sea in the Blood* explore. These embedded agencies and their embeddedness in patients' perspective will be the focus of the rest of the chapter. They make us wonder if are they necessarily melancholic ones that are detrimental to subjects of wounded sentiments, or does woundedness suggest the production and quasi-presence of attachments that covers over certain dynamic processes and can potentially overturn the detrimental passivity of woundedness as such? It is my contention that *Sea in the Blood* yields complicated and extremely productive answers to such questions.

But in order to understand the video's complex relationship with "woundedness," it is important to investigate the chronic meantime because it is by problematizing this sense of time that video answers what precisely is "chronic" about the wounded attachments. Also, the meantime is necessary, even desirable, and simultaneously the bane of our existence because it makes the present bearable while making us feel, as it were, anaesthetized to its implications in relation to the chronic. This is why besides being too austere a claim that is deeply reliant on an affective logic, the focus on proleptic suffering in *Sea in the Blood* generates an all subsuming definition of "loss," which in turn risks dissolving certain aspects of the video that engage with discourses that Fung borrows from and responds to. For instance, how does *Sea in the Blood* participate in the emergence of the "politicized patient" (Diedrich, xx) of critical medical studies in relation to this meantime? How does this figure through its relationship with the chronic mode work in memory narratives—a genre that offers highly nuanced reading of the category of "experience" and thus provides fertile grounds for exploring the experiential impasse and an ethical and political stalemate enabled by the chronic? And, how does Fung's work contribute to the rich archive of a counternarrative to medicine and hegemonic versions of history by mobilizing life stories, memory narratives, and subjugated knowledges of patients and caregivers?

4.3 The "politicized patient" of *Sea in the Blood*

Sea in the Blood situates chronic medical conditions as evinced in a narrative of thalassemia and HIV as a problem of not just modern medicine or historical facets of diasporic cultural memory but a crucial interrelation of both. It does so by underscoring suffering in the aftermath of prolonged and indefinite periods of time as a state that experiences mourning and inherited traumas in embodied and embedded terms. In Fung's artistry, grieving not only address inheritances and transmissions of pain, but grieving also necessitates an admission of unbearably painful moments. Consequently, making those unbearable moments "surface" through the work of memory and transmissions of trauma becomes a political work that enables transformation because chronic medical conditions attempt to numb sentient capacities of the subjects without actually engaging with pain.[98] The politicized patient of Fung's illness narratives is one with narratives that account for the production of the surfaces where delegitimized pain is acknowledged and affirmed. We see such an attempt at acknowledging pain in the instance when the voiceover disappears in the middle of a sentence on Richard returns to Toronto, that is, after Nan's death. He cannot ask his other sister, Arlene, who has come to receive him at the airport, about Nan's death. We later learn that it took him twenty years to talk about Nan's death with his mother and sister. And when he describes his journeys away from Nan after he's asked to return home the screen goes momentarily blank, and he says, "I don't know why but I don't go home. Not yet." It is not just a self-conscious guilt and shame associated with his decision to go elsewhere with Tim that gets reflected here, but the similarities between Nan's life and Tim's. "I've always lived close to illnesses," Richard writes to Arlene. Remembering Nan's death presages the possibility of losing Tim to HIV. But it is not only an emotional response to the certitude of a loss in the future, but also a mode of experiencing the exacting nature of the contemporary notion of illness itself. As Lisa Diedrich (2007), in conversation with Arthur Frank's *The Wounded Storyteller* (1995), writes:

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[98] Cazdyn writes in *The Already Dead* (2012), "What is the relation between unbearability and revolution? Or between bearability and the status quo? Or between deadening environments (both social and ecological) and our relationship to death itself? This is where politics, culture, and medicine come together, especially around the concept of the already dead and the problem of time. We have entered a new chronic mode, a mode of time that cares little for terminality or acuteness, but more for an undying present that remains forever sick, without the danger of sudden death" (5).

> Partly because of the shift in the twentieth century from acute to chronic illness (thanks, of course, in no small part to the successes of modern medicine), the experience of illness has shifted as well. Formerly patients generally either got better or died; now, however, patients are often neither fully cured of nor dead from their illnesses, but, rather, are in and out of remission. The body remains haunted by illness and its threat; the person is neither fully healthy nor precisely ill; they are somewhere in between. […] [T]hus, in the late-twentieth-century West, we live in what Frank calls a "remission society." (3)

The fact that the "experience of illness has shifted" in our times is an important reminder because it tells us that an experience of illness is not so much cataclysmic anymore, as *Sea in the Blood* also suggests, but living with illnesses, both for the subject and caregivers around her, is implied to be "ordinary" in a way that covers over slow violences in a remission society. If all illnesses in a remission society carry an element of "chronicity", Fung's narratives of AIDS and thalassemia would suggest that historically signified illnesses and their complex experiences in narratives of sufferers and caregivers have had to re-evaluate their chronic conditions from shifting perspectives and not just the perspectives that "past" experiences afforded them. The insight that Fung's partner Tim takes "fifty-six pills a day and injects himself four times a week," as Richard tells us, then, becomes telling of a different way to engage with the politicized patient of AIDS history. Here, this patient is not only the historically disenfranchised subject of AIDS; instead, we get more than just a glimpse of survivor of AIDS epidemic, we learn of a subject of chronic illness in a remission society who experiences the past as a "quasi-present", which is a present in which technologies of amelioration aggressively manage his potentially deteriorating health condition. The past is thus, in part, present, and the present is aggressively extended into the future, and what connects the two timeframes is the focus on the "ordinariness"—the meantime—of the experience of chronic illnesses. In a remission society, this dynamic promises to manage potential cataclysms and "buy off big troubles if we submit to a little ritualized distress every day" (cf. Farrell, 17).[99] In such a society, or what critics have also described as a culture of "reflexive medicalization", the ability to make a decision on illnesses and act on that decision "is passed back to laypeople", so subjects of chronic illness

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[99] Cf. See Kirby Farrell's *Post-traumatic Culture: Injury and Interpretation in the Nineties*, p. 17.

who endure illnesses for long periods of time become “active knowledgeable subjects”, on the one hand, and, again, these subjects don’t “really have a choice” to act on their own, on the other.[100] Processes that generate reflexive medicalization can, however, be gauged, if not entirely subverted, through reflective capacities of life writing texts like Fung’s and how these texts account for the politicized patient, so the chronically ill body’s haunting with illnesses and its many threats can thus be (re)imagined through narratives.

The most important sign of ordinariness that promises to manage medical and epochal cataclysms like the AIDS crisis and buy off big troubles perhaps lies in the tone of the voiceover when Richard says Nan’s eventual death due to thalassemia was a fact he grew up with, “like mangoes in July.” Richard is, of course, not directly commenting on the chronic mode of experiencing illnesses in contemporary culture of a remission society, but it is nevertheless interesting to note how this image of ordinariness covers over slow violences that structure his use of the metaphor and gives meaning to its referential return in his stories. This, in turn, bears a striking resemblance with notions of the “chronic” in the conceptualizations that I have highlighted. While having a congenital illness like thalassemia means that the terminal stage of the illness is an eventuality, it is interesting to note that the intimation of loss that illnesses puts forth through the chronic character of the meantime can be both productively metaphorized as a condition of subjectivity for historically constituted identities and interpreted as an expression of the demands of chronic illness on the subject in our cultural moment in the West. I choose to focus on the latter possibility more because it seems this idea has been overlooked in the context of Fung’s work. And I suggest there is something complicated happening in moments when the possibility of a chronic illness actually becoming terminal is spoken about in the video. Richard’s familiarity with death, his associations with illnesses, and use of images from daily life suggest not just a description of his and his family’s experiences, but perhaps their presences in the language of everyday life function as a critique of the contemporary remission society at large. Thus, the body’s perpetual haunting by illnesses and threats often goes unrecognized precisely because of its naturalization in our culture. In the process, though, the body’s dialogues with these hauntings offer important ways to understand the knots between culture, politics, and

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[100] Cf. See Timo Heimerdinger’s “Pacifiers and Fairies: Family Culture as Risk Management—A German Example” (2011), p. 205-6.

medicine. Specifically in the context of *Sea in the Blood*, the haunting of illnesses in contemporary chronic time legitimizes experiences of grief for subjects of illness it interrogates. In so doing, the video comments on the question of the chronic in a way that identifies queer diasporic experience of illness as a lens for interpreting the mode of the chronic. This is done, in part, by focussing on the way chronic illnesses intersect with and is informed by a proleptic sense of suffering: experiencing suffering prior to the fact of its arrival, a kind of dying prior to the fact of death are related to different ways in which the "chronic" is (re)defined by reflecting on the history of AIDS and the condition of (initially undiagnosed) thalassemia in Nan's story. It seems *Sea in the Blood*'s ability to put personal histories in conversation with broader questions relies on the video's ability to zoom in and out, so to speak, of its own immediate concerns, which then becomes a powerful critique of significations of chronic illnesses like thalassemia and HIV and how patients and caregivers endure these conditions.

In response to these question that the video pushes us to think, it seems productive to interrogate how the indeterminable valence of pain and suffering in *Sea and the Blood* brings together disparate aspects of cultural conditions in conversation with one another through its complex stylization.[101] For instance, when the narrator tells us, "Tim takes fifty-six pills a day and injects himself four times a week", he mentions this just before we are introduced to Tim, who also participates in Richard's memory narrative and gives an important perspective about his relationship with his parents and siblings. There is a beautiful ambivalence about Tim's presence in this video, just as there was a plurality around Nan's condition and the many faces of Nan that we get to see from her childhood days to her adulthood. But it is through these multiple faces of chronic illnesses that we can begin to understand forms of pain in an active mode in *Sea in the Blood* that are never just about the pain itself but how it remains in relation with others. As Morris writes, pain is not like "the wheeze and cough from a broken motor" (20) that modern medicine makes it out to be. I agree with this assessment, but I would also like to add that, discussions of chronic pain need to deploy more than just a diagnostic language ("where does it hurt?") in order to come to terms with the

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[101] As David B. Morris writes, "Pain, unfortunately, is not a subject that we can master through the knowledge of drugs alone. The question of how we should think about pain should be raised—and held open—so that we may examine the assumptions we now take for granted" (12).

complexities of this kind of pain and how pain relates to one's health and wellbeing. To understand chronic pain (as we see not only in Nan's and Tim's stories but also in Richard's grief), we are perhaps better off revitalizing the diagnostic language with a close reading of what pain does and what chronic pain itself is capable of reading. Perhaps because pain is always influenced by the idea of its own extinction that it is prone to attach itself and stick to anything that it perceives as a remedy; in this process, as Elaine Scarry notes, pain creates a structure of incommensurability that is its own making: "to have pain is to have certainty; to hear about pain is to have doubt" (13). Recovering knowledges that have been "too hastily set aside in favour of drugs, surgery, and nerve blocks" (cf. Morris, 20) and neoliberal futures in a remission society is thus a challenge for chronic pain because through processes of social negation the subject of chronic pain, by definition, come to desire nerve blocking remedies that are not remedial. However, recovering those invalidated and incapacitated knowledges that chronic pain experiences is a complicated process in Fung's work in general and happens in conversation with different techniques and styles at play in *Sea in the Blood*, namely, memory narrative, interpretative and illustrative visuals, critical medical studies, and reflections on histories of illnesses through the knowledges that patients and caregivers bring forth. I will be exploring this in the following section.

4.4 Encountering Subjugated Knowledges

Knowledges that have been historically invalidated have been the emphasis of life writing narratives in diverse ways. Because disenfranchised knowledges, or what Michel Foucault called "subjugated knowledges" (1977), are "whole set of knowledges that has been disqualified as inadequate to their task or insufficiently elaborated: naïve knowledges, located low down on the hierarchy, beneath the required level of cognition or scientificity" (82), they are often at the edges of semantic availability that life writing is able to explore. These knowledges are hard to identify and thus difficult to recuperate; Fung's queer auto-ethnography, however, effectively expropriates not so much these knowledges but spaces in which they reside and how they reside in the mode of the chronic. Foucault understands the political work of "criticism" in excavating these "non-scientific" knowledges in the following terms:

> [A] differential knowledge incapable of unanimity and which owes its force only to the harshness with which it is opposed by everything surrounding it—that it is

> through the re-appearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work" (82).

The utilization of the chronic mode shows how historical pathologization of foreign bodies takes place in the context of every body that Fung's narrative deals with: Nan's and Tim's sick bodies, young Richard's queer body, and Rita Fung's ageing body. (The ageing body is captured with the recurring image of just Rita's ageing hands tending to plants in her garden while answering Richard's questions about Nan and his childhood and young Richard's queer body is seen in a homemade video footage, which shows the children playing in the snow.) But what also facilitates in locating the chronic itself is the vast archive of time frames that *Sea in the Blood* navigates because, as I suggest, chronic illnesses accrue meaning in relation to the other histories that the video refers to. In this regard, the genre of auto-ethnography besides reflecting queer subjects' unique ways of identifying and creating meaning is particularly appropriate for Fung's exploration of subjugated knowledges because, on the one hand, they show how and why the narrator seems to be literally 'stuck' on certain archived and constructed images; while, on the other hand, he 'reads' those very images to show how they are useful for him to derive a political and ethical impetus to speak about illnesses in the present.[102] Furthermore, this expropriation of private histories to make

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[102] José Esteban Muñoz writes, "Queers are not always 'properly' interpellated by the dominant public sphere's heterosexist mandates because desire for the bad object offsets that process of reactionary ideological indoctrination. In a somewhat analogous fashion, queer desires, perhaps desires that negate self, desire for a white beauty ideal, are reconstituted by an ideological component that tells us that such modalities of desire and desiring are too self-compromising. We thus disidentify with the white ideal. We desire it but desire it with a difference. The negotiations between desire, identification, and ideology are a part of the important work of identification" (1999: 15). Referring to Althusser's example of ideological hailing by the police officer, Muñoz suggests, the queer's interpellation in the dominant order to become a proper subject remains compromised because her reactionary ideological indoctrination (in response to the moment of hailing) is clearly out of line in relation to the trajectory set forth by the desire for the bad object (that is, a woman's love for a woman or a man's love for a man). Yet, the desire to be associated with the dominant ideal, order, or heterosexist mandates, so to speak, exert a palpable pressure that is also internalized by the not-quite-interpellated queer subject. Herein lies a double bind: the queer subject's desires cannot be desired through the language of heterosexist mandates, which makes her queer, and again it is those mandates, heterosexist, white, and dominant social order in general that she learns to desire 'differently.' However, her complicated desire to be assimilated is also not the same as of those who are successfully interpellated, which makes her partial identifications productive for critique of heterosexist mandates. This is precisely what Muñoz terms as "crisscrossed identification and

them the basis of collective goals suggests the importance of making public those private and intimate griefs as a basis for collectivities that are yet to emerge. The role of the narrator of life writing here is also to be taken into account because of the considerable attention that life writing has given to embodiment and the body as what Sidonie Smith and Julia Watson have called "sites of knowledge and knowledge production" (41). As Smith and Watson write:

> [B]y reading the body and embodiment as sites of knowledge and knowledge production, life narrators do several things. They negotiate cultural norms determining the proper uses of bodies. They engage, contest, and revise cultural norms determining the relationships of bodies to specific sites, behaviours, and destinies. And they reproduce, mix, or interrogate cultural discourses defining and distinguishing the normative and ab-normative body. (Smith 41-2)

Although Smith and Watson are specifically interested in the genre of autobiography, I find their focus on "life narrators" instructive because it seems to make an important point about narrators who choose different forms other than the traditional autobiography. In fact, their insights help me to understand that the question of form is not a given template that Fung's readily takes up in *Sea in the Blood*—and that forms of narration are constructed from discursive conditions of Fung's narrative. The use of multiple sub-genres of life writing—memoir, ethnography, autobiography, critical illness narrative, and travel narrative—in *Sea in the Blood* is significant to juxtapose issues of illness in conversation with history as "an effort to reclaim the past and put it in direct relationship with the present" (Muñoz, 89). In this way, a negotiation of cultural and aesthetic norms is presented in which genres seem to bleed into each other. The interrogation of cultural discourses around pathologized and racialized bodies is addressed in relation to how "normative and ab-normative bodies" are constructed and to what end. In a section of the video when Richard incorporates the medicalized history of thalassemia, an omniscient, male "voice of God" (cf. Pidduck, 454)

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desiring circuits" (15) that is the bane of the disidentifying subject's inability to fully identify, or what he earlier on distinguishes from "what Sigmund Freud called that 'just-as-if' relationship" (7). "Identifying with the object, person, lifestyle, history, political ideology, religious orientation," he notes, "means also simultaneously and partially counteridentifying, as well as only partially identifying, with different aspect of the social and psychic world" (8).

appears from nowhere to “explain” how thalassemia is transmitted from biological parents to their children. The voice speaks without any emotional tone, perhaps because it is enunciating “scientific knowledge”; it informs us, “[t]here is a 25 per cent chance for a normal child to be conceived, a 50 per cent chance for a beta thalassemia minor child, and a 25 per cent chance for a beta thalassemia major child.” As the voice tells us, thalassemia (which come from a Greek word) translates as ‘sea in the blood’ with animated pictures of waves on a sea, which makes the video about two illnesses and their interconnections in the narrator’s life, and also about issues that are in part and formally absent from their own narrative but performatively present. The use of the authoritarian voice of science is at odds with images of cartoon-like drawings of sea waves; in this way, we are made to question the implications of the factual details of the illness but also what happens in the aftermath of a kind of internalization of the scientific discourse in a child’s perspective, which is what Richard and his siblings were when Nan received a prognosis. While the voiceover is in action we get to see a Punnett square diagram that makes these calculations in terms of percentages after the physical changes that the illness brings forth is highlighted on a hand drawn figure of child afflicted with the disease: we see the change that takes place around the nose and the forehead. As Pidduck notes, soon after it is “[c]ut back to the footage of the Fung family playing in the snow as captioned balloons appear above each figure, designating Richard and Arlene as ‘normal’, their mother, Rita, as ‘minor’, and Nan as ‘major’” (455).

Scientific knowledge is put to question in terms of how the clinical nature of a rational- scientific voice does not reflect the faces of historical experiences behind that which science offers: numbers, figures, and percentages shown on charts. The question of uses and responses to various genres and epistemologies encoded in them is tied to the recuperation of subjugated knowledges in close association with the form of autoethnography. Furthermore, it is not so much an outright rejection of scientific knowledge that seems to be the primary focus in the video, but more of an attempt to highlight interstitial zones where subjugated knowledges reside in their inchoate form in the psychic worlds of the characters. Fung not only shows what Foucault calls the “hierarchical order of power associated with science,” but also maps a “genealogy” of subjugated knowledges as a life narrator—and suggests that this genealogy can only realized by constructing through its brokenness, that is, through the violence that it has encountered in relation to "the coercion of a theoretical, unitary, formal and scientific discourse" (85). Foucault writes:

> [I]n contrast to the various projects which aim to inscribe knowledges in the hierarchical order of power associated with science, a genealogy should be seen as a kind of attempt to emancipate historical knowledges from that subjection, to render them, that is, capable of opposition and a struggle against the coercion of a theoretical, unitary, formal and scientific discourse. It is based on reactivation of local knowledges—of minor knowledges, as Deleuze might call them—in opposition to the scientific hierarchisation of knowledges and the effects intrinsic to their power: this, then, is the project of these disordered and fragmentary genealogies. If we were to characterize in two terms, then 'archaeology' would be the appropriate methodology of this analysis of local discursivities, and 'genealogy' would be the tactics whereby, on the basis of the descriptions of these local discursivities, the subjected knowledges which were thus released would be brought into play. (85)

Working against the hierarchical order of rational-scientific discourse, the liberatory work of genealogy is to reactivate "local knowledges […] in opposition to scientific hierarchisation of knowledges." Genealogies, which are anything but coherent, linear, or validated with the intrinsic power that scientific knowledge has, are understood as "disordered and fragmentary" when mapped as embedded knowledges that form a particular genealogy. Foucault's poststructuralist emphasis and interpretation of notions of "disorder," "fragments," and "play" in the construction of a genealogy is historically animated in Fung's world through the video's "decidedly queer" (cf. Muñoz, 93) use of misalignment tactics. These tactics are not just present to account for multiple perspectives, which they do, but they also offer a glimpse into states of experience that mediate between value-laden forms of knowledge, such as scientific and empirical understanding of illnesses, and knowledges that lie at an affective level, or those that cannot be described without the conditions of their emergence, without their embedded forms of thriving in psychic and somatic worlds of characters. It is the embeddedness of these knowledges that seems to be a highlighted in *Sea in the Blood* because, as Foucault suggests, once released disenfrenchised knowledges are greatly susceptible to be "re-codi[fied] and re-coloni[zed]" by the very "unitary discourses, which first disqualified and ignored them when they made their appearance" (86). Embeddedness of subjugated knowledges and the life worlds in the wake of that subjugation are what we find in the video. For instance, at a point when the narrator describes how as a child he imagined Nan's eventual death, he says he imagined angels coming from heaven to take away Nan's soul. The visual represents what seems like red blood cells under a microscopic gaze (that are splattered across the screen) transforming into a shape of angels, rather little human-shaped figures with wings; they seem to offer a glimpse into a child's imagination. The coalescing of scientific and religious epistemologies and their habitation in a child's imagination in regards to illness and death is telling of processes of subjugation that results in an epistemological violence in this particular perception of illness.

3.5 The politics of "loss" and intercultural cinema

Thus far I have discussed scenes from *Sea in the Blood* in conversation with theoretical and conceptual insights to understand how the image, sound, and text work in the video. I have tried to provide a close textual analysis of the video while situating a critical vocabulary that helps me to engage with Richard the narrator's stories. In this section, I want to discuss the political implications and the interventions that the video makes possible. I will examine *Sea in the Blood* within the economy and aestheticization of "loss" that is a fairly common trope in contemporary cultural productions emerging out of queer and diaspora studies. It is important to explore, however, how Fung's video is conscious of its own conditions of emergence as a text and uses queer as a heuristic to reorient its foundational themes: historical traumas of diasporic and immigrant experiences, domestic traumas around coming-of-age narratives of a queer childhood, and chronic illnesses by representing processes of reading those states of experience.[103] I am suggesting that *Sea in the Blood* is nuanced in terms of its queering of aesthetic practices to represent chronic illnesses because it identifies those named and unnamed traumas related to illnesses in their embeddedness, at intersecting zones of experiences. Embeddedness—forms of attachment to histories around chronic

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[103] But to understand "queer" simply as "the" method is limiting, and not supported by definitions of the term. As Judith Butler writes in "Critically Queer" (1993): "If the term 'queer' is to be a site of collective contestation, the point of departure for a set of historical reflections and futural imaginings, it will have to remain that which is, in the present, never fully owned, but always and only redeployed, twisted, queered from a prior usage and in the direction of urgent and expanding political purposes, and perhaps also yielded in favour of terms that do that political work more effectively. Such a yielding may well become necessary in order to accommodate—without domesticating—democratizing contestations that have and will redraw the contours of the movement in ways that can never be fully anticipated" (19-20).

illnesses—bears a cue in regards to how identifying embeddedness can transform our conceptions of chronic illnesses and their histories. Radical expropriation of given historical conditions vis-à-vis what is deemed as personal narratives to locate the embeddedness of pain that has over time come to be perceived as "chronic" is an achievement of the video that can be hardly be overestimated; through expropriation Richard locates precise moments from his childhood, what they suggest, and the complicated implications of his feelings around Nan's life and death. Significantly, the embedded quality of the meantime is neither ahistorical in terms of a propensity to fetishize the "present" through images nor simply transient; it is, on the contrary, crucial in *Sea in the Blood* to understand the potential of expropriation. To borrow Anne Anlin Cheng's (2000) terms, expropriation in this context may be understood as making collective use of privately held griefs through a sustained commitment to transform those into political grievances. Embeddedness provides a critique of dominant forms of knowledge and their productions and circulations; a focus on embeddedness does not speak to sacralized notions of "trauma" because it *is* embedded—that is to say, trauma understood as too serious to be interfered with and questioned in regards to how it structures given forms of sociality through its sacrosanct positions in cultural life and institutional practices of "remembering" traumatic histories.[104] Quite to the contrary, it shows how the narrator uses transgenerationally received traumas and diasporic losses to speak about disparate things, how he creates links, and sometimes fail to do so. By representing embeddedness, Fung seems to be putting histories of violence in what Gabriele Schwab has called "a dialogical relationship with one another, thus creating a transferential dynamic for those who participate in it, witness, or inherit those histories transgenerationally" (29).[105] Specifically interested in the complicated inheritances of the

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[104] See Naomi Mandel's introductory chapter in *Against the Unspeakable: Complicity, the Holocaust, and Slavery in America* (2006).

[105] In *Haunting Legacies: Violent Histories and Transgenerational Traumas* (2003), Schwab writes: "A model of intercultural transference between different violent histories expands the narrower psychoanalytic notion of interpersonal transference. I am indeed arguing that histories of violence can be put in a dialogical relationship with one another, thus creating a transferential dynamic for those who participate in it, witness, or inherit those histories transgenerationally. Epistemologically, the notion of transference between discourses and narratives rests upon the acknowledgment that discourses have embedded agencies. Those embedded agencies can be the facilitators of transference. In turn, those who engage in these discourses do so on the basis of their own historical memories. In

Holocaust for the descendants of the perpetrators and victims on "the basis of their own historical memories" (29), Schwab's project of bringing texts that discuss "histories of violence"—postcolonial texts, war and refugee narratives, and representations of the *Shoah*—through her emphasis on "intercultural transference." Her understanding of trauma across generation is insightful in terms of how she registers somatic memories of children who do not have "first-hand" experiences of violence but multiply mediated ones. As Schwab writes:

> Children of traumatized parental generation, I argue, become avid readers of silences and memory traces hidden in a face that is frozen in grief, a forced smile that does not feel quite right, an apparently unmotivated flare-up of rage, or chronic depression. Like photography, traumatized bodies reveal their own optical unconscious. It is this unconscious that second-generation children *absorb*. Without being fully aware of it, they become skilled readers of the optical unconscious revealed in their parents' body language (14; emphasis added).

The paradoxes here are profound and crucial to understand how trauma itself becomes "agential" in some sense and reads its material contexts. While the parental generation succumbs to the effects of trauma—the most devastating one being the loss of a capacity to form links and relationality through language (2)—the next generation become "skilled readers" and is enabled to construct narratives around those broken links, where embedded agencies that can facilitate transferential possibilities reside. And the numbing effect of trauma in one generation becomes heightened sensitivity and perception in the following one. I find it important to underscore this mode of thinking about trauma in this autoethnography that, at least in part, uses its own conditions of inception and self-constitution as a practice in order to make sense of the world it finds itself in. How do aesthetic practices respond to cultural tendencies to either "tame" (Farell, 18) trauma, which eventually enables a certain kind of disengagement with trauma? This is not to discount mediated or multiply mediated traumas as "less traumatic" in any way, but to suggest that the spatiotemporal distance that is

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this process, they use intersecting discursive memories as basis of their own transference. If the term 'collective memory' is meaningful, it cannot be in the sense of a common identical memory in service of identity politics. Collective memory rather emerges as an evolving and internally diverse process that unfolds when histories intersect and different participants or agents read them in conflicting ways, especially when they come from the different sides of the divide between victims and perpetrators" (29).

afforded to the so-called second generation "absorbs" (Schwab, 14) a political unconscious that then writes back, so to speak, to the referential returns of trauma. This is precisely a dialectical exchange of repetition and dissociation in the "originary" moment and experience of trauma that others have described in the following terms: trauma, as Ball (2000) suggests, "is the experience or event that broke through the protective barriers of consciousness and startled it into an anxious dialectic between dissociation and compulsory repetition" (2). Mapping this experience across generations, across spatiotemporal distances that trauma, by definition, breaches is productive in the context of *Sea in the Blood*'s expropriative uses of historical griefs to discuss patients' perspective. If trauma means to be "possessed by an image or event" as Caruth (1995: 5) suggests, this quality of being possessed need not be imagined in entirely incapacitating terms; to the contrary, in Fung's video, as the narrator produces a narrative by the fact of being "possessed" by an image or an event "stuck" in diasporic cultural memory, he also repossesses those image and events and recasts them in the meantime. Trauma's referential return then transforms as it undergoes a shift in this narrative; this shift also informs a constitution of a new genre of hybrid and intercultural cinema.

At the same time, it is important to move away from theorizations of trauma in an entirely psychoanalytic mode because Fung's *Sea in the Blood* emerges as a part of a cinematic genre that (even while it speaks of traumas) is involved in certain practices and dialogue formations that psychoanalytic definitions of trauma cannot account for. These are intercultural and hybrid cinematic forms that have specific stakes in interrogating the "ideological presumption" that cinema (irrespective of its form) can readily represent all kinds of historically precipitated realities and, in so doing, also promotes the dialogue of "interculturality" that is envisioned by Fung's creative work and certain strands of trauma theory alike (cf. Marks 1; Schwab 29). This is a presumption that just because cinema primarily speaks through the visual mode and upholds the "representational convention" by working with images does not, for Laura Marks (2000) as well as for directors of experimental cinema that she discusses, mean that cinematic images are in and of themselves direct reflections of realities that they depict. Minoritarian forms and various sub-genres of cinema, Marks argues, have challenged such conventions through diasporic, queer, and multicultural experiences that have clearly stated the political stakes of their experimental forms that aim to subvert practices of documentation and making of documentaries. Thus, although Fung's understanding of attachments, bodily and historical ones, is predicated on absorption and selective uses of historical traumas across at least two generations (as we see in the video) to legitimize griefs around chronic illnesses, those losses, however, are not a part of trauma in an all-subsuming sense that inevitably dissolves structures but have material bases. It is because of this reason that injuries of queer diasporas and broadly around intercultural and transferential issues cannot be recast in terms of a psychoanalytic language that some branches of trauma theory have tended to do. This is largely because the individual model of psyche that psychoanalysis tends to valorize cannot explain the proliferation of collectivity or collective negotiations and uses of trauma in *Sea in the Blood.*[106] Fung's narrative consistently refers to identity formations of groups such as queer diasporas, HIV-positive gay men, and, of course, people with chronic conditions in general. While the video is about personal family narrative, it is about group identity formation, so it is imperative to understand the dynamics of collectivity and how the video is part of a larger movement that grew out of collective needs and desires to come to terms with experiences of some of the aforementioned groups.

A productive way to think about these intersecting issues that *Sea in the Blood* discusses is to consider the emergence as what Marks has called "intercultural cinema" and its uses of embodied forms of knowledge (2000).[107] For Marks, the term intercultural is not a rigorously conceptual term; in fact, she agrees with the view that the conceptual work of intercultural issues is better done with terms that have had a great deal of uptake over the last

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[106] To be clear, Gabriele Schwab's and Naomi Mandel's arguments suggest a considerable emphasis on moving away from strictly psychoanalytic versions of trauma and transference to more cultural explanations. Also, see Lily Cho's critique of Anne Cheng's notion of "inheritances" of racial grief (Cho 428), although Cho does not explain why the notion of "inheritance" is problematic because of its essentialist overtone, especially given that partiality of recovered memory is consistently worked out in Cheng's formulation of "racial grievances."

[107] According to Marks, "Intercultural cinema is a movement insofar as it is the emerging expression of a group of people who share the political issues of displacement and hybridity, though their individual circumstances vary widely. On the one hand I see this movement eventually leading to significant changes in the politics and poetics of representation at a broad cultural level. On the other, I recognize that many of these works are quite ephemeral, and I wish to celebrate them at the moment of their brief flowering" (2).

few decades in cultural theory, such as, “minority”, “marginal”, “antiracist”, “multicultural”, “postcolonial”, and “hybrid” cinemas (6). But what the term intercultural makes possible is that it allows us to do address the diverse concerns of experimental cinema that speak of the presence of multiple cultures while examining flows and transmissions among them. Not only does the term suggest the cultural product as not referring to any one context, by highlighting hybrid zones, it is also equipped to historicize cultural processes and critical purchase of the thematic concerns in a compelling way. Offering an analysis that “assumes the interestedness, engagement, and intelligence of its audience” (19), hybridized and intercultural cinema’s contestations over knowledge claims of various subgenres is not done quite in the spirit of paranoid mode of criticism that places its only goal in unmasking ideological presumptions even though they often begin with that task; through its patient and nearly archaeological work of making soon-to-be or nearly forgotten traces of states of experience hybrid forms of intercultural cinema strive to reach out to forging collectivities. As Marks writes, “[s]creenings of intercultural cinema witness the building of an audience, often from surprisingly disparate individuals” (19)—and in so doing, “[f]rom the traumatic dislocations of culture and efforts at remembering, ‘newness enters the world’” (cf. Bhabha qtd. in Marks, 5). Discussing the trope of loss in hybrid and intercultural cinema, Marks writes:

> [I]t is the product of a process of mourning, a search for loved ones who have vanished and cannot be recalled with any of the means at the artist’s disposal. These loved ones may be people, places, or even ways of inhabiting the world. The grief may be individual or widely shared, but in these films and tapes it becomes a collective experience. (5)

There are multiple lines of inquiry here in regards to Fung’s video, but to my mind the most important feature of hybrid cinematic forms in Marks’s conceptualization that resonates with *Sea in the Blood* is this subgenre’s ability to generalize from a specific set of experiences and vice versa, which essentially speaks of a constant movement, a dialectical process that conveys an idea with which intercultural cinema is conceived and practised. More specifically, intercultural cinema suggests a public practice of speaking of inner lives and stories of losses that need to be mourned. Through the specificities of an intercultural film a collective experience comes to be recognized in ways that suggest communal griefs have a public life and dynamic forms of representation to speak of those griefs can trigger and sustain the public nature of their historical presence. Intercultural cinema does not, however, ontologize griefs and losses in terms locating their "causes" or how grieving subjects are determined by their specific conditions. Through its investments in aesthetic practices such as queer autoethnography, tactics like misalignments of textual matter, and expropriations of traumatic history it investigates the makings of what Sara Ahmed understands as "surfaces" and, like Marks, also discusses through the metaphor of a "skin" (24). Ahmed writes, "It is through sensual experiences such as pain that we come to have a sense of our skin as bodily surface […], as something that keeps us apart from others, as something that 'mediates' the relationship between internal or external, or inside and outside" (cf. Ahmed, 24). The deployment of griefs in these cinemas in general and Fung's video in particular is something akin to such an understanding of the internal and external, inside and outside, and public and private divides: it shows how forms of attachment to histories of privately held grief sediment into experience as a surface, or what Marks refers to as the "skin of the film." The focus on stylization in *Sea in the Blood* is then of immense significance to distinguish itself as not a documentary on various aspects of diasporic and queer lives, but to observe how griefs make surfaces and structure experiences around those (un)documented surfaces. As Ahmed writes:

> [I]t is through the flow of sensations and feelings that become conscious as pain and pleasure that different surfaces are established. […] It is through such painful encounters between this body and other objects, including other bodies, that 'surfaces' are felt as 'being there' in the first place. To be more precise, the impression of a surface is an effect of such intensifications of feeling (24).

The production of a surface is confirmed by the impression it emanates when our intensified feelings bump up against those surfaces. The "surface" is where the pain surfaces but not the surface itself, so naming the surface does not find much significance in intercultural cinema but the subject's arrivals at those moments of contact with the surface do. In other words, when the surface becomes palpable and when does it get defamiliarized in the subject's encounters with it is of importance in this kind of storytelling because this genre of cinema is invested in making collectivities through expropriation of largely private griefs. *Sea in the Blood* as a queer autoethnography of those surfaces that are too familiar to be recognized but are registered in relation to the sensations and feelings that emerge at their encounters. The narrative begins with a description of what I understand as a "surface" that is then reviewed from different points of view, points that the surface itself is positioned to belie. For instance, while showing a picture of himself as a youth in his early twenties, Richard the narrator tells us, “This is me,” and goes on to talk about his excitement of having joined an art school in Toronto, having moved out of his family home, and living alone for the first time. His meeting with Tim and his affection for him are conditioned by these formative experiences, and when he goes on to say that, unlike Tim, who has travelled widely and has been a political activist for years, “this is all new to me,” we begin to see the narrative assuming the work of auto-ethnography by showing how surfaces, states of experience come into being and participate in what can be called a world-making project. The focus on these surfaces, the outermost layers of experience are not flat, however; to the contrary, they reflect the uneven distribution of griefs, pains, hopes, and joys through which surfaces—in this case a photography on the screen—are constructed. These surfaces are important to be recognized through their unevenness that produces them because intercultural cinema is largely dependent on its audience to “complete” itself (Marks, 20), which is through processes of (dis)identification with construction of surface itself. Through an attention to surfaces of different experiences, cinema of hybrid forms like *Sea in the Blood* speaks to its audiences, who, as Marks suggests, have a “more proprietary relationship with the works than do audiences of commercial cinema” (20). The attention to formation of surfaces and how they are constructed also allows cinema of this genre to refine its understandings of “hybridity”: hybridity for intercultural cinema is, thus, not simply the presence of multiple forms of but situating hybridizing narrative tropes in relation to the inherent differences they bring forth. In so doing, it reflects upon diverse modalities of hybridity. In *Sea in the Blood*, we see the different implications of these hybridizing narrative structures through shades of queer diasporic griefs and momentary arrivals of joy and hope.

4.6 Conclusion: towards the possibility of a medical ethnography

I want to return to the issue of cultural discourses (of “loss,” for instance) shaping engagements and encounters with the patient’s perspective. As we see in the story in *Fearless*, if reflective pain of PTSD can tap into cultural discourses in its struggle to be alleviated from pain, how does this interaction sit with the material contexts that “pain” finds itself in? In a video text like *Sea in the Blood* where this perspective can largely be gleaned from its reflections of someone who directs a video on having experienced it as a survivor of a queer childhood, a caregiver, and a medical ethnographer, it defeats the purpose of our engagement if we do not read such narratives both with and against the grain of its narration. As Leigh Gilmore (2001) suggests, "it is important to notice how against-the-grain engagements at the limit of autobiography reveal those limits in ways that more conventional autobiographies obscure" (13). Fung's autoethnography is itself an against-the-grain engagement with the notion of a "conventional autobiography," so in breaking away from the conventions it has had to amplify its stylization of its narratives of historically precipitated pain. But if Fung's autoethnography is a necessary betrayal of conventions of autobiographies, what are the implications of this turning away from a dominant model of autobiography for the intersecting definitions of "autoethnography" and "medical ethnography" it produces in the process of this turning, that is, in the meantime of this moment of turning away from a dominant genre?

I have highlighted, in this as well as other chapters, that all mediated, incrementally sustained, and transgenerationally inherited traumas are traumatic (cf. Hirsch 2012; Schwab 2010). In order to engage with the effect of such mediations and how they are circulated and absorbed in concepts of "engagement" with the patient's perspective however, we need to focus on the zones of interrelationships. Thus, what are the connections between Fung's medical ethnography of others and his autoethnography? We have in the video Fung the narrator who lives close to illnesses, Fung the auto-ethnographer of his queer childhood, but also Fung the medical ethnographer of other people's illnesses that he is shown to "live with." This position complicates our engagement because we get a glimpse of lived experiences of thalassemia and HIV from someone who does not experience these conditions first-hand but observes and narrates it from the point of having his vocation as a professional video artist, essayist, cultural critic, and an academic. I don't have any easy answers for these complicated subject-positions that one frequently encounters when working in the field of life writing, but I am certain they cannot offer us any clear verdict (if one is looking for one) on a scale of "complicity" and "innocence." At the same time, it is important to highlight that in the last two chapters I have examined narratives written by sufferers and survivors of chronic illnesses like endometriosis and domestic traumas, which are also not without their own unique intellectual histories and politics of representation. Hilary Mantel was already a literary success when she chose to write her only memoir till date in 2003 and published it with the media mogul Rupert Murdoch owned publishing house, Harper Collins (cf. Rak 135); and Dorothy Allison, having studied anthropology at the undergraduate and graduate levels, was well-versed in ethnography before she turned to writing her first semi-autobiographical novel set in her native town of impoverished Greenville, South Carolina, *Bastard* (cf. Behar 2009). Thus, I want to ask: what does this mean for our methodological practice as readers of life writing narratives who are interested in deriving multiply mediated definitions of "engagement" to examine how sufferers and those who live close to suffering narrate their experiences, which, in turn, could supplement notions of engagement in other epistemologies? What kind of an engagement is needed for a producing a medical ethnography of others' pain?

Without taking up the self-righteous task of offering solutions, of which I have none, I want to suggest a modest proposal: *mapping cultural discourses* in the spirit and pursuit of an intellectual transparency to "believe", to use Ruth Behar's term, in (auto)ethnographic projects "as literature." This would mirror how we believe in stories in terms of all their complications, complicities, and the life-worlds they depict (cf. Behar 2009; Couser 2004).[108] If autoethnography can be literature then literary narratives can accommodate without domesticating the tensions between Fung's medical ethnography of others and his queer life narratives. This kind of a "believing in [a form of writing] as literature" which is generated through elaborate aesthetic strategies in memoryscapes, childhood narratives, and referential returns of trauma in what is remembered through others, derived from interviews, and dialogue allows us to think through various subject-positions on a spectrum. This is particularly important in regards to *Sea in the Blood.* The exercise of mapping discourses in medical and (auto)ethnography to gauge the specific valence of engagement hopes to reposition narratives in relation to the discourses of engagement they speak to while interrogating those discourses. We could do this by listening, by examining descriptions, imagining where these descriptions go and come from, what kind cultural scripts they borrow from and, in turn, contribute to. It is through such a mapping that we can appreciate the force of these narratives. Mapping, in part, corresponds to the notion of "radical dispersals of

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[108] See G. Thomas Couser's *Vulnerable Subjects* (2004) on the importance of anthropology's ethical guidelines for life writing projects, p. 15. Also, see Ruth Behar's "Believing in Anthropology as Literature" (2009).

structures of subjectivity" (cf. Hutcheon 1989: 168) and enables us to examine where and how these structures of subjectivity intersect to tell a story. On the other hand, the intersections and interrelationships of these structures are not abstractions evacuated from specific experiences but are lived as worlds apart: the narrative persona of Fung who has "lived close" to illnesses, and the medical ethnographer and a professional video artist who views a collective set of experiences from behind the lens of the camera and one who has the director's ability to say, "cut!" Ultimately, constructing a map that also circumscribes this narrator, his directorial prowess, is important to engage with his narratives meaningfully and not to discount these narratives in search of a fetishist pursuit of an innocent position of Fung's "autoethnography"; rather, it is to understand what Thomas Couser calls the importance of the "fiduciary relationship" between life writing collaborators such as Fung the narrator when he discusses Nan's and Tim's illnesses with members of his own family (cf. Couser, 17).[109] From a medical ethnographic standpoint, *Sea in the Blood* suggests at once a crisis and need for ethical imperatives that this field demands. The video's meantime raises the question of an audience—this is not just the erudite audience of intercultural cinema but the ideal audience who could engage with the life narratives, and, in so doing, perhaps, offer us a cue in regards to what kind of an engagement does pain as embedded in *Sea in the Blood*'s medical ethnography demands. As Behar, an anthropologist, writes in "Believing in Anthropology as Literature", "My mother is the only reader I ever see in my mind when I'm writing. […] I am very aware that I had to turn away from my mother in order to become the person I became. But I suffer bouts of imposter syndrome" (111). In this formulation, an ethnographic description hopes, even if in vain, to engage with the linguistic debt to the figure of the mother when it constructs itself. Significantly, this engagement is not meant to get rid of the debt but *stay indebted*. This is the (im)possible ethical horizon of ethnography, which it gleans from literary narratives (cf. Behar, 111). It is also a horizon that Fung's auto-ethnography in its hubris of a "decidedly queer" (cf. Muñoz, 93) form attempts to live up to but it is should be possible to suggest that it does not, it cannot.[110] This is because to get over

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[109] G. Thomas Couser defines this relationship as "relationships of trust akin to those between physicians and patients, in which 'the benefit to one party is maximized by leaving that party vulnerable to being taken advantage of by the other'" (17).

[110] Muñoz writes, "I would also suggest that we might understand the actual storytelling practice of

this linguistic debt to the figure of the mother or even to think in terms of such a possibility is to look for a "ratio of exchange" in the hope of being freed from the ethical obligations of narrating a medical ethnography and writing about other people's pain (cf. Readings, 188).[111] Like all intellectual projects constituted under the aegis of institutionalized rhetoric and technical language, Behar suggests, ethnography might never sustain the (im)possible ethics of being able to fully communicate what one "sees" in an ethnographic locale and what one receives as "knowledge" to its ideal audience: a mother. To be sure, anthropology as discipline, as Behar indicates, however, is predicated on ontologizing the figure of the mother in terms of "a mother", whereas postmodernism of a particular stripe that deliberately refuses any political purchase tells us that the linguistic debt is a notion that is related to the "figure of the mother." We can avoid an impasse, however, if we go by Linda Nicholson's notion on what she calls "social postmodernism," which would suggest that *Sea in the Blood* generates "a discourse that recognizes itself as historically situated, as motivated by values and, thus, political interests, and as a human practice without transcendent justification" (80-81).[112] In this way, we may be able to hold on to Fung's project without wholly essentializing his "autoethnography" or negating its instructions—and failures—in relation to its medical ethnography of others, especially in regards to Rita Fung. Thinking of *Sea in the Blood* as a literary text in distinction from its autoethnographic impulses is then useful to derive a robust ethics for medical ethnography and engaging with others' pain. This ethics is also important when engaging with subjugated knowledges of politicized patients and their perspectives in a medical ethnography.[113] From a postmodernist standpoint, however, the ideal reader, the

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the film, the not-lining-up of image, sound and text, as something that is decidedly queer about Fung's production. This not-lining-up of image and sound is a deviation from traditional documentary, which is chiefly concerned with sound and image marching together as a tool of authorization" (93).

[111] For a brilliant reading of the notion of "social bond" and the fact of an "obligation to others" that can only be negotiated in language, see Bill Readings's *The University in Ruins*, p. 188.

[112] See Linda Nicholson's "Feminism and the Politics of Postmodernism" In: *Feminism and Postmodernism* (1994), pp. 69-85.

[113] Also, see Gayatri Gopinath concept of "impossible desires" and queer subjectivity in *Impossible Desires* (2005).

figure of the mother, is elusive because our institutionalized and jargon-inflected forms of writing and telling stories are imaginably off-putting for her. This kind of writing is not worth her attention, her time, and her engagement; at the same time, this is the engagement that medical ethnography needs to strive for—mimic. This is the attention of the mother towards her "sick child," an attention that engages with the notion of the mother figure in relation to its self-constitutive linguistic debt to this figure, and hopes to produce a counter-narrative of "staying indebted" in a way that is worth her time to listen to, to engage with. But medical ethnography nevertheless has to persistently encounter with this impossibility through its practice, that is, in spite and because of its failures. *Sea in the Blood*, then, perhaps can be productively interpreted in working through such tension between its desire for medical ethnography of others, and a "decidedly queer" auto-ethnography that falls short of a committed engagement at certain moments when it depicts others' illnesses. Without dismissing Fung's project, we may understand this aspect of the video as its constitutive performative contradiction.

The discourse of "loss", particularly queer losses as they intersect with the narratives of thalassemia by Fung's mother and sister and heteronormative familial griefs in general, which haunts *Sea in the Blood*, I have suggested, is a rhetoric that we need to sift through to engage with the patient's perspective. It is perhaps for this reason that a focus on the "meantime" or the highly stylized time between two shots, the time between when the e-mail scripts roll across the screen, the stylizations around the time between Nan's final diagnosis and Tim's impending death that is important. They are important because these moments perhaps, and imaginably, struggle to speak to the ideal audience, which, according to *Sea in the Blood* as well, is Fung's mother, Rita Fung—someone he repeatedly turns to. Rita is interviewed throughout the video; we see her ageing hands tending to plants in her garden while answering her son's numerous questions. Fung's need to know about the last moments of Nan's life requires answers, even though there was twenty-year old silence about this event between the mother and son. Thus, one wonders, and rather naively indeed, if Rita's ageing cognitive abilities can catch up with the nuances that Fung the director works with and produces in the space of the meantime. The baroque stylizations and the "decidedly queer" aesthetics, at least in part, risk losing the attention and engagement of certain subjects of illness and entropy. This loss is of profound significance for Fung's medical ethnography when the subject of entropy is Rita Fung.[114] This loss for medical ethnography is something that discourse of "loss" in diaspora studies on Fung's work is yet to fully recognize and reckon with. But again, that is not the point for dismissing Fung's work but take its failures seriously, that is, as instructions for the risks, complicities, and pitfalls of engaging with other people's pain even when they are related to one's "own." This is also the inescapable complicity of Fung's much celebrated "autoethnography," and how it intersects with his medical ethnography of others. As theories of visuality and public cultures have suggested (Marks 2000), the spectacular passages of the meantime possesses the erudite audience of intercultural cinema who gives meaning to this time, but the meantime is also an apprentice to subjugated knowledges of patients and caregivers. Thus, we need to engage with this passage of this time carefully and even compulsorily to understand the ethical ramifications of this medical ethnography.

Finally, the meantime helps us to distinguish between different implications of "loss." It allows us to understand "loss" to be a somewhat slippery term that reveals little about what exactly is lost, and even when used in the context where precise historical losses have happened. It is never an easy answer whose loss we are talking about—Nan's, Arlene's, Rita's, Richard the narrator's, or the loss in relation to (im)possible ethical horizon that needs to be retained when autoethnography attempts to disaffiliate itself from a more conventional autobiography, which is a genre that Rita provides when she discusses Nan's illness and her life and death. On the one hand, I find the recalcitrant opacity of this term is productive to talk about a range of losses that cannot be named and thus cannot be easily mourned but needs to be processed; and, on the other hand, I worry that it's susceptible to inaugurating a disengaged climate of interpretation perhaps even without wanting to do so. At the same time, "trauma" itself is a difficult term on many counts and, as John Mowitt suggests, it is deeply reliant on its "study" because it is through the study of trauma that it receives a "voice" of sorts (278). Significantly, as Mowitt and Ahmed suggest, trauma, like pain, necessitates a "structure of capitalization" and leads to over-representation in terms of themes

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[114] We may understand this dynamic in queer theory in terms of what Jack Halberstam calls "queer betrayals" in his essay "Queer Betrayals" (2013). See *Queer Futures: Reconsidering Ethics, Activism, and the Political.* But while queer theory risks exculpating this position because of its focus on queer subjectivity, albeit in all its complications, medical ethnography and life writing on patients' perspective must dwell on these ethical conundrums, however impossible they may be.

in cultural productions, whereas loss has a propensity to usher in a potentially disabling attachment to the concept of loss because it cannot quite specify its losses, or at least tends to lose sight of it in the course of its own emergence through various discourses that it easily sticks to, and those that inherently sticks to a particular notion of "loss." The term itself gets murky when used as a catchall term that is not commensurate in regards to patients' narrative in this medical ethnography. This is why I have tried to suggest the narrative of queer losses intersects with the patients' perspective and needs to be carefully examined. We may say, with a focus on journeys, returns, and arrivals in the video, this meantime, however, unsettles any monolithic concept of "loss." In so doing, the dialectical engagement with complicated reflections on loss is worth thinking about. The meantime views the emergence of the politicized patient of illness narrative and how her stories and narratives that emerge from those around her could be engaged with from the perspective of new knowledges and experiences of unknown illnesses that were not recognized in Western medicine at certain points in history—AIDS and thalassemia. The presence of these knowledges in representation in a video narrative enables the emergence of the politicized patient in intercultural cinema. Their presences also allow us to speculate what an ideal medical ethnography and its engagement with its subjects of illness would be like. The exploration of various intersections between "medical ethnography" and "autoethnography" in *Sea in the Blood* is important to situate historical griefs of diaspora and medicalization of race, sexuality, ageing and entropy. *Sea in the Blood* invites us to do this.

Conclusion—Reading as Repair Work

The desire of a reparative impulse, on the other hand, is additive and accretive. Its fear, a realistic one, is that the culture surrounding it is inadequate or inimical to its nurture; it wants to assemble and confer plenitude on an object that will then have resources to offer to an inchoate self.

Eve Sedgwick, "Paranoid Reading, Reparative Reading" (2003)

At this point I am beginning to sense a tedious and imaginably off-putting earnest tone of my analysis. It is tedious to me because it tries to "think" of human suffering and chronic illnesses of others from multiple perspectives so that it can resist being called out on having missed or misinterpreted any perspective. Paranoia, as Eve Sedgwick, the late queer theorist and historian of the HIV epidemic in North America, taught us, is an anxiety that tries to anticipate what may come from the other—its "future-oriented vigilance" is meant to eliminate all "bad surprises" (130). Although Sedgwick famously criticizes this affect she does not ask us to abandon it; rather, she reminds us that paranoia in itself, that is, as practised in literary criticism under aegis of "hermeneutics of suspicion", cannot enjoin us to "any specific train of epistemological or narrative consequence" (124). We need a concomitant effort to make time for reparative critical practices, or a mode of thinking and feeling that allows us to affirm ourselves, add to what is already known, be surprised by the text that one reads and be subjectively undone and redone with the quality of that surprise. Why am I saying all this? And what do these things have to do with the last few pages of this text where I should not, as the protocols of the genre demand, introduce new ideas? I want to assure my reader I am not about to.

Between the issue of a staid paranoid impulse and a reparative reading that could balance out this impulse is the shared understanding that "the culture surrounding [the possibility of a repair work through reading practices] is inadequate and inimical to its nurture." While paranoia, with its quintessential "trust issues" succumbs to the wounds of the given culture, the reparative mode of reading, too, yields to this violence but is not defeated by it. Instead, the reparative mode attends to different layers of the text, reads it anew each time to attribute new meanings to it, and in a way that allows one to ward off the more than unfriendly blows from what Sedgwick calls the "surrounding" culture.[115]

We need to remember here that Sedgwick, who succumbed to breast cancer in 2009 at the age of fifty-eight, wrote about the possibility of this anti-homophobic reading practice in relation to the HIV epidemic. The fact that homosexual men died due to this disease because it remained "contested" (Epstein 1996; Treichler 1999) in the views of the medical and political establishments in the US and Canada for a long time, and because it was a disease that, at least when it broke out, largely affected gay men lead Sedgwick to theorize "reparative practices." Simply put, she means that reading and interpretative practices in the wake of such a cultural homophobia needed queers and their allies to be kind to themselves and each other. This is because "knowing" that the medical and political establishments deliberately neglected recognition and treatment of a disease because it disproportionately affected gay men is a "poisonous knowledge"; it is one that the LGBTIQ community has internalized to such an extent that they were effectively robbed of their capacities to repair themselves and offer a productive criticism of the status quo. This is an irrevocable trauma that needs a space and time of nurturing its wounds in a way that teaches us queers to be kind to ourselves and others—empathize. Such a criticism would offer something anew, which would not be confined to the "fact" of the knowledge that the LGBTIQ community was harmed because they are a sexual minority; instead, it would challenge dominant forms of knowledge formation from a minority standpoint. Significantly, however, the gift of reparative reading and what it can do is meant as "resources to offer to an inchoate self" (149). This imagined self is not just members and allies of the community but "an other." It is in relation to this "inchoate self" who is need to be "nurtured" through repair work that I have tried to think of slow engagement. It is a repair work that demands this kind of an engagement, one which enables us nurture to multiple inchoate selves.

In this dissertation I have tried to engage with this inchoate self. I still don't know what Sedgwick means by this term, what this self's ontological address is, and what kinds of social chronicity shape her experiences. But I have been curious to learn forms of inchoate

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[115] This also, in part, the notion of "growing sideways" (Bond Stockton 2009) that I have discussed in the second chapter.

experiences of illness that Sedgwick's queer theory enables us to engage with. Doing this has been important for me as a health researcher and as a queer, able-bodied, cis-male person of color who is interested in understanding the intersectional aspects of identity's given constructs, and how one approaches autobiographical narratives that speak through similar complications of lived experiences. One way in which I have tried to situate this inchoate self in need of resources in the texts I have read is by thinking of this self in terms its literally "rudimentary" quality as suggested in the figure of the child: an incapacitated figure due to a particular social history of grief (Allison); violently infantalized in the face of sacrosanct and godlike power of the medical establishment (Mantel); and revisiting a queer childhood to make sense of a psychic health of one's self and that of others (Fung and Allison). The presence of this elusive figure, Sedgwick's inchoate self, in a way forms the rationale for the texts I have selected and the order in which I read these. Let me explain.

I began this dissertation discussing issues in health and medical humanities where disciplinary lines are strictly drawn along the lines of some very significant questions: who speaks for whom? And, whose suffering and whose health are being considered in narratives? The need to ask these questions in life writing studies can hardly be overemphasized. Also, the fields of health and medical humanities are challenged by varied subject positions that produce narratives for very different reasons: largely to come to terms with a violated pasts in the wake of illness (Hawkins 1993), to understand what is "health" in relation to what is perceived as "the medical", but also to "purge" oneself (and seek sympathy in our estimation) of what one sees and goes through during a surgery or while talking to an afflicted subject from the standpoint of an health provider, a "doctor." Furthermore, from a historical point of view, we have had health researchers conducting ethnographic research on communities that have considered the word "research" to be something akin to an offence, "dirty" (Tuhiwai Smith 1999; Tallbear 2013). In short, the fields of health and medical humanities in relation to autobiographical narratives are riddled with hard ontologies. And not highlighting these issues would be a terrible mistake. Yet, autobiographical narratives play with signification and offer complicated portrayal of suffering with chronic illness (Mantel), caregiving and tracking diverse histories of grief and health in childhood (Fung), attending to pasts where embodied shame and trauma predominate (Allison); thus, reading these texts have been crucial to see how subjects of chronic illness make meaning through their experiences.

In engaging with the face of suffering with chronic illnesses, and given that the fields of health and medical humanities require us to think on what basis are “diseases” and “disabilities” identified and defined, I have tried to think of the narrative’s grief, its materiality, and how it can be tracked through a slow engagement. In so doing, my primary focus has been sufferers who provide an account of grief and produce a patient’s perspective. Hilary Mantel’s and Dorothy Allison’s narratives are read in this spirit. Fung’s work is read in a different light: he, too, is a face of suffering, but his narrative positions him as recording the health griefs of his deceased sister Nan from others’ narratives, his partner Tim’s life before and after his diagnosis with HIV, his mother’s illness and ageing, and his own accounts of his sister’s and partner’s illnesses. My attempt at thinking of his work in terms of the complexities of the position of a “medical ethnographer” of his family members is both a reminder of the health humanities perspective that asks us to consider hard ontologies that are indeed hard to be ignored in relation to the fields I refer to. At the same time, I borrow from Fung’s desire to engage with an “inchoate self” (not just his own childhood self), which is deeply related to other bodies and narratives.

A notion of an inchoate self is then helpful for me to discuss how slow engagement could be deployed. This project thus would like to move on to working on similar issues where people take incalculable risks to talk about their pasts and others’ pasts while trying to touch the opacity of inchoate selves. At the same time, without fretting over a less productive question of who is “really” suffering, this project nevertheless remains somewhat biased towards first-person accounts from subjects of illness, when available, over those that are not. In this, I am guided by Sedgwick’s idea that we do not need to “get over” our hermeneutics of suspicion and paranoid tendencies, but perhaps through a slow engagement wonder why we take recourse to this mode of interpretation when we do, what bothers us about a particular narrative, and why our feeling of discomfort needs to be highlighted to further illuminate the health and medical humanities points of view.

This project concludes with the idea that interactions around health issues, of people telling their health stories and pasts both to themselves and others who learn these through interviews and such means, are incredibly risky endeavours. And this is an endeavour that health and medical humanities have to take. The danger of hurting oneself (through narration) and through engaging with others stories is high, but it is a risk that is worth taking. I am referring to Fung’s narrative, of course, but also to more traditional autobiographies that I have read because, as we know, a narrative does not guarantee a recovery in the way we imagine it (Eakin 1999), not always, and in this way a committed engagement that we find each of the texts that I have read is important to be examined. A new politics and practice of reading and repairing that I have tried to imagine hopes to lessen and perform the kinds of repair work that I have discussed thus far.

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