



University
of Exeter

**Out of Time: Temporality, Form and Fugitive Care in Contemporary Literature
and Culture**

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to the University of Exeter as a thesis for the degree of
Doctor of Philosophy in English
June 2023

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A handwritten signature in black ink, appearing to read 'K Anucha', written over a dotted line.

Signature:

Abstract

Much of the scholarship on narratives of illness and death proceeds from the assumption such accounts offer universal insights into the human experience. This thesis challenges this assumption, highlighting the occlusions produced by dominant disciplinary and narrative approaches. This project recognises the ways in which those living lives conceptualised as ‘ungrievable’¹ and deathly are concealed by and yet support dominant narratives of dying.

Focusing on experiences of the end-of-life in an extended contemporary period (1990 – present), and beginning with narrative form, this project moves outwards to consider what insights other genres might offer to understandings of illness and death in contexts of temporal incommensurability. I argue that an experimental orientation to genre disrupts and offers critical purchase on representations of death outside of normative temporality and normative embodiment. Indebted to and building upon formulations of fugitivity originating within Black studies, this project develops the concept of fugitive care, the ever-shifting offers and practices of care that exceed institutions of science, medicine and policing, arguing that experimental form foregrounds such practices.

I draw on queer theory to explore dying that is conscious of a fraught relation to the linear progression of the life course, tracking the relationship between cancer and HIV/AIDS and formulations of kinship in Kathlyn Conway’s *Ordinary Life* (1997), Ruth Picardie’s *Before I Say Goodbye* (1998), Gillian Rose’s *Love’s Work* (1995) and Eve Kosofsky Sedgwick’s *A Dialogue on Love* (1999). Thinking with Édouard Glissant’s notion of ‘opacity’,² I consider the double-bind of aspiring to legibility/visibility for the sudden deaths and the slow attrition of living while Black under the conditions of late capitalism in the US, through readings of Edwidge Danticat’s *Brother, I’m Dying* (2007) Jesmyn Ward’s *Men We Reaped* (2013), Harryette Mullen’s poem ‘All She Wrote’ from the collection *Sleeping with the Dictionary* (2002), and Claudia Rankine’s epic poem *Citizen* (2014). Finally, responding to the conceptualisation of the ‘undying’ and ‘Zombie time’ within poet Anne Boyer’s and artist Martin O’Brien’s work respectively, I also consider the intersection between chronic illness and ecology in a time of

¹ Judith Butler, *Frames of War: When Is Life Grievable?* (London; New York: Verso, 2009), p. 24.

² Édouard Glissant and Betsy Wing, *Poetics of Relation* (Ann Arbor: University of Michigan Press, 1997), p. 49.

environmental crisis increasingly and ambivalently conceptualised as apocalyptic, reading across Susanna Antonetta's memoir *Body Toxic* (2001) and Jesmyn Ward's novel *Salvage the Bones* (2011).

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Acknowledgements

Thank you to my supervisors Laura Salisbury and Jana Funke, I am so grateful for your insight, advice and encouragement. I would not have reached this point without your guidance and confidence in me.

Thank you to the Waiting Times team, Lisa Baraitser, Jos Catty, Stephanie Davies, Michael Flexer, Martin Moore, Martin O'Brien, Jordan Osserman, Deborah Robinson, Elena Shampanova, Raluca Soreanu and Lizaveta van Munsteren. You have made the experience of research incredibly enriching and rewarding through your critical and practical support, and your kindness and friendship.

Thank you to the research community at the Wellcome Centre for Cultures and Environments of Health, with a special mention to the administration team for their indefatigable logistical and institutional support. I am grateful also to Lara Choksey for championing my research and providing me with opportunities to develop my work. I would be remiss not to mention the incredible privilege it has been to embark on my research with such an excellent PhD research cohort. Veronica Heney and Jessie Stanier it has been a pleasure to think with you. Thank you for being my community in Exeter.

Thank you to the members of the Black Health and Humanities Network, who have helped me expand and consolidate my thinking and offered a deeply appreciated form of community over the pandemic.

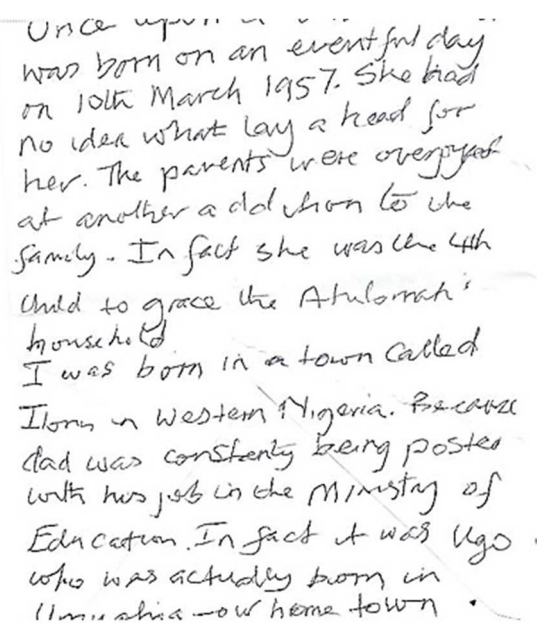
I am grateful to the team at Hospiscare who welcomed Michael and I as we undertook engaged research at the day hospice. It was an honour to spend time with the service users who participated in our storytelling sessions and a brilliant way to learn more about the histories of Devon (and beyond!)

I am eternally grateful to my extended family whose love and care has sustained me over the course of this thesis. Thank you, Hannah, for your consistent friendship and unfailing kindness, you know how much it has meant to me. Thank you Uncle Chik, Auntie Debbie, Rach and Grace for being my home away from home in the South

West. Thank you Koochi, you have been a professional and personal inspiration to me, always motivating me to keep going. Thank you, Daddy, for your boundless faith in my abilities, your practical support and your grounding presence. Ebs and Ogs, I do not have words to express how much it has meant to have sisters like you, thank you for your affirmation, care and love. Finally, Mummy, what an honour to know you. It is my dearest hope I make you proud.

Preface

My mother's green handbag was among the personal effects which returned home to us after she died. After sixteen years the contents are still basically undisturbed. The bag contains a stick of mascara, her appointment diaries and address books, NHS hospital appointment cards, her driving license, a checkbook, some old receipts and other papers – permission slips for school trips, old envelopes – and some information brochures on chemotherapy, repeat prescriptions and coping with hairloss. On the back of one of the empty envelopes are a few sentences written in her handwriting. The writing is uncharacteristically untidy, as if she was writing quickly, or perhaps as if her hands were shaking. She has written about the day she was born, who her parents were, where they lived and her siblings. It looks to me like what might have been, or become, the beginnings of a memoir, although I cannot know with what intention the words were written.



Once upon a time
 was born on an eventful day
 on 10th March 1957. She had
 no idea what lay a head for
 her. The parents were overjoyed
 at another addition to the
 family. In fact she was the 4th
 child to grace the Atulomah's
 household.
 I was born in a town called
 Ilorin in western Nigeria. Because
 dad was constantly being posted
 with his job in the Ministry of
 Education. In fact it was Ugo
 who was actually born in
 Ilorin, which is now home town.

I had not thought about that envelope for a very long time, but it seems obvious to me now that this thesis is about what it meant to find that scrap of paper with its abbreviated gesture towards a personal narrative. I admit that it is a part of what has compelled me in my reading of the many cancer narratives I have encountered over the course of this research. I hoped that I might find a version of her story somewhere, improbably, miraculously complete. However, while I was deeply moved by much of what I read, my mother – or a version of the kind of woman she was – remained missing from most popular accounts of cancer and terminal illness.

Reflecting on the narratives I encountered, I began to wonder about their form and structure, their affective charge for readers like me, the bereaved, or for the dying themselves. I wondered how I was reading them and about the kind of reading they invite, how they are perhaps consumed rather than read, generating a particular textual appetite. I found myself thinking about my mother's envelope and about other absent and unfinished narratives.

This thesis is much indebted to the thinking of Saidiya Hartman, a scholar whose work and methods centre on the question of the absent or abbreviated record and the incomplete or missing narrative. Her book *Lose Your Mother: A Journey Along the Atlantic Slave Route* (2006) is about the search for a missing lineage which begins with a break of sorts with her biological mother: Hartman changing her name from Valarie to Saidiya in college in order to leave behind 'the princess [her] mother wanted [her] to be'.³ Valarie was a name 'weighted with the yearning for cotillions and store-bought dresses and summers at the lake', representing the 'striving' to erase 'the poor black girl [her] mother was ashamed to be'.⁴ 'Saidiya' seemed to represent something different, both a gesture of solidarity and the beginnings of a desire to remedy the great 'breach of the Atlantic' and 'expunge' 'the ugly history of elites and commoners and masters and slaves'.⁵ *Lose Your Mother* is a reckoning with the fact that attempts to 'rewrite the past' or complete the archive in relation to the Black subject are often thwarted.⁶ Hartman's journey to Ghana is one of deep sorrow and loneliness, she does not find the hoped-for traces of relatives or ancestors. However she finds other unlooked-for kin, unrelated by blood, in a community descended from fugitives fleeing slave raiders in Gwolu. 'In the small clearing made by the ring of houses, four girls were playing a game of jump rope'; there 'the girls are singing about those taken from Gwolu and sold into slavery in the Americas...about the diaspora'.⁷ In their words Hartman experiences a frisson of recognition: she writes, 'here it was – my song, the song of the lost tribe'.⁸ My thesis,

³ Saidiya V. Hartman, *Lose Your Mother: A Journey Along the Atlantic Slave Route*, First published in Great Britain (London: Serpent's Tail, 2021), p. 27.

⁴ Hartman, p. 27.

⁵ Hartman, p. 28.

⁶ Hartman, p. 35.

⁷ Hartman, pp. 380–81.

⁸ Hartman, p. 381.

which began with a differently oriented search for an absent ancestor, developed in similar ways into something other than what I expected to find.

It was in reading Christina Sharpe's *Ordinary Notes* (2023) that I finally had a parallel experience of unexpected recognition: 'I've been here before'.⁹ It was all there in Sharpe's careful assembling of her mother's archive: the hands that made the 'purple gingham dress with purple and lilac and blue applique tulips' and the 'Christmas ornaments', the hands 'cupped, fingers not quite touching', 'what they make, the shapes they trace in the air', even the handwriting captured on a 'worn slip of paper'.¹⁰ This extraordinary book distilled something about the kind of care, death and grief familiar to me, while giving shape to questions I had subconsciously been asking. I was struck by Sharpe's mother's injunction: "'Don't write about me'".¹¹ Sharpe interprets this partly as a signal of 'her [mother's] recognition of the difficulty of narrating a life', an understanding of the limits of narrative form. She also wonders if her mother 'did not believe that her life could be sounded with a note of care...such is the damage that anti-blackness, domestic and state violence, and other abuses can wreak on the self'.¹² Reading this, I wonder if there is also something of what Hartman describes in *Wayward Lives, Beautiful Experiments*, of the record – the photograph, the account – as one of many forms of capture to be navigated by the Black subject. As Hartman writes, historically, 'the photograph coerced the black poor into visibility as a condition of policing and charity, making those bound to appear suffer the burden of representation...to be visible was to be targeted for uplift or punishment, confinement or violence'.¹³ To elude such capture might be to evade the disparaging or pitying gaze, or to avoid the reinscription of hierarchies that can attend narrative form. Sharpe negotiates this problem, as others in this thesis have done, through formal experimentation. Her mother appears in *Ordinary Notes* in and as fragments, unfixed and uncomplete, like a secret Sharpe keeps for herself. Together, Hartman and Sharpe helped me to formulate some of the questions which have underpinned this project: what are the stakes of attachment? what are the

⁹ Christina Elizabeth Sharpe, *Ordinary Notes* (London: Daunt Books, 2023), p. 117.

¹⁰ Sharpe, *Ordinary Notes*, pp. 82, 176, 80.

¹¹ Sharpe, *Ordinary Notes*, p. 106.

¹² Sharpe, *Ordinary Notes*, pp. 106, 136.

¹³ Saidiya V Hartman, *Wayward Lives, Beautiful Experiments: Intimate Histories of Social Upheaval* (London: Serpent's Tail, 2019), p. 21.

implications of capture? What are the politics of being seen or becoming legible in an attempt to count?

In the last year of her life, my mother did not like to be photographed. There is a picture of her taken by my sister, in which she is scowling, unrecognisably severe. My sister tells me that in that moment she is asking her not to take the photograph. When I think of this picture it reminds me inexplicably of another, completely unrelated photograph from a different time, in which my mother is juggling. There is one lime in her left hand, in her right she is in the act of either catching or throwing another, the third lime is suspended in mid-air, partially obscuring her face. Despite the fact that the picture captures objects and a body in motion, the effect to me is one of curious temporal suspension, as if the action of juggling that has happened will also always be happening, in process and incomplete. I like to imagine my mother liked this picture of herself, which conveys so much of her playfulness and dexterity, and how seriously she took the serious business of joy. Over the course of this thesis I explore texts that attempt to represent, through language and form, similar encounters with temporal incommensurability: things that have happened but are also still somehow happening, beginnings that enfold endings, the past in the present and future tense.



Introduction: Contexts, Conventions, Cancer and Capitalism

Why are some end-of-life narratives, specifically cancer narratives, so emotionally compelling? What is at stake in attempting to thoroughly understand their cultural power? And how are particular histories of occlusion implicated in establishing what a wider audience perceives as emotionally compelling?

Cancer, conceptualised as “the rich man’s disease”, has overtaken heart disease as the leading cause of death in wealthy, western high-income countries.¹⁴ As Susan Sontag observes, cancer is a disease representative of ‘middle-class life, a disease associated with affluence’ and economic stability.¹⁵ Cancer narratives have come to eclipse other ways of writing about dying, and other kinds of death. They are representative of illness narratives, as they have been conventionally defined, that affirm cultural assumptions that health crises, illnesses and death are universal experiences that have a democratising impact, beyond the ordinary, ongoing experiences of socio-economic struggle. They place the individual and their solitary battle or quest at the centre of the text, with far reaching implications for questions of attention to health inequality. I argue that in constraining writers to narratives of individualism and heroism, they align with imperatives towards labour-oriented self-development, self-management and self-care underpinning neoliberalism and Late capitalism. Far from representing a universal, democratising illness, I consider the ways in which cancer narratives obscure a politics of race, poverty, sexuality and ecology that both unevenly distributes experiences of illness and death and forecloses on the potential for flourishing and recovery.

As others have observed, the ways in which these narratives have historically been prioritised for study within the medical humanities demonstrates how the discipline initially has overlooked critiques that explore identities related to sexuality, race and disability.¹⁶ This thesis is part of a critical turn within the discipline that seeks

¹⁴ Reuters staff, ‘Cancer Overtakes Heart Disease as Biggest Rich-World Killer’, *Reuters*, 3 September 2019, section Healthcare & Pharma <<https://www.reuters.com/article/us-health-cancer-cancer-idUSKCN1VO0VP>> [accessed 5 April 2023]; Gilles R Dagenais and others, ‘Variations in Common Diseases, Hospital Admissions, and Deaths in Middle-Aged Adults in 21 Countries from Five Continents (PURE): A Prospective Cohort Study’, *The Lancet*, 395.10226 (2020), 785–94.

¹⁵ Susan Sontag, *Illness as Metaphor; and, AIDS and Its Metaphors* (New York: Picador USA, 2001), p. 15.

¹⁶ *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Anne Whitehead and others (Edinburgh: Edinburgh University Press, 2016), p. 2.

alternatives to these dominant narratives. I focus on different kinds of illness account – those that ostensibly recount difference, failure and abjection. Through readings of these texts, this thesis offers a critique of imbricated structures of has been formulated differently as ‘racial capitalism’,¹⁷ ‘compulsory heterosexuality’ and ‘compulsory able-bodiedness’.¹⁸ What distinguishes this work from a growing body of texts and criticism that share scepticism of the cultures and affects demanded by neoliberalism, is its argument that time is central to the clash of these cultural contexts. Extended temporalities that require endurance or other forms of waiting are particularly central.

My starting point is that waiting is one of healthcare’s central experiences. Waiting usually describes the experience of involuntary delay asymmetrically distributed among the vulnerable. As part of *Waiting Times*, a broader research project that considers the temporalities of healthcare, my project also explores the practical and conceptual facets of care in these works.¹⁹ I examine and uncover other modes of untimeliness and think about how these might support or require certain formulations of care for self and others. I am interested in several different but interconnected formulations of time emerging from queer theory, crip theory, Black studies and environmental studies. I am also interested in the timelines of academic disciplines – meaning the genealogies of ideas which culminate in the fields covered by this research. I focus my initial analysis on literary texts emerging in an extended contemporary period from the 1990s up to the present day,²⁰ at a time of rising interest in the illness narrative genre within the medical humanities and in clinical practice. I look to how these genealogical trajectories bear out in the contemporary state of medical humanities and ask questions about the ways in which the field until recently has remained a silo – distinct from the genealogies and contemporary critical practices of Black studies and disability studies.

Key also is my engagement with the temporalities of popular illness narratives. Roger Luckhurst suggests it is a distinctly contemporary form and that ‘one of [its]

¹⁷ Cedric J. Robinson, *Black Marxism: The Making of the Black Radical Tradition* (Chapel Hill, N.C: University of North Carolina Press, 2000), p. 2.

¹⁸ Robert McRuer, *Crip Theory: Cultural Signs of Queerness and Disability*, Cultural Front (New York: New York University Press, 2006), pp. 1–2.

¹⁹ *Waiting Times*, <<http://waitingtimes.exeter.ac.uk/>>

²⁰ This is a slightly longer period than in ordinary usage within Literary Studies, in which the ‘contemporary’ would strictly refer to work emerging within the last 10 years or so.

principal vectors' was the newspaper columns devoted to illness published in the 1990s.²¹ Luckhurst argues that at this time 'an injunction to perform their traumatic identities had taken over a certain element of the liberal intelligentsia'.²² Since then, digital cultures have accelerated discussions and representations of death, enabling people to document and record their illnesses on blogs, social media sites such as Facebook, Twitter and Instagram, or even, on online giving sites such as GoFundMe or JustGiving, as part of the 'medical crowdfunding' phenomena.²³ These proliferating narratives share a linear temporal structure that tracks the stages of illness from the point of diagnosis as a kind of rupture, or shattering of "ordinary" life. I contrast these dominant forms with the counter-temporalities of the narratives I attend to in this thesis: the queer cancer narratives of Gillian Rose and Eve Kosofsky Sedgwick; accounts of Black death and dying in the memoirs of Edwidge Danticat and Jesmyn Ward, and in the poetry of Harryette Mullen and Claudia Rankine; the slow deaths of toxic pollution and climate change in a memoir by Susanne Antonetta and a novel by Jesmyn Ward. These texts defy linearity by reversing or scrambling the narration of diagnosis, treatment, prognosis, relapse/recovery. Their writers de-emphasise their illness by interweaving their stories with the stories of others, thereby making broader political contentions about how illness is always part of larger social problems. Death in these texts exceeds the temporalities of the cancer narrative: it is shockingly sudden – abbreviating life and futures – or else chronically drawn out over decades and generations.

In its close attention to marginal experiences of time, a key outcome of this project will be to demonstrate that care in these spaces refers not only to medical treatment or some idealised, positive affect. Instead, it aims to reveal the ways in which care is inventive, improvised and endlessly challenging, taking place in excess of sanctioned clinical and social pathways. Building on formulations of fugitivity originating in Black studies, I define this practice as fugitive care. Through it, strategies emerge for resisting and negotiating the structures of medical institutions; in order to forge pathways through, alternative kinship structures are made, and at

²¹ Roger Luckhurst, *The Trauma Question* (London ; New York: Routledge, 2008), p. 130.

²² Ibid.

²³ Jeremy Snyder, Glenn Cohen, Peter Chow White, Valerie A. Crooks, 'Medical crowdfunding supports the wealthy and endangers privacy – here's how to make it more ethical', *The Conversation*, (26 June 2019) <<https://theconversation.com/medical-crowdfunding-supports-the-wealthy-and-endangers-privacy-heres-how-to-make-it-more-ethical-116894>> [accessed 3 January 2020]

times ancestors are invoked. These practices enable mainstream health care services, for better and for worse, to continue to function as they do. In a contemporary moment conceptualised as a time of crisis in healthcare, where discourses of resource scarcity abound, it seems particularly important to attend to enclaves in which scarcity and lack have been routinely encountered and yet in which people find different ways to go on living and dying. In the face of unthinkable futures, the narratives I examine pay attention to those who have been living in a time of no future, or in a future endlessly deferred. This project recognises that those living lives currently conceptualised as unthinkable have always existed, concealed by and yet supporting dominant narratives of dying.

Bringing together these lines of thinking on illness narrative conventions, untimeliness and care, my thesis argues that – against the temporalities of heroic narratives of illness and the established genealogies of the medical humanities field – attention to marginal experiences of time in extra-canonical illness texts can reveal new insights about how medical care is experienced, endured and made im/possible for patients who are not straight and white, in states of illness and ‘debility’.²⁴

By carrying out this research, I will contribute to ongoing debates about the role of narrative within the medical humanities, which up to this point have centred around a tension between Arthur Frank’s suggestion that narrative is an intuitive way of remaking the ‘body-self’ shattered in illness, and Angela Woods’ contention that human beings are not necessarily naturally narrative, or that a narrative outlook is not a prerequisite for personhood or “the good life”.²⁵ Attending to cultures and literatures of health and advancing its argument through the methodology of close reading, this thesis sits within the fields of the medical humanities and literary studies. However, it also aims to find a mode in which to intervene in the wider fields of Black studies, disability studies and the environmental humanities. There has been heightened focus on questions of the end-of-life in these spaces and in the wider cultural sphere. My initial research on the relationship between the “universality” of cancer narratives and their connection to health inequalities

²⁴ Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability*, Anima (Durham: Duke University Press, 2017), p. 2.

²⁵ Angela Woods, ‘Beyond the Wounded Storyteller: Rethinking Narrativity, Illness and Embodied Self-Experience’, in *Health, Illness and Disease: Philosophical Essays*, ed. by Havi Carel and Rachel Cooper (Acumen Publishing, 2012), pp. 113–28.

contributed to an internationally broadcast World Health Organisation (WHO) Seminar on the Cultural Contexts of Palliative Care, which is in turn connected to ongoing work being done as part of the *Lancet* Commission on the Value of Death.²⁶

I anticipate therefore that this thesis stands to make a meaningful contribution not only to the literary criticism of life writing that has embraced narrative as a universal language of recovery and resistance, or else approached the form with what Sedgwick, following Paul Ricoeur, critiques as the ‘hermeneutics of suspicion’: a set of critical practices characterised by a refusal to take things at ‘un-mystified’ face value, a ‘paranoid’ impulse to expose knowledge as ‘true’ or otherwise.²⁷ Rather, this thesis will attempt to engage meaningfully with the specificities of the grounded and lived experiences of death from a queer and racialised perspective.

Existing Literature: Narrating Illness in and beyond the Medical Humanities

Reviewing the literature suggests that the illness narrative genre emerged as a way to contain and define the messy and multi-formed accounts of lived experience of illness proliferating in the latter half of the twentieth century. The medical humanities, a field which formed in tandem with the concept of illness narratives, has navigated similar questions of positioning in relation to other fields attending to the subjects of health and culture. Editorials in early issues of BMJ’s *Medical Humanities* reflected a preoccupation with the question of what it would mean in the context of the United Kingdom (UK) to ‘attempt to establish medical humanities as both a credible field of university level inquiry, and as a practical resource for the development of professional health care’.²⁸ I am interested, in the first instance, in what the ‘medical’ or ‘professional’ orientation of the medical humanities has maintained. As Jana Funke and Sherri Foster observe in their editorial ‘Feminist Encounters with the Medical Humanities’, as early as 2000 Jane MacNaughton was arguing ‘against a

²⁶ Kelechi Anucha, ‘Time Conventions in Cancer Narratives’, unpublished paper delivered at the World Health Organisation seminar ‘A good death? The cultural contexts of palliative care’, (Wellcome Centre for Cultures and Environments of Health, University of Exeter, 8 October 2019).

²⁷ Eve Kosofsky Sedgwick, *Touching Feeling: Affect, Pedagogy, Performativity*, Series Q (Durham: Duke University Press, 2003), pp. 124–25.

²⁸ H M Evans, ‘“Medical Humanities”--What’s in a Name?’, *Medical Humanities*, 28.1 (2002), 1–2; D A Greaves and H M Evans, ‘Coming of Age? Association for Medical Humanities Holds First Annual Conference’, *Medical Humanities*, 29.2 (2003), 57–58.

“use value” model of the humanities, insisting that the humanities have an “intrinsic value in their own right” rather than existing as a soft technology for medical training and practice.²⁹ Beyond this, I am also interested in how the evolving ways in which the field has defined itself shaped its uneven dialogue with disability studies, queer theory, environmental studies and Black studies. As Jack Halberstam observes, ‘there are spaces and modalities that exist separate from the logical, logistical, the housed and the positioned’.³⁰ It follows that something is lost in the process of defining the conventions of a genre, or the proper sphere of a discipline, even as intellectual coherence and legitimacy are achieved.

Illness narratives – and their attendant conventions and distinct temporalities – first emerged as an object of study in medical humanities in the United States (US). In his seminal text *Awakenings* (1973), which recounts the life histories of Parkinson’s disease and 1920s encephalitis lethargica patients, Oliver Sacks voices a widely shared criticism of the ways in which ‘modern medicine, increasingly, dismisses our existence’, failing patients through its inflexible data-oriented approach to illness: ‘nowhere, nowhere, does one find any colour, reality, or warmth; nowhere any residue of the living experience’ of illness and treatment.³¹ The antidote for Sacks is attention to a ‘perfectly shaped and detailed *history*, (or disclosure), or *biography*’, (emphasis in original) one that recognises that ‘diseases have a character of their own, but they also partake of our character’.³² He concludes, ‘in our own time, the most perfect examples of such biography (or ‘pathography’) are the matchless case-histories of Freud’.³³

Sacks’ influence can be felt everywhere in the medicine-oriented early medical humanities scholarship of the 1980s and 1990s. Notably, he furnishes scholars with the terminology ‘pathography’ to describe personal accounts of illness. He also establishes the idea that patient biographies – or clinical tales, as he has also

²⁹ Sherri L. Foster and Jana Funke, ‘Feminist Encounters with the Medical Humanities’, *Feminist Encounters: A Journal of Critical Studies in Culture and Politics*, 2.2 (2018), p. 1 <<https://doi.org/10.20897/femenc/3882>>; Jane Macnaughton, ‘The Humanities in Medical Education: Context, Outcomes and Structures’, *Medical Humanities*, 26.1 (2000), 23–30 (p. 24) <<https://doi.org/10.1136/mh.26.1.23>>.

³⁰ Jack Halberstam, ‘The Wild Beyond: With and for the Undercommons’, in *The Undercommons: Fugitive Planning & Black Study*, by Fred Moten and Stefano Harney (Wivenhoe, New York, Port Watson: Minor Compositions, 2013), p. 11.

³¹ Oliver Sacks, *Awakenings* (New York: Vintage Books, 1976), pp. 265, 268.

³² Oliver Sacks, p. 266.

³³ *Ibid.*

described them – capture something of the lived experience of illness neglected in the clinical encounter: going beyond the medical case history, clinical tales are ‘personal’ stories, presenting with ‘naive immediacy and force’ the substance of what the patient ‘has been experiencing, been feeling’ and ‘suffering’.³⁴ Psychiatrist Arthur Kleinman extends this line of thinking in his book *The Illness Narratives* (1988), which coined the term now most frequently used to describe the genre and is considered a ‘classic’ which ‘helped shape thinking in the medical humanities’.³⁵ His argument that illness narratives communicated something fundamental about ‘the human condition, with its universal suffering and death’ had far reaching implications for their valuation in scholarship as an accessible, egalitarian medium.³⁶ Such narratives, he argues, also function to ‘give coherence’ to suffering and are the means by which ‘a wild, disordered natural occurrence [is] domesticated, mythologised, [and] ritually controlled’.³⁷ Rita Charon echoes Kleinman’s emphasis on the ordering potentiality of narrative, in her observation that understanding why things happen involves putting ‘events in temporal order, making decisions about beginnings, middles, and ends or causes and effects by virtue of imposing plots on otherwise chaotic events’.³⁸ Narrative ‘suggests causes for events, represents the passage of time’ reinforcing a logic of rationalism and coherence.³⁹ In *Talking with Patients* (1985) Eric Cassell similarly states that ‘all diseases, all illnesses, play themselves out over time. They are an unfolding story of changes in function. As the story evolves, the task is to understand what is happening in the body and to form a hypothesis’.⁴⁰ Cassell’s statement creates an imperative for narrative to follow the causative logics of diagnostic practices, in order to maintain utility and relevance.

In Frank’s *The Wounded Storyteller* (1995), first-person accounts of illness emerging from interpersonal encounters also challenge the omnipotence of the modern

³⁴ Oliver Sacks, ‘Clinical Tales’, *Literature and Medicine*, 5.1 (1986), 16–23 (pp. 16–17).

³⁵ Neil Vickers, ‘Illness Narratives’, in *A History of English Autobiography*, ed. by Adam Smyth (Cambridge: Cambridge University Press, 2016), pp. 388–401 (p. 390); Brian Hurwitz and Victoria Bates, ‘The Roots and Ramifications of Narrative in Modern Medicine’, in *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Anne Whitehead and others (Edinburgh: Edinburgh University Press, 2016), p. 673 (p. 560).

³⁶ Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988), p. xiii.

³⁷ Kleinman, pp. 48–49.

³⁸ Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford: Oxford Univ. Press, 2008), p. vii.

³⁹ Charon, p. 40.

⁴⁰ Eric J. Cassell, *Talking with Patients*, MIT Press Series on the Humanistic and Social Dimensions of Medicine (Cambridge, Mass: MIT Press, 1985), p. 43.

medical narrative (symbolised by the patient's chart).⁴¹ He argues that these first-person accounts reflect the shift towards a 'postmodern experience of illness' in which ill people 'recognise that more is involved in their experiences than the medical story can tell'.⁴² Frank's title is a nod to Henri Nouwen's *The Wounded Healer* (1972), which 'bases the spiritual vocation on the minister's acceptance and sharing of [their] own woundedness'.⁴³ Similarly, the storytellers of Frank's texts, while ill and in need of care, are not passive but uniquely qualified to provide healing for others through the potency of their stories.⁴⁴ Frank typifies illness stories into three categories: 'restitution narratives' which attempt to 'outdistance mortality' by conceptualising illness as a temporary state; 'chaos narratives', with a tacitly negative valence, in which the ill person's sense of coherence and structure are completely overwhelmed by disaster; and 'quest narratives', where the ill person 'meets suffering head on, [accepting] illness and seek[ing] to use it'.⁴⁵

Responding to the context in which these works emerged, medical institutions and medical professionals appointed humanities scholars in their departments. Like Charon, Kathryn Montgomery Hunter came to the medical humanities following training in literary studies, and both scholars established prestigious humanities and narrative medicine programs in the 1980s. Their books *Doctors' stories* (1991) and *Narrative Medicine: Honoring the Stories of Illness* (2006) are leading examples of materials produced for instructing medical students in the art of close reading, with the intention of honing their skills of perception and interpretation in order to transform them into better doctors. Other works in this vein produced by practitioners included Howard Brody's *Stories of Sickness* (1987), which performed readings on literary texts from a philosophical perspective, and a plenitude of anthologies of medicine-themed literature, such as Richard Reynolds' *On Doctoring* (1991), Richard Gordon's *The Literary Companion to Medicine* (1993), John Ballantyne's *Bedside Manners* (1995) and Iain Bamforth's *The Body in the Library* (2003). These texts engaged a similar roster of writers established in the literary canon: Anton Chekhov, Charles Dickens, George Eliot, Thomas Mann, Somerset Maugham, Aleksandr

⁴¹ Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), p. 5.

⁴² Frank, p. 6.

⁴³ Frank, p. xi.

⁴⁴ Frank, p. xii.

⁴⁵ Frank, p. 115.

Solzhenitsyn, Leo Tolstoy, William Carlos Williams and others. Some, like *On Doctoring*, include more contemporary personal writing on illness, making a case for their value by aligning them discursively with literature of undisputed canonical value and thus elevating their status. These selections also spoke to an aspiration to return to the figure of the doctor as renaissance humanist conversant in both the arts and the sciences, at a time of both rapid technical advancement and increasing ambivalence towards biomedicine.

This early scholarship demonstrates how, as the medical humanities developed as a discipline, narrative was conceptualised as a support or aid to the hard sciences of biomedicine.⁴⁶ Illness narratives then took on a particular role within the field, came to be associated with certain conventions – such as rationality, mastery, individual agency, temporal coherence and linearity – and were approached in increasingly systemised ways, reflecting processes of ‘analysis, stocktaking, classification, and specification’ that Michel Foucault associated with the discursive organisation of sexuality in the nineteenth century.⁴⁷ I draw attention to this trend in the early scholarship to highlight the extent to which these and other conventions relating to illness narratives have persisted, maintaining an ongoing politics of occlusion. Part of the work of this thesis is to continue the thinking scholars have done in recent years to problematise these early approaches to illness narratives, which, as illustrated, made claims about their universalism based in an insufficiently reflective or critical humanism, which overrepresents a particular subject position at the expense of others.⁴⁸

The Illness Narratives is a good example of the ways in which early scholarship positions itself as interrogating the stigma of illness through narrative, though with insufficiently rigorous attention to the politics of culture. Significantly, for example, the illness narrative subject central to the case studies of Kleinman and others is overwhelmingly white, heterosexual and adjacent to a particular kind of middle-class professionalism. Kleinman does consider the role of stigma, reflecting on the fear of contagion attached to historically prevalent diseases such as leprosy and bubonic

⁴⁶ *Narrative Research in Health and Illness*, ed. by Brian Hurwitz, Trisha Greenhalgh, and Vieda Skultans (London: Wiley, 2008), pp. 1–2.

⁴⁷ Michel Foucault, *The History of Sexuality* (London: Penguin, 1990), p. 24.

⁴⁸ Sylvia Wynter, ‘Unsettling the Coloniality of Being/Power/Truth/Freedom: Towards the Human, After Man, Its Overrepresentation--An Argument’, *CR: The New Centennial Review*, 3.3 (2003), 257–337 (p. 260).

plague, and contemporary illnesses such as cancer, heart disease, herpes and AIDS. However, his concern centres on the ways in which these diseases evidence a breaking-down of the mastery, morality and temporal organisation associated with a healthy and productive embodiment. Cancer forces individuals to confront ‘unpredictability and uncertainty’ and the ‘failure to explain and master much in our world’, whereas heart disease invokes ‘ubiquitous tension’ and ‘the loss both of leisure and of sustained physical activity in our workaday world’.⁴⁹ Herpes and AIDS speak to the hypocrisy of the ‘dominant, commercialised sexual imagery of postindustrial capitalist society’.⁵⁰ In characterising these stigmas, Kleinman echoes the ways in which Sontag tracks and challenges the cultural meanings attached to diseases in *Illness as Metaphor* (1978) and *AIDS and its Metaphors* (1989). Sontag notes how the diagnosis of Tuberculosis (TB), Cancer and AIDS constituted a death sentence at various points in history, accruing with this discursive power potent metaphorical and mythic associations. TB is constructed as a febrile ‘disease of extreme contrasts: white pallor and red flush, hyperactivity alternating with languidness’, an effeminised, ‘edifying, refined disease’ associated with nineteenth century literary Romanticism by way of John Keats.⁵¹ Sontag tracks how, in contrast, cancer is constructed as a slow and steadily progressing ‘disease of insufficient passion, afflicting those who are sexually repressed, inhibited, unspontaneous [and] incapable of expressing anger’.⁵² AIDS is situated in relation to cultural understandings of ‘perversity’, linked with ‘shame’, ‘guilt’, ‘indulgence’ and ‘delinquency’, ‘flush[ing] out an identity that might have remained hidden from neighbors, jobmates, family, [and] friends’.⁵³ Yet where Sontag’s critique remains productively directed towards the politics which create stigma, Kleinman’s attempt to situate illnesses within the social worlds of his subjects tended to essentialise them and reaffirm stigma, rather than interrogate and deconstruct it. In the case study of Rudolph Kristeva, ‘a thirty-eight-year-old white unmarried male, of Bulgarian-Jewish background’, Kleinman connects Kristeva’s destructive shame and self-loathing to his homosexuality, retreating from an analysis of the role of homophobia in his illness

⁴⁹ Kleinman, p. 21.

⁵⁰ Kleinman, p. 22.

⁵¹ Sontag, p. 16.

⁵² Sontag, p. 21.

⁵³ Sontag, pp. 112–13.

to focus on the pathology itself.⁵⁴ Similarly, Kleinman's case study of Comrade Yen, 'a forty-year-old teacher in a rural Hunan town' (in China) experiencing a severe case of depression, essentialises the presentation of her illness in relation to assumptions about the Chinese national character in ways that are, at best, reductive.⁵⁵

Other scholarship in the social sciences attempted a more rigorous engagement with the ways in which the social contexts of illness narratives are shaped by relations of power. Lars-Christer Hydén and Jens Brockmeier's edited collection *Health, Illness and Culture: Broken Narratives* (2008) echoes Charon's interest in narrative's efficacy in clinical and professional care settings. The collection explores a range of lived experiences of disability, cognitive disorder, brain injury, HIV/AIDS, death and dying and domestic violence. Significantly, they are most interested in accounts that are 'undecided, fragmented, broken, narrated by voices struggling to find words', which 'have been given less attention' than increasingly formally 'sophisticated' fiction and non-fiction illness stories, highlighting the context in which only certain narratives attain legibility.⁵⁶ In her book *Death and the Migrant: Bodies, Borders and Care* (2013), Yasmin Gunaratnam attends to the diasporic dying of healthcare workers of colour in the NHS.⁵⁷ She demonstrates that far from being a neutral provider of care, the Hospice movement has always been preoccupied by an Other – the foreigner or the dying. Commenting on the radically de-contextualising and de-familiarizing experience of dying, Gunaratnam writes that 'when borders are reimagined as a temporality, dying people, wherever they have come from, are already foreigners of a sort, unmoored from everyday worlds and all that is familiar, by the vicissitudes of the body'.⁵⁸ Far from a culturally clichéd 'safe haven' – the Hospice in Gunaratnam's research emerges as a very public, multivalent interstice where: 'fantasized 'roots' meet up with cosmopolitan "routes" so that hospice and hospital wards have that similar feel of the airline transit lounge, characterized by long chains of cultural interconnectedness and intergenerational migration...with

⁵⁴ Kleinman, pp. 75, 77.

⁵⁵ Kleinman, pp. 104, 108–9.

⁵⁶ *Health, Illness and Culture: Broken Narratives*, ed. by Lars-Christer Hydén and Jens Brockmeier (New York: Routledge, 2011), pp. 3–4.

⁵⁷ Yasmin Gunaratnam, *Death and the Migrant: Bodies, Borders and Care*, 1. paperback ed (London: Bloomsbury Academic, 2015).

⁵⁸ Gunaratnam, p. 18.

illness and disease the interconnections proliferate. Hallucinations, paranoia and hypersensitivities can cohabit with and jostle among prayers, promises, plans, rituals and life-long habituations, pulling the body and self down familiar and new paths'.⁵⁹ Gunaratnam's is an important contribution which highlights how terminal illness and dying are processes which heighten, rather than erase, perceptions of social and racial difference.

A separate 'cluster' of medical humanities scholarship on illness narratives approached from a literary perspective also emerged. Anne Hudson Jones, editor of *Literature and Medicine*, edited *Images of Nurses: Perspectives from History, Art, and Literature* (1988) which spoke to the gendered nature of caring work revealed in textual and visual art, arguing that nurses' images equal women's images.

Overwhelmingly though, this scholarship focused on written, rather than oral, accounts of illness, which in turn produced a different kind of "narrator" and new audiences. Reviving Sacks' terminology, *Reconstructing Illness* (1993) defines pathographies as 'book-length' forms of 'autobiography or biography that describes personal experience of illness, treatment, and sometimes death'.⁶⁰ Hawkins' book rehearses established ideas about the ordering and meaning-making function of illness narratives, as well as their utility for medical professionals. Following Frank and Sontag, she is also interested in 'the myths, attitudes, and assumptions that inform the way we deal with illness', identifying common myths of 'rebirth and the promise of cure', 'battle and journey' and 'healthy-mindedness' as organising concepts.⁶¹ There is a distinctly spiritual element to these typographies and to Hawkins' formulation of pathographies as a whole, reflecting how *Reconstructing Illness* grew out of her early work on spiritual autobiographies and John Donne's *Devotions Upon Emerging Occasions* (1624).⁶² However, noting the growing presence of pathographies on best seller lists and supermarket checkouts, in addition to hospital patient's bedsides, she highlights how commercial viability was

⁵⁹ Gunaratnam, pp. 18–19.

⁶⁰ Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, Ind: Purdue University Press, 1993), pp. 1, 3.

⁶¹ Hawkins, *Reconstructing Illness*, pp. ix, 28.

⁶² Nathan Carlin, *Pathographies of Mental Illness* (Cambridge University Press, 2022), pp. 2–3.

as key to the success of these works as their perceived instructive or inspirational value.⁶³

G. Thomas Couser was one of the first to think with the burgeoning field of disability theory to ‘articulate the political implications of studying illness narrative’, drawing on the work of Lennard J. Davis in his book *Recovering Bodies: Illness, Disability, and Life Writing* (1997).⁶⁴ *Recovering Bodies* builds on Couser’s work as guest editor of the *a/b: Auto/Biography Studies* journal special issue on ‘Illness, Disability and Life-writing’, demonstrating his interest in narratives of illness and disability as ‘an extension of a long-term concern with autobiography and other “life writing” genres’, and showing how this interest shaped an awareness of the latent politics of illness writing, directing his focus to ‘issues of authority – who (or what) controls or shapes life narratives’, ‘who gets a life and who doesn’t: whose stories get told, why, by whom, and how’.⁶⁵ Couser suggests that life writing genres, ‘located on the borders of the literary...are particularly accessible to marginalised individuals’.⁶⁶ However, Couser acknowledges that other elements effect access and recognition within the medium: ‘in practice, life writing genres have hardly been equal opportunities employers’. He characterises the genre as ‘male-dominated’, ‘not diverse in terms of race or class’, privileging the voices of ‘white and upper middle class’ individuals and existing members of the intelligentsia.⁶⁷

Building on the work of Hawkins and Couser, further work emerged on illness narratives from literary and cultural studies perspectives, which began to evidence greater sensitivity to how the politics of gender and race shape illness. This scholarship continued to focus on how narrative functions to contradict the stigmas associated with illness and reaffirm the independence and agency of the self. Journals such as *Literature and Medicine* helped consolidate these approaches alongside a focus on cancer, with the publication of a special issue on ‘Cancer Stories’ in 2009.⁶⁸ Mary DeShazer extended the analysis of cancer narratives

⁶³ Hawkins, *Reconstructing Illness*, p. 1.

⁶⁴ Vickers, p. 397.

⁶⁵ G. Thomas Couser, ‘Introduction: The Embodied Self’, *A/b: Auto/Biography Studies*, 6.1 (1991), 1–7; G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life-Writing* (Madison: University of Wisconsin Press, 1997), pp. 2–3.

⁶⁶ Couser, *Recovering Bodies*, p. 4.

⁶⁷ Couser, *Recovering Bodies*, pp. 2–3.

⁶⁸ ‘Special Issue: Cancer Stories’, ed. by Jane E Schultz and Martha Stoddard Holmes, *Literature and Medicine*, 28.2 (2009) <https://muse.jhu.edu/issue/21436#info_wrap>.

through an explicitly gendered framework through a broad reading of illness accounts across genres in *Fractured Borders: Reading Women's Cancer Literature* (2005) and *Mammographies: The Cultural Discourses of Breast Cancer Narratives* (2013). DeShazer examines memoirs, auto-theory, photonarratives, plays, poetry, blogs, graphic works by Sedgwick, Margaret Edson, Audre Lorde, Jackie Stacey, Lucille Clifton, S. Lochlann Jain, Catherine Lord, Lynn Kohlman and others, using critical approaches from feminist theory, literary and performance theory, and disability studies.⁶⁹ DeShazer places these writers and artists in dialogue with one another, highlighting creative genealogies, for example, between Lorde's memoirs *The Cancer Journals* (1980), *A Burst of Light: Essays* (1988) and Zillah Eisenstein's *Manmade Breast Cancers* (2001), centering a shared 'critique [of] white patriarchy for enforcing gender and racial privilege'.⁷⁰ In the process DeShazer models a productively flexible and expanded understanding of forms used to express experiences of illness, death and dying, speaking to the different social and cultural contexts which produce one form in comparison to another.

Inspired by Hawkins' work, Kimberley Myers edited *Illness in the Academy: A Collection of Pathographies by Academics* (2007) an original collection of 'shorter, chapter-length narratives' by academics, which functioned both as accounts of illness and reflections on the genre, by virtue of the reflexivity contributors had cultivated as part of their disciplinary training.⁷¹ Myers suggested these shorter narratives were better suited to theoretical and practical use in educational settings, one of several outcomes envisioned for the collection, alongside the 'empowering' benefit of telling such stories for contributors and the capacity of the narratives to act as a form of 'bibliotherapy' or healing for readers.⁷² Myers also suggests that the shorter form enabled the inclusion of a wider and more diverse set of voices, an argument substantiated by the contributions from queer disability studies scholars

⁶⁹ Mary DeShazer, *Fractured Borders: Reading Women's Cancer Literature* (Ann Arbor: University of Michigan Press, 2005), pp. 7–9; Mary DeShazer, *Mammographies: The Cultural Discourses of Breast Cancer Narratives* (University of Michigan Press, 2018), pp. 8, 12–16.

⁷⁰ Mary DeShazer, *Mammographies*, p. 61.

⁷¹ *Illness in the Academy: A Collection of Pathographies by Academics*, ed. by Kimberly Myers (West Lafayette, Ind: Purdue University Press, 2007), pp. xi, 1–2.

⁷² Myers, pp. xi, 4.

Ellen Samuels and Chris Bell and others, alongside the many narratives focused on illness in the family unit and on breast cancer.⁷³

Valerie Raoul's edited collection *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma* (2007), which includes a contribution from Hawkins, is similarly wide-ranging, offering reflections on lived experiences of illnesses such as cancer, cystic fibrosis and multiple sclerosis, in the form of roundtable discussions, case studies ethnographic works, and responses to film and literary texts. *Unfitting Stories* is interested in 'a story of research that is not confined within disciplinary and academic frames', raising the question of 'what "fits" into preconceived stories about health, disease, disability, or trauma', and through its wide scope of focus, demonstrating the extent to which these states co-exist, overlap and are sometimes entangled.⁷⁴ The collection attempts to break down barriers between the disciplines, between theory and practice, and between academic research and the community of those with lived experience.⁷⁵

In *Beyond Words: Illness and the Limits of Expression* (2007), Kathlyn Conway challenges the dominance of triumph narratives in illness writing. While writing her own memoir of breast cancer, *Ordinary Life* (1997), Conway notes 'the inexorable pull of the triumph myth'.⁷⁶ In her analysis of illness narratives in *Beyond Words*, she asks 'why the impulse to plot illness stories as tales of self-realization or personal transcendence is so overwhelming'.⁷⁷ Conway likens the triumph arc to Frank's 'restitution narratives', and citing Couser she interrogates the ways in which they are highly 'culturally validated', noting that 'a reverence has grown up around illness narratives that in itself can block a deeper exploration of their value and limits'.⁷⁸

It is clear then how these works by Conway, Raoul, Myers and DeShazer position themselves as connected to the scholarship of Hawkins, Kleinman, Frank and others, while beginning to push back against established definitions and conventions of the illness narrative form. Overall, they demonstrate flexible and multi-modal

⁷³ Myers, pp. 2, 7.

⁷⁴ *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma*, ed. by Valerie Raoul (Waterloo, Ont: Wilfrid Laurier University Press, 2007), p. 8.

⁷⁵ Raoul, p. 9.

⁷⁶ Kathlyn Conway, *Beyond Words: Illness and the Limits of Expression*, Literature and Medicine Series (Albuquerque: University of New Mexico Press, 2013), p. xi.

⁷⁷ Conway, *Beyond Words*, p. xi.

⁷⁸ Conway, *Beyond Words*, pp. 4, 12.

approaches that move away from dominant forms and generalizations, and seek to recognise the complexity, variety and individuality of personal accounts of illness from a range of subject positions.

More theory-oriented approaches to illness narratives focused on ‘works exhibiting a high degree of literary complexity’.⁷⁹ David Morris examines in further detail what Frank previously identifies as the ‘postmodern’ nature of illness, characterised by rapid technological change and the collapse of the ‘grand narrative’ of biomedical authority.⁸⁰ Morris moves between a wide range of sites and genres: from cancer and the impact of the environment on health and depression, to the phenomenological experience of pain and the suffering of AIDS; from memoirs to fiction. He argues that the narrative turn is a fitting response to medical and social contexts of increasing instability and complexity, offering readings of critically valourised texts such as Don DeLillo’s postmodern novel *White Noise* (1985) and novelist William Styron’s *Darkness Visible: A Memoir of Madness* (1990) among others.⁸¹ Einat Avrahami’s *The Invading Body: Reading Illness Autobiographies* (2007) challenges poststructuralist theory to argue that narratives and bodies – particularly terminal narratives and dying bodies – exist as more than cultural and social constructions or discursive practices, but also as ‘concretely situated...as an undeniable reality’.⁸² Her reading of philosopher Gillian Rose’s ovarian cancer memoir *Love’s Work* (1995) praises its atypical and experimental form suggesting, contra to the insistence on value inherent to all illness narratives, ‘that telling the truth about an illness might require a great deal of literary or artistic sophistication’.⁸³ Ann Jurecic’s *Illness as Narrative* (2012) recognises the difference between the pragmatic medical humanities and the aesthetic-theoretical literary studies approaches to illness narratives.⁸⁴ Arguing against Arlene Croce’s famous New York Times review condemning a dance performance by HIV-positive choreographer Bill T. Jones’ as ‘victim art’, she makes a case for the value of creative responses to

⁷⁹ Vickers, p. 398.

⁸⁰ David Morris, *Illness and Culture in the Postmodern Age*, Reprint 2020 (Berkeley, CA: University of California Press, 2020), p. 11.

⁸¹ Morris, p. 89.

⁸² Einat Avrahami, *The Invading Body: Reading Illness Autobiographies* (Charlottesville: University of Virginia Press, 2007), pp. 9–10, 11.

⁸³ Avrahami, pp. 21, 39; Vickers, p. 398.

⁸⁴ Ann Jurecic, *Illness as Narrative* (Pittsburgh: University of Pittsburgh Press, 2012), p. 3.

illness beyond voyeurism or their utility for medical professionals.⁸⁵ She seeks to close the gap between these two positions by drawing on a range of theoretical interventions, for example, Paul Ricoeur's 'hermeneutics of suspicion', Sedgwick's counter-theory of 'reparative reading', Ulrich Beck's thinking on the 'risk society' and Elaine Scarry's work on the body in pain, to offer analysis of 'living *at risk*, *in prognosis*, and *in pain*' (emphasis in original).⁸⁶ Jurecic uses this critical scaffolding to read memoirs of cancer, illness and disability including David Rieff's *Swimming in a Sea of Death* (2008), Jean-Dominique Bauby's *The Diving Bell and the Butterfly* (1997), Anne Fadiman's *The Spirit Catches You and You Fall Down* (1997) and Antonetta's *Body Toxic* (2001).

Building on her contribution to *Unfitting Stories*, Lisa Diedrich's monograph *Treatments: Language, Politics, and the Culture of Illness* (2007) examines in depth the 'cultural work illness narratives do in contemporary Western culture' and asks valuable questions about what sort of subject is formed in the practice of writing a memoir.⁸⁷ Her method and focus turn on the double meaning of 'treatments' as both a medical intervention and a method of careful attention to a text.⁸⁸ Using 'three theoretical frames...poststructuralism, phenomenology, and psychoanalysis' she explores several cultural sites and objects: tuberculosis in the mid-twentieth century, Lorde, Sontag and Sedgwick's 'politicized' cancer narratives, the ironic self in British illness narratives, and doctor's narratives.⁸⁹ Diedrich also takes up the questions raised by Croce's polemical article: responding in part to a growing backlash against what was viewed as the 'self - indulgent mining of personal experience' for memoir, Diedrich demonstrates instances of their cultural and aesthetic value while avoiding an uncritical endorsement of the universal benefit of illness narratives.⁹⁰ Like Diedrich, S. Lochlann Jain moves away from a purely aesthetic approach to the contexts of illness writing, in order to emphasise and interrogate the political terrain that produces disease itself in their cultural study of cancer, *Malignant: How Cancer Becomes Us* (2013).⁹¹ Engaging, as Diedrich does, with Barbara Ehrenreich's 2001

⁸⁵ Jurecic, pp. 12, 14.

⁸⁶ Jurecic, pp. 3, 4, 44, 104.

⁸⁷ Lisa Diedrich, *Treatments: Language, Politics, and the Culture of Illness* (Minneapolis: University of Minnesota Press, 2007), pp. vii–viii.

⁸⁸ Diedrich, p. viii.

⁸⁹ Diedrich, pp. ix, xix–xxi.

⁹⁰ Diedrich, pp. xiv, xii.

⁹¹ S. Lochlann Jain, *Malignant: How Cancer Becomes Us* (Berkeley: University of California Press, 2013), p. 14.

Harpers Article 'Welcome to Cancerland', they are critical of the parasitic alliance between capitalism and breast cancer culture.⁹² *Malignant* pays attention to the experience of cancer from a queer and butch subjectivity, in ways that evoke the contributions Lorde and Stacey make to the typically heteronormative culture reaffirmed by cancer advocacy and treatment protocols.⁹³ Jain also makes interesting arguments about the paradoxes of 'prognosis time'.⁹⁴ Their intervention falls into the category of works which are both critical responses to illness narratives and their contexts, and illness narratives themselves. This is a hybrid approach effectively utilised more recently by writers such as Anne Boyer and Alice Hattrick.⁹⁵ In *Writing Otherwise: Experiments in Cultural Criticism* (2013), editors Jackie Stacey and Janet Wolff engage with a similar preoccupation with the 'question of the personal and its place in academic writing' from a feminist perspective, noting that one way to indirectly arrive at the study of illness narratives is through this question.⁹⁶

In the last decade, the beginnings of what Woods, Will Viney and Felicity Callard first described in a special issue of *Medical Humanities* as a 'critical medical humanities', began to take shape in the UK, distinct from the original US context of the field. Focused less on how the field is defined and more on what it can achieve, this turn is 'critical' in a sense that is 'urgent, sceptical, evaluative', 'keep[ing] the field...open to new voices, challenges, events, and disciplinary (and anti- or post-disciplinary) articulations of the realities of medicine and health' and alive to 'the domain of the political'.⁹⁷ As early as 2011, Woods was calling for a more rigorous criticality, even scepticism, about the perception of narrative as a natural or universal way of responding to experience. She warns that 'promoting (particular forms of) narrative as the mode of human self-expression, in turn promotes a specific model of the

⁹² Jain, p. 242.

⁹³ Jain, pp. 20, 82, 205.

⁹⁴ Jain, p. 28.

⁹⁵ Anne Boyer, *The Undying: A Meditation on Modern Illness* (s.l.: Allen Lane, 2019); Alice Hattrick, *Ill Feelings* (London, United Kingdom: Fitzcarraldo Editions, 2021).

⁹⁶ *Writing Otherwise*, ed. by Jackie Stacey and Janet Wolff (Manchester University Press, 2013), p. 5. They cite Mary Cappello's, *Called Back*; Sandra Butler and Barbara Rosenblum's, *Cancer in Two Voices* – as well as the texts I have chosen for to prioritise for my analysis – Stacey's, *Teratologies: A Cultural Study of Cancer*, Gillian Rose's, *Love's Work: A Reckoning With Life* and Eve Kosofsky Sedgwick's, *A Dialogue on Love* as paradigmatic examples.

⁹⁷ William Viney, Felicity Callard, and Angela Woods, 'Critical Medical Humanities: Embracing Entanglement, Taking Risks', *Medical Humanities*, 41.1 (2015), 2–7 (p. 2).

self—as an agentic, authentic, autonomous storyteller... as someone...whose stories reflect and (re)affirm a sense of enduring, individual identity'.⁹⁸ Extending this critique, Woods engages with Galen Strawson's polemical article 'Against Narrativity' to question the very basis of the narrative turn in medicine: the assumption that 'we are narrative selves'.⁹⁹

Thinking with a heightened reflexivity, these works demonstrated an understanding of how the representation of illness is always informed by politics and shaped by particular socio-cultural contexts. Highlighting the clinical encounter between the doctor and the patient at the moment of cancer diagnosis as the primal scene of the medical humanities, Woods and Anne Whitehead attempt to challenge and make visible what is taken as given and remains unconscious and occluded from view within the field: namely how the bodies of doctors and patients are 'marked' by relations of power 'in terms of race, class, gender, ability and disability'.¹⁰⁰ *The Edinburgh Companion to the Critical Medical Humanities* attempts to trace and interrogate such assumptions and occlusions, compiling a wide range of scholarship across the humanities and social sciences following the 'critical' turn: the culture and politics of biomedical technologies and advances, sites of care, the role of language, as well as particular illnesses and historical moments from early modern through to contemporary contexts. In the *Routledge Handbook of the Medical Humanities* (2019), Alan Bleakley stressed the points of connection between science and the humanities, drawing out the political and aesthetic dimensions of the former and exploring a range of topics including medical education and bioethics, activism, illness in art, media, performance and culture.¹⁰¹ In *Metaphors in Illness: Fight and Battle Reused* (2022), Anita Wohlmann argues that metaphors, even when 'worn-out', 'are precious resources that we can and need to work with rather than throw away': 'rather than considering such metaphors useless or expendable... we can

⁹⁸ Angela Woods, 'The Limits of Narrative: Provocations for the Medical Humanities', *Medical Humanities*, 37.2 (2011), 73–78 (p. 74).

⁹⁹ Angela Woods, 'Beyond the Wounded Storyteller: Rethinking Narrativity, Illness and Embodied Self-Experience', in *Health, Illness and Disease: Philosophical Essays.*, ed. by Havi Carel and Rachel Cooper (Newcastle upon Tyne: Acumen, 2012).

¹⁰⁰ Whitehead and others, *The Edinburgh Companion to the Critical Medical Humanities*, p. 2.

¹⁰¹ *Routledge Handbook of the Medical Humanities*, ed. by Alan Bleakley (London: Routledge, 2019), pp. 1–20.

extend a metaphor's longevity, we can repair it, or we can repurpose it... and thereby – in the spirit of upcycling –discover new value'.¹⁰²

Looking back on attempts to expand understandings of narrative in the field, Wohlmann highlights work by Stella Bolaki and Sara Wasson as attempts to turn away from the ubiquity of certain forms. Bolaki has argued for the expansion of multimedia narrative to include alternative mediums such as artist's books, reaffirming both the value of fragmentation, discontinuity and genre-shifting, alongside the 'inadequacy of verbal forms of communication'.¹⁰³ Wasson is interested in how episodic modes of writing might differently represent the realities of chronic illness and pain.¹⁰⁴ Similarly, examining understandings of aphasia in the context of literary modernism, Laura Salisbury asks questions of the 'dehistoricised, oddly conservative account of language that have tended to dominate in medical humanities', building on critical questioning of certain narrative forms to explore what 'explicitly "disordered" representation' might offer to the discipline.¹⁰⁵ Earlier scholarship by Marilyn McEntyre argued persuasively that 'poetry opens a very different window from narrative, emphasizing discontinuity, surprise, experiential gaps, and the uneasy relationship between words and the life lived in the body'.¹⁰⁶ Turning to fiction instead of life-writing, Anne Whitehead critiques 'dominant understanding[s] and deployment of empathy in the mainstream medical humanities', arguing that the study of empathy should not only focus on the act of accessing the illness experiences of another, but also encompass a reflexive consideration of the limits of the affect itself through other creative formal structures.¹⁰⁷

Current scholarship in the field includes the recently published edited collection *Culture and Medicine: Critical Readings in the Health and Medical Humanities* (2022)

¹⁰² Anita Wohlmann, *Metaphor in Illness Writing: Fight and Battle Reused*, Contemporary Cultural Studies in Illness, Health and Medicine (Edinburgh: Edinburgh University Press, 2022), p. 1.

¹⁰³ Stella Bolaki, *Illness as Many Narratives: Arts, Medicine and Culture* (Edinburgh: Edinburgh University Press, 2016), pp. 1–2; .

¹⁰⁴ Sara Wasson, 'Before Narrative: Episodic Reading and Representations of Chronic Pain', *Medical Humanities*, 44.2 (2018), 106–12.

¹⁰⁵ Laura Salisbury, 'Aphasic Modernism: Languages for Illness from a Confusion of Tongues', in *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Sarah Atkinson and others (Edinburgh University Press, 2016), pp. 444–62 (pp. 445–46) <<http://www.jstor.org/stable/10.3366/j.ctt1bgzddd.30>> [accessed 7 May 2023].

¹⁰⁶ Marilyn McEntyre, 'Patient Poets: Pathography in Poetry: Pathography in Poetry', *Literature Compass*, 8.7 (2011), 455–63 (p. 455) <<https://doi.org/10.1111/j.1741-4113.2011.00779.x>>.

¹⁰⁷ Anne Whitehead, *Medicine and Empathy in Contemporary British Fiction: An Intervention in Medical Humanities* (Edinburgh: Edinburgh University Press Ltd, 2017), p. 13.

which continues the movement towards interdisciplinarity, and is notable for Travis Chi Wing Lau's chapter on an emerging crip medical humanities.¹⁰⁸ Personal narratives continue to re-emerge in the field in different forms, with the increasing focus on how engaged research might offer new, critically informed ways of collaborative and co-constructed knowledge-making.¹⁰⁹ Whitehead's recent book *Relating Suicide: A Personal and Critical Perspective* (2023) also demonstrates the ways in which expectations around the appearance of distanced objectivity in the field are now, more and more, giving way to work in which the researcher includes themselves in their inquiry. The critical turn then, is making way for new forms of interdisciplinarity and reviving traditional paradigms and approaches with a fresh attention to relations of power and a wider range of subjectivities.

Thinking across fields in *Medical Humanities and Disability Studies: In Disciplines* (forthcoming 2023), Stuart Murray suggests there is something generative in the uncertainty around where one discipline ends and another begins. He writes, 'as my own work has developed, I have found that being indisciplined provides the clearest mode for the criticism I hope to write'.¹¹⁰ Murray's book makes use of an archive of life stories on Black women's mental health, autoimmune conditions such as lupus and endometriosis, stressing their relational dimensions. Murray also reflects on the development of a crip medical humanities, noting that while there is much of value to be learned from crip and disability studies, the medical humanities too has something to offer in the exchange. Overall, looking back on work across the disability studies canon, he argues for an indisciplined approach which fosters best examples of work in both fields.¹¹¹

Texts such as Lennard Davis' *Disability Studies Reader* (1997) and Rosemarie Garland Thompson's *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (1997) contributed to the founding of an intellectual canon in their argument that disability is socially constructed, countering the narrative that it

¹⁰⁸ *Culture and Medicine: Critical Readings in the Health and Medical Humanities*, ed. by Rishi Goyal and Arden Hegele (New York: Bloomsbury Academic, 2022).

¹⁰⁹ Kelechi Anucha and others, 'Investigating Waiting: Interdisciplinary Thoughts on Researching Elongated Temporalities in Healthcare Settings', in *Temporality in Qualitative Inquiry: Theories, Methods and Practices*, ed. by Bryan C. Clift (New York: Routledge, 2021).

¹¹⁰ Stuart Murray, *Medical Humanities and Disability Studies: In Disciplines* (London: Bloomsbury, Forthcoming 2023), p. 12.

¹¹¹ Murray, p. 19.

constitutes a physical property of individual bodies.¹¹² Davis' *Reader*, however, relied on reductive "like race" analogies in making the case for the value of the emerging discipline: he argued that people with physical disabilities experienced discrimination similar to, or even worse than, other minorities and the 'time has come' to attend to this 'unequal' 'level of oppression'.¹¹³ As Alison Kafer, Mel Chen, Eunjung Kim and Julie Avril Minich recognise, Davis' critique is representative of a white disability studies that asserts that it is 'disability's turn in the spotlight, that it is time for disability studies now that "we've done race/gender/sexuality"', ignoring the 'intersectional' nature of questions of disability and access.¹¹⁴

In these early texts it is clear disability studies struggled to position itself in relation to questions of race, in a similar way to the medical humanities. The second edition of Davis' reader benefited greatly from Christopher Bell's now oft-cited contribution 'Introducing White Disability Studies: A Modest Proposal', which levelled an incisive critique at the racial homogeneity of the discipline and opened up an orientation to intersectional critique that disability studies has, by and large, maintained.¹¹⁵

Elsewhere, Bell writes about the difficulty of finding a disciplinary home for his thinking and lived experience of HIV/AIDS, moving away from literary studies and feeling drawn towards traditions of scholarship that centred activism.¹¹⁶ Bell's early work towards a Black disability studies has been taken up in the recent publication of monographs by Therí Alyce Pickens and Sami Schalk, who ground their theoretical perspectives on the lived experience of madness and illness in the speculative fiction of Black women writers such as Octavia Butler, privileging these speculative ways of knowing over the ostensible transparency of life writing.¹¹⁷ Their use of the speculative echoes Hartman's methodology of critical fabulation, and is a similarly

¹¹² Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997); *The Disability Studies Reader*, ed. by Lennard J. Davis, 1st ed (New York: Routledge, 1997).

¹¹³ Davis, p. 1.

¹¹⁴ *Crip Genealogies*, ed. by Mel Y. Chen and others, ANIMA: Critical Race Studies Otherwise (Durham, NC: Duke University Press, 2023), pp. 10, 14.

¹¹⁵ Chris Bell, 'Introducing White Disability Studies: A Modest Proposal', in *The Disability Studies Reader. 2nd Ed*, ed. by Lennard Davis (New York: Routledge, 2006), pp. 275–82.

¹¹⁶ Chris Bell, 'AIDS in Academe: A Story of Silence, Struggle and Success', in *Illness in the Academy: A Collection of Pathographies by Academics*, ed. by Kimberly Myers (West Lafayette, Ind: Purdue University Press, 2007), pp. 263–70 (p. 266).

¹¹⁷ Sami Schalk, *Bodyminds Reimagined: (Dis)Ability, Race, and Gender in Black Women's Speculative Fiction* (Durham: Duke University Press, 2018); Therí A. Pickens, *Black Madness: Mad Blackness* (Durham ; London: Duke University Press, 2019).

necessary approach to reading the occlusions and gaps in archives and literary canons that fail to capture the Black body in pain, illness and death.

Disability studies thus demonstrates a productive porousness at times lacking in the medical humanities, in the way that it has made space for connections not only with Black studies but also with queer theory. Robert McRuer was central in articulating the scope of a new strand of thinking in *Crip Theory* (2006), which brought disability studies into conversation with queer theory. Crip theory explores queerness and disability against the normativity enforced by forms of cultural and political pressure McRuer theorises as ‘compulsory heterosexuality... and able-bodiedness’.¹¹⁸ Kafer’s *Feminist, Queer, Crip* (2013) made another important contribution to crip theory in her engagement with theories of queer temporalities, by proposing the concept of crip time. Building on the social model of disability, Kafer suggests that the distinction between able-bodiedness and disability might be thought through as a question of time, as no-one moves through life without periods of heightened (inter)dependence on others.¹¹⁹ In a two-part special issue of the *Journal of Literary and Cultural Disability Studies* in 2014, McRuer and co-editor Merri Lisa Johnson coined the term ‘cripistemology’ to encapsulate the varied kinds of embodied knowing available to the disabled subject.¹²⁰ Making space as it does for ‘negativity, failure, hopelessness, and passivity’, their work paralleled Eli Clare’s groundbreaking thinking on disability and cure, which offered a further challenge to the dominance of the personal recovery narrative while reprioritising the ecological.¹²¹ More recently the theme of crip time has been expanded in ‘Crip Temporalities’, a special issue of the *South Atlantic Quarterly* edited by Elizabeth Freeman and Ellen Samuels, while *Crip Genealogies* (2023) the edited collection by Kafer, Chen, Kim and Minich further reflects on the kinds of knowledge produced by the field.¹²² Crip theory’s vital contribution to the ongoing debate about what conventional narratives occlude is to

¹¹⁸ McRuer, *Crip Theory*, pp. 1–2.

¹¹⁹ Alison Kafer, *Feminist, Queer, Crip* (Bloomington, Indiana: Indiana University Press, 2013), pp. 25–26.

¹²⁰ Merri Lisa Johnson and Robert McRuer, ‘Cripistemologies: Introduction’, *Journal of Literary & Cultural Disability Studies*, 8.2 (2014), 127–48 (p. 130).

¹²¹ Johnson and McRuer, p. 128; Eli Clare, *Brilliant Imperfection: Grappling with Cure* (Duke University Press, 2017).

¹²² Ellen Samuels and Elizabeth Freeman, ‘Introduction: Crip Temporalities’, *South Atlantic Quarterly*, 120.2 (2021), 245–54; *Crip Genealogies*, ed. by Mel Y. Chen and others, ANIMA: Critical Race Studies Otherwise (Durham, NC: Duke University Press, 2023).

offer a theoretical base from which to challenge assumptions about the kinds of temporalities and agentive subjects traditionally associated with the genre.

Significantly, there is a section of *Crip Genealogies* devoted to crip ecologies and senses, attesting to the ways in which the environment is increasingly understood as an important object of attention within disability studies. In their introduction, Kafer, Chen, Kim and Minich critique the narrow conception of access barriers, which focuses on regaining the privileges of disabled subjects with ‘white skin/citizenship/gender normativity’, ignoring the barriers faced by ‘those from economically racially suppressed communities subject to environmental injustices [without] any opportunity for remedy or reparation’.¹²³ While environmental humanities has historically occupied yet another relatively autonomous space with its own intellectual heritage, as early as 2012 *Environmental Humanities* acknowledged the extent to which ‘what have traditionally been termed “environmental issues” have been shown to be inescapably entangled with human ways of being in the world, and broader questions of politics and social justice’, in the very ways that *Crip Epistemologies* attempts to here formulate.¹²⁴ While he is identified primarily with the field of ecocriticism, Rob Nixon is an example of a scholar doing the kind of work that bridges concerns across literary studies, disability studies and the medical humanities. Notably, his seminal book *Slow Violence and the Environmentalism of the Poor* (2011) develops its key line of argument through a close reading of the protagonist of Indra Sinha’s *Animal’s People*, a physically disabled boy born within days of the 1984 Bhopal chemical disaster. Nixon argues that Sinha makes use of the elasticity of fiction maintain the political energies of his project, while navigating the risks of alienating an already oversaturated audience by over-polemicising or sentimentalising the realities of toxic pollution in the global South.¹²⁵ Elsewhere, Sarah Jaquette Ray and Jay Sibara’s edited collection *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory* (2017) created a space of recognition for the work Chen, Kafer, Clare and others were doing to acknowledge and navigate the entanglement between these concepts, expanding beyond the

¹²³ Chen and others, p. 34.

¹²⁴ Deborah Bird Rose and others, ‘Thinking Through the Environment, Unsettling the Humanities’, *Environmental Humanities*, 1.1 (2012), 1–5 (p. 1).

¹²⁵ Rob Nixon, *Slow Violence and the Environmentalism of the Poor*, First Harvard University Press paperback edition (Cambridge, Massachusetts London, England: Harvard University Press, 2013), p. 69.

personal scale of illness narratives focused on the human lifetime to think about how race, politics and disability relate to planetary temporalities.¹²⁶ In the UK, Jonathan Coope shared his anticipation of a “green turn”, arguing that ‘the project of a more ecological dimensioned medical humanities appears both timely and urgent’.¹²⁷ The field already shows signs of answering, with the publication of *The Bloomsbury Handbook to the Medical-Environmental Humanities* (2022), the first collection to bring the environmental humanities and medical humanities into conversation in a systematic way. Significantly, the handbook returns to the work of Lorde, revaluing the ways in which her early intervention in *The Cancer Journals* represented a critical and reflexive narrative in which the connections between illness, race, gender, politics and environmentalism are drawn out.¹²⁸

The depth and breadth of this survey of the literature attests to the sheer volume of scholarship which has accrued in the medical humanities around narrative. Mapping these intersecting fields of study strongly suggests the ways in which a meaningful engagement with the politics of literary representations of illness and death will find itself going beyond the medical humanities as the discipline has historically construed itself. I situate my research in this emerging landscape of heightened disciplinary openness, picking up on provocations that encourage thinking in ‘post-disciplinary’ and ‘indisciplined’ ways.¹²⁹

Part of Woods’ critique of the narrative turn in the humanities and social sciences warns against the risk of ‘overinflating what counts as narrative’ to include ‘virtually all forms of creative self-expression, including painting, poetry and dance’.¹³⁰ Writing in 2011, Woods’ concern is that this ‘risks mistaking a specific form of primarily linguistic expression for the master-trope of subjective experience’ and diverting attention ‘away from systemic analysis of the diverse functions and effects of specific types of storytelling’.¹³¹ I argue instead that narrative is already a master-trope of

¹²⁶ *Disability Studies and the Environmental Humanities: Toward an Eco-Crip Theory*, ed. by Sarah Jaquette Ray, Jay; Sibara, and Stacy Alaimo (Lincoln, NE: University of Nebraska Press, 2017), p. xv.

¹²⁷ Jonathan Coope, ‘On the Need for an Ecologically Dimensioned Medical Humanities’, *Medical Humanities*, 47.1 (2021), 123–27 (p. 123).

¹²⁸ Samantha Walton, ‘Eco-Recovery Memoir and the Medical-Environmental Humanities’, in *The Bloomsbury Handbook to the Medical-Environmental Humanities*, ed. by Scott Slovic, Swarnalatha Rangarajan, and Vidya Sarveswaran (London New York Oxford New Delhi Sydney: Bloomsbury Academic, 2022).

¹²⁹ Viney, Callard, and Woods, p. 2; Murray, p. 13.

¹³⁰ Woods, ‘Limits of Narrative’, p. 74.

¹³¹ Woods, ‘Limits of Narrative’, p. 74.

subjective experience. As scholars such as Bolaki, DeShazer, MacIntyre, Salisbury, Wasson and others have since demonstrated, expanding the formal constraints on what counts as narrative is a productive endeavour, one that encourages, rather than obscures, a deeper understanding of the interventions different forms are situated to make. Over the course of this thesis, I take up their interest in the capacity of experimental form, arguing that the narratives often absent from dominant canons and discourses can be located in a range of different formal containers.

As the literature I have surveyed suggested, for a long time narrative has been yoked with particular kinds of subjectivity central to humanism. Murray observes how in *Darkness Visible: A Memoir of Madness*, Styron can shore up his depression with reference to ‘a humanist selfhood specifically because of the social space and capital he accrues as a privileged (and here, white) novelist’. In contrast, Murray’s reading of Meri Nana-Ama Danquah’s memoir of her depression *Willow Weep For Me* (1998), demonstrates how Danquah’s racialisation as Black denies her ‘such security and community’.¹³² Part of the work of this thesis is to explore how, for those who have been consigned historically to a position outside of the category of the human, engaging with narrative form involves negotiating a politics of exclusion in ways that denote an answering attention to both the limits and experimental potential of form. The critical turn in the medical humanities has created a context in which the discipline can be characterised as ‘guilty about its humanist past and insecure about its own methodologies’, aiming ‘to acquiesce and improve its activist credentials’.¹³³ Black studies offers a sophisticated and, by now, well-developed critique of humanism. I see this as an opening to instantiate a meaningful dialogue between the fields, to think towards what is tentatively emerging as a Black health humanities, in complement to a crip and queer medical humanities.¹³⁴ In this thesis, I take up the ways in which, following Wynter, scholars such as Akwugo Emejulu have turned to theories of fugitive time and being to expose the violence of that category, or how Tiffany Lethabo King, for example, teases out the *longue durée* of the relationship

¹³² Murray, p. 43.

¹³³ Murray, p. 19.

¹³⁴ Black Health and Humanities Network, ‘About’, <www.blackhealthandhumanities.org/about/> (Accessed 5 May 2023)

between white supremacy and logocentrism.¹³⁵ In order to think beyond cancer and beyond linear narratives, attending to the racial and gendered contexts that produce and sustain illness and untimely death, it is necessary to adopt a fugitive attitude to discipline, in order to move through what scholars are increasingly coming to recognise as a system of messy conceptual ‘entanglements’.¹³⁶ I argue that key to this approach is the question of time. In the first sense, in taking time to extend the analysis of inequalities and occlusions identified by the scholars I have discussed, but also in the sense of a keen attention to both dominant and marginal temporal models.

Critical Contexts: Theories of Time

In this thesis, I explore literary representations of death alongside different forms of temporal incommensurability related to waiting: delayed or deferred milestones in the life course, the sense of “stuckness” or continuity of historical violence, interruptions, breaks, cancelled futures, circularity and forms of haunting. I think about the ways in which these forms of temporal incommensurability are expressed, occluded or challenged by different literary forms, focusing primarily on accounts of death and dying across the genres of life-writing, poetry and fiction. I am interested in their relation to formulations of marginal time existing outside of the temporalities of biomedicine and capitalism: queer temporality, crip temporality, environmental time and theories of time operative in Black studies.

These narratives emerge in a contemporary historical context regularly temporalised as neo-liberal, Late Capitalism, or Late Liberalism.¹³⁷ The first of these terms – neoliberalism – is used, as Neil Rollings points out, in multiple and contradictory ways: far better to speak of ‘neoliberalisms’.¹³⁸ It usually describes a set of policies

¹³⁵ Akwugo Emejulu, *Fugitive Feminism* (London: Silver Press, 2022), p. 35; Tiffany Lethabo King, *The Black Shoals: Offshore Formations of Black and Native Studies* (Durham: Duke University Press, 2019), p. 88.

¹³⁶ Des Fitzgerald and Felicity Callard, ‘Entangling the Medical Humanities’, in *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Sarah Atkinson, Jane Macnaughton, and Jennifer Richards (Edinburgh University Press, 2016), pp. 35–49 (p. 36); Bleakley, p. 8.

¹³⁷ Lisa Baraitser, *Enduring Time* (London Oxford New York, NY New Delhi Sydney: Bloomsbury Academic, 2017), p. 159.

¹³⁸ N. Rollings, ‘Cracks in the Post-War Keynesian Settlement? The Role of Organised Business in Britain in the Rise of Neoliberalism Before Margaret Thatcher’, *Twentieth Century British History*, 24.4 (2013), 637–59 (p. 642).

that emerged in or around the UK in the 1970s as cracks in the post-war settlement began to appear. Citing Stephanie Lee Mudge, neoliberal periodicity seems to enfold an 'ideational or intellectual project' and also 'the policies and the rhetorical parameters of political contest', both built an underlying principle of 'the superiority of individualized, market-based competition over other modes of organization'.¹³⁹

The notion of Late Capitalism is central to the work of contemporary queer theorist Lauren Berlant, whose 'point of departure' for their influential essay 'Slow Death (Sovereignty, Obesity, Lateral Agency)' is David Harvey's polemical assertion that capitalism defines illness as the inability to work.¹⁴⁰ In their book *Cruel Optimism* (2011), Berlant explores the paradox of late capitalism which forces individuals into libidinal investments in systems which exploit, undermine and ultimately destroy their health, futurity and wellbeing.¹⁴¹ The concept is also rooted in the canon of western political philosophy, namely in Fredric Jameson's *Postmodernism, or, the Cultural Logic of Late Capitalism* (1989). Jameson's cultural analysis of the postmodern takes as its basis Ernest Mandel's Marxist elaboration of late, or end-stage capitalism. Mandel recognises the 'arrival and inauguration of a whole new type of society', one that is 'consumer' 'media' 'information' 'electronic' and 'high tech' oriented. Mandel sees this intensification in classical capitalism of 'the primacy of industrial production and the omnipresence of class struggle', as 'a third stage or moment in the evolution of capital'.¹⁴² Cedric Robinson's analysis of a specifically 'racial capitalism' adds a useful further dimension to the understanding of how racism 'inevitably permeate[d] the social structures emergent from capitalism', shifting 'the center of radical thought and revolution from Europe to the so-called "periphery"', extending the field of inquiry to include 'the colonial territories, marginalised [people]...those Frantz Fanon identified as the "wretched of the earth"'.¹⁴³

The nature of medical time is also significant. As doctoring work within the National Health Service (NHS) towards the late-twentieth century is brought in line with standards of professionalism, clinical practice is increasingly expected to conform to

¹³⁹ S. L. Mudge, 'What Is Neo-Liberalism?', *Socio-Economic Review*, 6.4 (2008), 703–31 (pp. 704–7).

¹⁴⁰ Lauren Berlant, 'Slow Death (Sovereignty, Obesity, Lateral Agency)', *Critical Inquiry*, 33.4 (2007), 754–80 (p. 754).

¹⁴¹ Lauren Berlant, *Cruel Optimism* (Durham: Duke University Press, 2011), pp. 1, 13.

¹⁴² Fredric Jameson, *Postmodernism, or, The Cultural Logic of Late Capitalism*, *Post-Contemporary Interventions* (Durham: Duke University Press, 1991), p. 3.

¹⁴³ Robinson, pp. xii, 2.

principles of efficiency: skilful time management for maximum productivity. As part of the ‘Watchful Waiting’ stream of the Waiting Times project, Martin Moore has historicised the shifting temporalities General Practitioners (GPs) are under pressure to negotiate, noting that ‘in growth of collectivised state funding for health care, time in NHS general practice was increasingly divided into standard abstract units, synchronised with public time, and cast as an economic resource that needed to be spent wisely and in the most efficient manner possible’.¹⁴⁴ In the same project stream, Stephanie Davies is doing extensive work from a psychosocial perspective on the temporal practices GPs in the NHS use to manage their workloads – in the context of pressures to be *doing*, waiting (as ostensibly “passive”) is an undervalued *practice of everyday life*, one difficult to locate as an object of study.¹⁴⁵ Their work can be situated within traditions of historical and sociological research tracking the changing temporalities of medical care.¹⁴⁶

What kind of units and models are a feature of clinical settings? ‘For doctors, time is constructed in relationship to both ...task[s] and existing socio-temporal structures [such as] ward rounds and outpatient appointments’.¹⁴⁷ Temporal priority setting models used to organise care, such as ‘triage’, are familiar. Practitioners hold regular clinics of particular, recurring duration. They sometimes describe setting aside a weekly designated time to write up patient notes: the demand to perpetually update digital notes databases disrupts time and challenges the ability to provide care.¹⁴⁸ For senior clinicians, medical time is necessarily also filled with auditing and teaching

¹⁴⁴ Martin Moore, *Hurry up and Wait: Time, Care and Waiting in English General Practice 1948 - 2018* (Forthcoming).

¹⁴⁵ Stephanie Davies, ‘Waiting, Staying and Enduring in General Practice’ (unpublished doctoral thesis, Birkbeck, University of London, 2022), p. 24, in Birkbeck Institutional Research Online [accessed 3 August 2023].

¹⁴⁶ MacBride-Stewart’s article comprehensively draws together the work on time and doctoring in these fields; among the highlights are J.A Roth, *Timetables: Structuring the Passage of Time in Hospital Treatment and Other Careers* (Indianapolis: Bobbs-Merrill Company, 1963); P Pritchard, ‘Doctors, Patients and Time’, in *Time, Health and Medicine*, ed. by R. Frankenberg (London: Sage, 1992); Sarah Nettleton, Roger Burrows, and Ian Watt, ‘Regulating Medical Bodies? The Consequences of the “Modernisation” of the NHS and the Disembodiment of Clinical Knowledge: NHS “Modernisation” and the Consequences for Doctors’, *Sociology of Health & Illness*, 30.3 (2007), 333–48 <<https://doi.org/10.1111/j.1467-9566.2007.01057.x>>.

¹⁴⁷ Sara MacBride-Stewart, ‘The Effort to Control Time in the “New” General Practice: The Effort to Control Time in the “New” General Practice’, *Sociology of Health & Illness*, 35.4 (2013), 560–74 (p. 561) <<https://doi.org/10.1111/j.1467-9566.2012.01503.x>>.

¹⁴⁸ Private conversation, Waiting Times advisory board meeting.

responsibilities. These conditions produce an NHS workforce who must constantly improvise in order to manage the increasing proliferation of bureaucratic tasks.

On a larger scale, the naming of certain NHS provisions, such as ‘urgent care centres’, or ‘Out-of-Hours’ services, underline the heightened regulation of time and the ways in which medical care has moved away from the cultural ideal or trope of a doctor who is ready to answer a call to the bedside at any hour of the day or night. One practitioner remarked dryly that it is in the patient’s best interest to fall ill Monday – Friday, 09:00 – 17:00.¹⁴⁹ The NHS’s increasing deployment of locum clinicians also results in doctor-patient relationship circumscribed by time, characterised by immediacy rather than continuity.

Conscious that my focus leans primarily towards writing emerging from a US context, I note a similar emphasis on neoliberal management in American medical institutions. In chapter two of this thesis in particular, I discuss the ways in which the forward thrust of medical discoveries and pharmaceutical innovation have come at the cost of Black bodies: from J. Marion Sims’ violent experiments on enslaved Black women in the service of gynaecology, and Albert Kligman’s experiments to develop the ubiquitous cosmetic ingredient retinol on the local Black inmates, to the Tuskegee Syphilis Study.¹⁵⁰ Yet these unvalued demographics, whose bodies provide the sites on which the forward-moving temporality of medicine can consolidate itself, are themselves left behind in the provision of care. More so even than UK medical institutions, the American medical system demonstrates how its temporal dynamics are driven by notions of value and capital. Reflecting on her experience of chemotherapy, Boyer describes how, in a logic where time equates with money, ‘bodies must orbit around profit at all times, even a double mastectomy is considered an outpatient procedure’. After her invasive surgery, Boyer describes

¹⁴⁹ Closed workshop, Waiting Times Clinician’s Day.

<<http://waitingtimes.exeter.ac.uk/2019/08/17/temporalities-of-clinical-practice-12-june-2019>> [accessed 3 January 2020]

¹⁵⁰ D Ojanuga, ‘The Medical Ethics of the “Father of Gynaecology”, Dr J Marion Sims.’, *Journal of Medical Ethics*, 19.1 (1993), 28–31 <<https://doi.org/10.1136/jme.19.1.28>>; Allen M. Hornblum, *Acres of Skin: Human Experiments at Holmesburg Prison: A Story of Abuse and Exploitation in the Name of Medical Science* (New York: Routledge, 1998); Vanessa Northington Gamble, ‘Under the Shadow of Tuskegee: African Americans and Health Care’, *American Journal of Public Health*, 87.11 (1997).

how, 'the eviction from the recovery ward came aggressively and early...they made me leave, and I left'.¹⁵¹

My thinking on temporal incommensurability moves outwards from a question: if the temporality of medical treatment is intensively regulated and increasingly dictated by workplace norms such as "efficiency" and "productivity", then how might what some critical theorists have named as 'queer time' offer itself as a counterpoint? Queer theory erupted into literary and cultural studies in the 1990s and is a movement oriented, temporally and affectively, backwards – focused on its origins in the HIV/AIDS epidemic of the 1970s and 1980s.¹⁵² It initially progressed through a deep engagement with the past, as many of its scholars evidence an abiding interest in the long nineteenth century.¹⁵³ This temporal orientation could not be more different from the emphasis on efficiency that characterises the forward thrust of Medicine-as-Management-Consultancy.

In a 1995 article *What Does Queer Theory Teach Us About X?*, Berlant and Michael Warner observe that 'word of new intellectual developments tends to travel...like gossip', perceiving that their article itself constituted 'an invitation to pin the queer theory tail on the donkey', in the flurry of critical activity determined to produce a queer theory cottage industry.¹⁵⁴ The primary vehicles of the early field were 'the star system, which allows a small number of names to stand in for an evolving culture' and graduate students, who unlike faculty members, were the majority 'practitioners of the new queer community'.¹⁵⁵ These conditions support the sense that, compared to more established literary critical traditions (such as structuralism), queer theory might indeed behave like gossip: 'casual, unconstrained', easy in its status of being not positively disproved or positively verifiable.¹⁵⁶

¹⁵¹ Boyer, *The Undying*, p. 149.

¹⁵² Lauren Berlant and Michael Warner, 'Guest Column: What Does Queer Theory Teach Us about X?', *PMLA*, 110.3 (1995), 343–49 (p. 344).

¹⁵³ See Eve Kosofsky Sedgwick, "'Jane Austen and the Masturbating Girl'", in *Tendencies* (Durham: Duke University Press, 1993); Lauren Berlant, 'The Female Woman: Fanny Fern and the Form of Sentiment', *American Literary History*, 3.3 (1991), 429–54; Elizabeth Freeman, *Beside You in Time: Sense Methods and Queer Sociabilities in the American Nineteenth Century* (Durham: Duke University Press, 2019).

¹⁵⁴ Berlant and Warner, p. 343.

¹⁵⁵ Berlant and Warner, p. 343.

¹⁵⁶ 'Casual or unconstrained conversation or reports about other people, typically involving details that are not confirmed as being true'. 'Gossip, n.', *Lexico* (Dictionary.com; Oxford University Press, 2020) <<https://www.lexico.com/en/definition/gossip>> [accessed 10 January 2020].

I highlight this to suggest, more importantly, true to the ‘gossip’-like propensities of the field, there is no single coherent articulation of “queer time”. Rather, the term brings together a host of disparate work under its banner. The most cogent example of these overlaps and clashes in the literature can be found in the edited roundtable discussion in the *GLQ* ‘Queer Temporalities’ special issue, published in 2007. As chair, Freeman invites colleagues to reflect on ‘how and why the rubric of temporality became important to [their] thinking as ...queer theorist[s]’.¹⁵⁷ It becomes clear that Jack Halberstam, who wrote *In a Queer Time and Place: Transgender Bodies, Subcultural Lives* (2005), formulates a trans-centric queer temporality very different from Lee Edelman, who is invested in the afterlives of Freudian psychoanalysis in the anti-reproductive refusal of the future by white, middle-class gay men.¹⁵⁸ Carla Freccero, on the other hand, invokes queerness in relation to the deathly historicity of her medieval subjects.¹⁵⁹ I am forcefully arrested by this formulation of queer time, and indeed queer lives, as already haunted and somehow deathly.

These scholars also pay attention to how queer time diverges from the reproductive time of heteronormativity. Freeman in fact speaks of the ‘chrononormativity’ used to manage entire populations: ‘marriage, the accumulation of health and wealth for the future, reproduction, childrearing, death and its attendant rituals’ which relate ‘properly temporalized bodies with narratives of movement and change’.¹⁶⁰ This formulation echoes through my thesis as a refrain, highlighting the linear temporal contexts in which conventional illness narratives are both positioned and position themselves. Halberstam similarly argues that ‘queer subcultures produce alternative temporalities by allowing their participants to believe that their futures can be imagined according to logics that lie outside of those paradigmatic markers of life experience – namely, birth, marriage, reproduction and death’.¹⁶¹ A queer relation to time necessarily seeks to assign value outside of these linear and productivity-oriented temporal conventions. Sedgwick’s account of conflictual queer time in *Touching Feeling* is a related intervention, which breaks up the congealed realities of

¹⁵⁷ C. Dinshaw and others, ‘Theorizing Queer Temporalities: A Roundtable Discussion’, *GLQ: A Journal of Lesbian and Gay Studies*, 13.2–3 (2007), 177–95 (p. 177) <<https://doi.org/10.1215/10642684-2006-030>>.

¹⁵⁸ *Ibid.*, pp. 181–182.

¹⁵⁹ *Ibid.*, p. 184.

¹⁶⁰ Elizabeth Freeman, *Time Binds: Queer Temporalities, Queer Histories, Perverse Modernities* (Durham [NC]: Duke University Press, 2010), p. 4.

¹⁶¹ Jack Halberstam, *In a Queer Time and Place: Transgender Bodies, Subcultural Lives, Sexual Cultures* (New York: New York University Press, 2005), p. 2.

generational time. Reading Marcel Proust “queerly” Sedgwick identifies a particular kind of ‘temporal disorientation’ in the face of mortality that is not possible in a ‘heterosexual pere de famille’, one of inexorably “progressing” identities, occasioned by the ‘regular arrival of children and grandchildren’.¹⁶² Sedgwick, parsing Proust, writes: ‘the narrator, after a long withdrawal from society, goes to a party where he at first thinks everyone is sporting elaborate costumes pretending to be ancient, then realises that they *are* old’.¹⁶³ How could he fail to apprehend such a significant passing of time? He must be out of time – or at least, out of generational time. Again and again temporal disorientation is encountered as a break with certain kinds of emotional palliatives linked with heteronormativity and conventional family structures. Staying with Proust, it is striking that the “time slip” at the beginning of *In Search of Lost Time* (1913) revolves around his mother’s failure to put him to bed – a kind of shattering or break with the guarantee of maternal temporality.¹⁶⁴ This alternate time that is also queer time, is characterised by a strange propensity for accelerations (through time, out of youth) and, simultaneously, stasis (in the face of pressure to progress through that linear pathway of family identity categories). In contrast to the reproductive temporalities of capitalism, forms of queer and crip time look outwards from the nuclear family to endorse multiplicitous forms of interdependence and relationality.

Crip theory offers a related perspective which reconfigures dominant understandings of time. It emerged as a critical intervention within disability studies that shares many features with queer theory. As noted, Kafer in *Feminist, Queer, Crip* reflects on the extent to which the socially constructed category of disability is also ‘a matter of time’.¹⁶⁵ Theories of crip time and crip futurity from McCruer and others are able to accommodate the difficult temporalities of chronic illness, while exploding mythologies that circumscribe futures for those who are not able-bodied.¹⁶⁶

Samuels writes that ‘crip time is time travel’, describing the propensity of disability and illness to confound ‘linear, progressive time with its normative life stages’ and

¹⁶² Sedgwick, *Touching Feeling*, p. 148.

¹⁶³ *Ibid.*, pp. 147 – 149.

¹⁶⁴ Marcel Proust, Lydia Davis, and Christopher Prendergast, *In Search of Lost Time. 1, 1*, (London: Penguin Books, 2003), p. 10.

¹⁶⁵ *Ibid.*, p. 26.

¹⁶⁶ McCruer, *Crip Theory*, p. 5.

introduce instead ‘a wormhole of backward and forward acceleration, jerky stops and starts, tedious intervals and abrupt endings’.¹⁶⁷ This configuration of time has much in common with the eruptions of the past Black studies scholars identify as a feature of racism. In their introduction to the *South Atlantic Quarterly* special issue on ‘Crip Temporalities’ (2021), Freeman and Samuels reflect on how the temporal shifts occasioned by COVID-19 initiated most otherwise able-bodied people into this crip time. They note how a wider demographic both inside and outside the academy were forced by the pandemic to navigate the kinds of temporal incommensurability that marginalised communities have long had to negotiate as a matter of course: struggles with ‘energy and motivation’, with balancing ‘exigencies...with expectations of professional performance, running out of hours in the day and energy in their bodyminds to keep up’.¹⁶⁸ In answer to these expanding temporal pressures, articles in the special issue puts forward the value of forms of slowed as suspended time: Margaret Price ‘foregrounds slowness as a key feature of academic crip time’; Moya Bailey offers the ‘ethics of pace’ a strategy for navigating the death drive of academic productivity for sick or disabled women of colour; Jina B. Kim and Schalk enact a crip-of-colour critique that rejects neoliberal notions of self-care as self-management in favour of community and personal survival.¹⁶⁹ More recently, *Crip Genealogies* has questioned the common practice of temporally organising research developments into ‘waves’, or even ‘fields’, arguing that these appellations ‘inscribe colonial temporalities and spatialities into our conceptions of scholarship’.¹⁷⁰ The introduction argues for an awareness of how this orientation towards knowledge, driven by the temporal imperatives of the institution, separate knowledge and the attribute of being able to know ‘from the communities most affected’ by questions of disability and health.¹⁷¹

Time is also central to a relatively new cluster of research and thinking in Black studies. This body of critical work takes as its point of departure the routine cataclysm of untimely Black death; thinking here begins from diurnal world-endings caused by the deaths of Black people across the diaspora. In his chapter within the

¹⁶⁷ Ellen Samuels, ‘Six Ways of Looking at Crip Time’, *Disability Studies Quarterly*, 37.3 (2017) <<https://dsq-sds.org/article/view/5824/4684>>.

¹⁶⁸ Samuels and Freeman, p. 247.

¹⁶⁹ Samuels and Freeman, pp. 249–50.

¹⁷⁰ Chen and others, pp. 14, 16.

¹⁷¹ Chen and others, p. 17.

edited volume *Time, Temporality and Violence in International Relations* (2016), Jared Sexton asks ‘what is the time of slavery?’¹⁷² Drawing on Hartman’s 2002 article ‘The Time of Slavery,’ as well as Fred Moten and Stefano Harney’s book *The Undercommons*, to conclude ‘we understand the time of slavery as a coeval temporality of the past, present and future’.¹⁷³ Charles W. Mills writes similarly of ‘white time’, the temporality of settler-colonialism, slavery and other racial regimes, which forcefully organise and redistribute time along racial lines as an extension of power.¹⁷⁴

The strain of this thought most significant for this project can be found in Christina Sharpe’s monograph *In the Wake: On Blackness and Being* (2016). Living in the wake describes a temporality which is both absolutely connected to the anterior event of racial subjugation and yet is its own individual, everyday phenomena. The wake is a polysemic spacio-temporality that for Sharpe signifies the afterlives of slavery; the suspension of the ordinary pressures of capitalist time in order to hold vigil with the dead or dying, which is both a kind of being-with, a form of celebration and a form of consciousness, in the sense of being awake to the historic, economic and social driving forces behind ongoing racial injustice.¹⁷⁵ Sharpe foregrounds the way in which ‘pastness’ is a privileged position, rather than an absolute, and how it can suddenly rupture the present. For Sharpe and other scholars in the field, theorising anti-blackness involves a perpetual reckoning with and reconfiguring of dominant understandings of time.

Significant also to this thesis is the concept of fugitivity, which I bring together with care as a new intervention. Formulations of fugitivity in Black studies can be thought through as a question of time, emerging as they do from an understanding of the *longue durée* of racism. In Moten’s scholarship, fugitivity names a way of being in the world, embodied first by ‘the shipped’ – those racialised as black and subjugated by the Transatlantic slave trade – bestowed by the ‘terrible gift’ of the hold of the ship as

¹⁷² Jared Sexton, ‘The Social Life of Social Death On Afro-Pessimism and Black Optimism’, in *Time, Temporality and Violence in International Relations (De)Fatalizing the Present, Forging Radical Alternatives*, ed. by Kyle D. Killian and Anna M. Agathangelou (London: Routledge, 2016), p. 70.

¹⁷³ *Ibid.*, p. 71.

¹⁷⁴ Charles W. Mills, ‘White Time: The Chronic Injustice of Ideal Theory’, *Du Bois Review: Social Science Research on Race*, 11.1 (2014), 27–42 (p. 31) <<https://doi.org/10.1017/S1742058X14000022>>.

¹⁷⁵ Christina Elizabeth Sharpe, *In the Wake: On Blackness and Being* (Durham London: Duke University Press, 2016), pp. 5, 10 -11, 14.

both a literal and figurative imaginary describing spaces of temporally enduring racialised violence.¹⁷⁶ Being fugitive also turns on an oppositional relation to the temporally bounded category of the Human, which historically and into the present has applied only to certain subjects at culturally and institutionally regulated moments. Moten's theorisation of fugitivity is bound up with Hortense Spillers' Black feminist ontology of the captive, who through the dehumanising violence of the hold become 'ungendered' 'flesh'.¹⁷⁷ Formulations of fugitivity embrace this ontology of gendered flesh by, in Emejulu's words, 'fleeing humanity'. Fugitivity is 'escapology', the art, dedicated study and practices of those in flight from the 'routine material violence of the slave economy and the symbolic violence of our status as the non-human Other, from which whiteness and humanity draw their meaning and purpose'.¹⁷⁸ This orientation towards flight opens up a space beyond an existence of abjection, one in which dreaming, fantasy, speculation, hope and collectivity gain heightened value and potency.¹⁷⁹

In this way, fugitivity is also futurity – an orientation to that which has not yet come into being. Returning to Ghana to retrace the broken lineages of her own enslaved ancestors in *Lose Your Mother: A Journey Along the Atlantic Slave Route*, Hartman unpicks how the literal flight of the Sisala was enabled and sustained by a flight of the mind. In 'dream[ing] of farms and watching their children grow up rather than disappear...dream[ing] of toiling for themselves' without the hierarchies and abusive appellations which marked them as less than human, freedom 'acquired texture and detail in their imaginations, so a place that they had never set their eyes on became tangible and then their own'.¹⁸⁰ Part of what I am proposing when I talk about fugitive care is that such dreaming constitutes a raw form of care, often the only care for futurity and survival possible to offer in unlivable conditions. Whilst aware of the challenges of using fugitivity as a trope that, in the words of George Shulman 'risks a glib disavowing (or trading on) its literal meaning',¹⁸¹ I follow Shulman in reading

¹⁷⁶ Stefano Harney and Fred Moten, *The Undercommons: Fugitive Planning & Black Study* (Wivenhoe New York Port Watson: Minor Compositions, 2013), pp. 95, 97.

¹⁷⁷ Hortense J. Spillers, 'Mama's Baby, Papa's Maybe: An American Grammar Book', *Diacritics*, 17.2 (1987), 64 (p. 65).

¹⁷⁸ Emejulu, p. 35.

¹⁷⁹ Emejulu, p. 11, 35, 36, 38.

¹⁸⁰ Hartman, p. 353.

¹⁸¹ George Shulman, 'Fred Moten's Refusals and Consents: The Politics of Fugitivity', *Political Theory*, 49.2 (2021), 272–313 (p. 305).

Moten's fugitivity as a way of seeing that is 'neither ethnically closed nor symbolically foreclosed, but politically and aesthetically open'.¹⁸² Halberstam echoes this sentiment, stating 'the coalition unites us in the recognition that we must change things or die. All of us'.¹⁸³ This openness makes way for reading practices of fugitive orientation and care across the wide range of texts I examine in this thesis.

Cumulatively, formulations of fugitivity seem to suggest something about what it is to live in an, at times, impossible state of paradox; to be 'more and less than one'; to refuse what has been refused to you.¹⁸⁴ For Moten, this paradox is also temporal: the fugitive is perpetually in flight, suspended in a meanwhile between escape and arrival. The fugitive 'always feel like running / Not away, because there is no such place', because the thing they fear 'cannot be escaped / Eluded, avoided, hidden from, protected from, gotten away from...'.¹⁸⁵ Fugitive care then, defies temporal logic by materialising in unexpected and unorthodox times and places; Sharpe herself finds them both by the deathbed and in the cadence of poetry. In her brother Stephen's last moments, Sharpe relates how friends and family gathered around his bed 'shared stories, played music, laughed and told [him] how much [they] loved him'.¹⁸⁶ However even in this space of care, Sharpe registers an awareness of the ever present 'Weather' – an 'orthography', or grammar, which 'registers and produces the conventions of anti-blackness in the present and into the future'.¹⁸⁷ Here, it takes the form of the medical racism which makes it necessary for the family to work hard to ensure Stephen received the palliative medication he needed.¹⁸⁸ Sharpe's analysis of Dionne Brand's 'Ruttier for the Marooned in the Diaspora' notes in the poem a similar awareness of the double-time of the 'Weather' and consequent necessity of 'way-making'.¹⁸⁹ Facing what Hartman has encapsulated as the 'skewed life chances' and the probability of early death,¹⁹⁰ engagements with fugitivity here and elsewhere express how Black people across the diaspora, and indeed

¹⁸² Shulman, p. 283.

¹⁸³ Halberstam, 'The Wild Beyond: With and for the Undercommons', p. 10.

¹⁸⁴ Harney and Moten, pp. 95, 98.

¹⁸⁵ Gil Scott-Heron, 'Running', *I'm New Here* (XL Recordings, 2010).

¹⁸⁶ Christina Sharpe, *In the Wake: On Blackness and Being* (Durham: Duke University Press, 2016), p. 10.

¹⁸⁷ Sharpe, *In the Wake*, p. 11.

¹⁸⁸ Sharpe, *In the Wake*, p. 10.

¹⁸⁹ Sharpe, *In the Wake*, p. 107.

¹⁹⁰ Hartman, p. 25.

marginalised communities of ‘Others’ living under the same conditions, might improvise community, care and conviviality, even in the time of extremis.

The time of racial capitalism is also the time of environmental crisis. This has been theorised in different ways. Nixon’s theory of ‘slow violence’, for example, names the ‘long dyings’ of communities and ecologies extending over time, produced by industrial pollution and military conflict.¹⁹¹ More recently, Kathryn Yusoff, drawing from work across Black studies has challenged the ‘undifferentiating and indifferent politic’ of the Anthropocene, a term used to describe this epoch of human impact on the environment.¹⁹² Here again the category of the human is unevenly applied, erasing the relations of power which drive and sustain climate change. Yusoff observes that ‘the past [is] the present [in] colonial mining empires of white settler nations’, just as the Anthropocene is a project of ‘White Geology’.¹⁹³ She aims to call attention to ‘how the descriptive qualities of geology’s nomenclature produce what Hartman calls a “cultivated silence” about the normalcy of those extractive modes as deracialized’.¹⁹⁴

I draw on these theories of the politics of (un)timeliness to attend to representations of death in marginal communities across a selection of literary texts. Dying in these texts is notable for its excess: it overflows familial and generational distinctions, or else appears suddenly or goes on too long to be neatly captured by dominant literary forms. I take up the call to attend to forms of extended temporalities that Lisa Baraitser makes in *Enduring Time* (2017). These ‘temporal tropes...are linked together by an apparent lack of dynamism or movement: waiting, staying, delaying, enduring, persisting, repeating, maintaining, persevering and remaining, in an attempt...to investigate the potential for transcending the immanence of [a] historical moment in...the places that it looks...impossible to happen, and to understand this transcendence in terms of something...call[ed] care’.¹⁹⁵ Over the course of the three chapters of the thesis, I attempt to trace the temporal paradoxes and contradictions of the texts I explore, enacting care both as Baraitser has defined it, and, in the

¹⁹¹ Nixon, p. 2.

¹⁹² Kathryn Yusoff, *A Billion Black Anthropocenes or None*, Forerunners: Ideas First from the University of Minnesota Press, 53 (Minneapolis: University of Minnesota Press, 2018), p. 13.

¹⁹³ Yusoff, p. 13.

¹⁹⁴ Yusoff, p. 13.

¹⁹⁵ Lisa Baraitser, *Enduring Time* (London Oxford New York New Delhi: Bloomsbury Academic, 2017), pp. 13–14.

words of Sharpe, as a kind of regard and attention. Sharpe writes, significantly, that ‘regard is a habit of care. It is appreciation and esteem. It is the right of repair’.¹⁹⁶

Thesis Outline

In chapter one, I consider women’s cancer narratives published in the 1990s, identifying two different traditions with distinct genealogies, politics, formal and temporal styles. Kathlyn Conway’s *Ordinary Life* (1997) and Ruth Picardie’s *Before I Say Goodbye* (1998) are popular examples of the genre that reflect gendered expectations of women around motherhood and femininity. In their narratives, cancer appears as a moment of rupture within an otherwise linear progression through such milestones, emphasising a conventional orientation to temporality even as they mourn its disruption. In contrast, Rose’s memoir *Love’s Work* and Sedgwick’s *A Dialogue on Love* (1999) demonstrate a different relation to time and can be situated within an alternative genealogy of queer women’s cancer narratives which can be traced back to Lorde’s *The Cancer Journals*, one that acknowledges points of contact between experiences of cancer and the HIV/AIDS crisis. I argue that *Love’s Work* and *A Dialogue on Love*, like texts produced by their contemporaries Kathy Acker and Jackie Stacey, are queer in the sense that they challenge gender expectations and place value on relationships outside of nuclear and heterosexual relational constellations. Through innovations in form and an emphasis on queer coalition and kinship, they approach the experience of illness as a further opportunity to challenge notions of value and care as ordinarily conceived within labour-oriented temporal frameworks.

I suggest they also demonstrate a willingness to dwell in the temporality of the Other, in an act of what Salisbury has thought through as ‘waiting *with*’.¹⁹⁷ In their different ways, Rose and Sedgwick revive the spiritual connotations of this kind of waiting as a form of vigil, discipline and service. In their work, gestures of queer kinship work to close the temporal gap which separates the historic stigma of cancer from the more immediate social stigmas associated with HIV/AIDS. In these texts, the failure of

¹⁹⁶ Sharpe, *Ordinary Notes*, p. 256.

¹⁹⁷ Laura Salisbury, “‘Between-Time Stories’: Waiting, War and the Temporalities of Care’, *Medical Humanities*, 46.2 (2020), 96–106 (p. 100).

medical institutions to foster spaces and affects of care becomes the ground for the different forms of inventive, improvised strategies and allegiances of what I have named as fugitive care, employed by the 'black people, indigenous peoples, queers and poor people' that Halberstam recognises as part of Moten's fugitive undercommons.¹⁹⁸

In chapter two I examine experiences of Black death and dying in a US context, addressing a demographic often unaccounted for in the kinds of narratives explored in chapter one. I draw on a significant body of research which demonstrates the ways in which Black people across the diaspora experience poorer health outcomes and shorter lives than their counterparts, connecting these experiences to what Hartman has called 'the afterlives of slavery' and what Sharpe has theorised as the 'Weather' and the 'wake' – the pervasive conditions of anti-blackness in the past and present.¹⁹⁹

Through readings of Edwidge Danticat's *Brother, I'm Dying* (2007), and Jesmyn Ward's *Men We Reaped* (2013), I argue for an expanded understanding of how narratives of chronic illness and death appear. While both memoirs represent Black people's experiences of disease and dying, neither have received sustained critical attention within the medical humanities. *Men We Reaped* also highlights the real sense in which many Black chronic illness or cancer narratives do not materialise because members of this demographic simply do not live long enough to develop diseases that typically present in the mid- and later-life.

Anticipating a line of argument I explore more fully in chapter three, I suggest that both memoirs represent death as fundamentally intertwined with life: rather than intruding as a moment of rupture, death underwrites reality for those excluded from the category of the Human. Significantly, Danticat and Ward present illnesses in their plural rather than singular forms, enveloping within their texts multiple narratives of illness which contribute to the broader racialised meanings they attach to death and dying. In this way, the expansive focus of *Brother, I'm Dying* and *Men We Reaped* capture how experiences compound generationally and are imbricated in wider environmental factors such as climate change and failing infrastructure.

¹⁹⁸ Halberstam, 'The Wild Beyond: With and for the Undercommons', p. 6.

¹⁹⁹ Hartman, *Lose Your Mother*, p. 25; Sharpe, *In the Wake*, p. 11.

Death in these texts often follows in the wake of the failure to be seen or “read” at critical moments. I argue that the narrative mode also represents a kind of complex attachment for Ward and Danticat, as narrating these marginal experiences of death holds out the posthumous possibility of becoming legible within a historic, logocentric system of white supremacy. Taking further the scholarship that has looked to expand the formal constraints of the illness narrative genre, I extend my argument to include poetry in the Black radical tradition, suggesting it offers a unique insight into strategies of fugitive care and survival. Reading Harryette Mullen’s poem ‘All She Wrote’ from the collection *Sleeping with the Dictionary* (2002), and Claudia Rankine’s *Citizen* (2014), I argue that the opacity and formal breaks native to poetry might offer a temporary reprieve or, even “shelter” from the ongoing temporality of racism. In contrast to the vexed histories of linear narrative, poetry presents itself as a site of integration which reasserts and reconfigures a productively fugitive relation to life under conditions of un-livability. What emerges from this chapter is an argument for the poetic form as a ground for care in relation to Black diasporic survival.

In the third and final chapter of this thesis I argue that the politics of illness and untimely death are shaped not only by gender and race, as argued in chapters one and two, but also increasingly by the ecological environment in the form of toxic pollution and climate change. Noting the “green” turn in the medical humanities, I consider how poverty and race intersect with environmental devastation to produce experiences of death and disease that are unequally distributed. With this in view, I reflect on the compounded impact of the petrochemicals industry on a cluster of coastal communities in the US, considering how their lived experiences are represented in Antonetta’s memoir *Body Toxic* (2001) and Ward’s novel *Salvage the Bones* (2011). I read them in conjunction with Boyer’s genre-defying cancer memoir *The Undying* (2019), an example of a text that “counts” as a cancer memoir in the illness narrative tradition while challenging and expanding past and existing definitions of the form. I suggest Boyer’s exploration of the ways in which cancer is a political, environmental and social disease creates a context in which *Body Toxic* and *Salvage the Bones* become freshly legible as literatures of illness and death. I argue that collectively these texts demonstrate how poverty and race are central to a necropolitics of ‘slow violence’ and “letting die” that shapes the existence of so-called

‘sacrifice communities’: poor, rural and ethnically diverse areas ‘chosen to house...toxic waste and nuclear power’.²⁰⁰²⁰¹²⁰² In so doing, they challenge the racial homogeneity of environmentalism and provide a compelling case for a further expansion of understandings of illness narratives beyond the scale of the personal and the individual.

I also take up Boyer’s conceptualisation of the ‘undying’— a collective of chronically ill people living with cancer, spanning time and space. I build on this concept with reference to the work of performance artist and scholar Martin O’Brien, who has theorised on the ‘zombie’ temporalities of those who outlive their prognosis and written about the ‘Last Breath Society’: those willing to both acknowledge and embrace their proximity to death.²⁰³ I use these figurations of the “undead” to think about how those bracketed off from life by ‘necropolitics’ negotiate their death-in-life through relations of collectivity and fugitive caring.²⁰⁴

Over the course of these chapters, I read against the conventions of individualism in illness narrative form and the medical humanities field. In her essay ‘The Carrier Bag Theory of Fiction’, Ursula Le Guin explores how narrative form has been dominated by the story of the hero, who presses others into the service of the masculinist forward thrust of his tale.²⁰⁵ For him, ‘the proper shape of the narrative is that of the arrow or the spear, starting here and going straight there and THOK! Hitting its mark’.²⁰⁶ As Le Guin wryly suggests, narrative is replete with the metaphorical ‘sticks and spears and swords’ that symbolise a certain kind of heroic agency and action, yet less attention has been granted to the unimposing ‘sack’ or ‘bag’ which models how to hold concepts, experiences and identities ‘in a particular, powerful relation to one another’.²⁰⁷ In this thesis I track how the writers I examine explore the relational potential of form, focusing on how temporal incommensurability reveals new insights

²⁰⁰ Nixon.

²⁰¹ Achille Mbembe and Steve Corcoran, *Necropolitics*, Theory in Forms (Durham: Duke University Press, 2019).

²⁰² Susanne Antonetta, *Body Toxic: An Environmental Memoir* (Washington, D.C.: Counterpoint, 2002), p. 26.

²⁰³ Martin O’Brien, ‘You Are My Death: The Shattered Temporalities of Zombie Time’, *Wellcome Open Research*, 5 (2020), 135 <<https://doi.org/10.12688/wellcomeopenres.15966.1>> [Accessed 31 May 2023].

²⁰⁴ Mbembe and Corcoran, p. 66.

²⁰⁵ Ursula K. Le Guin, ‘The Carrier Bag Theory of Fiction’, in *The Ecocriticism Reader: Landmarks in Literary Ecology*, ed. by Cheryll Glotfelty and Harold Fromm (Athens: University of Georgia Press, 1996), p. 150.

²⁰⁶ Le Guin, p. 152.

²⁰⁷ Le Guin, pp. 151, 153.

about how illness and death are experienced and endured for communities living in a fugitive relation to the Human.

Chapter One: Queering End-of-Life Narratives

Writing in *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century* (1999), Ellen Leopold notes that while ‘breast cancer may not yet have a well-documented past... it certainly has a vibrant present. There is no public forum now in which breast cancer is not at home’.²⁰⁸ Where it was once taboo, women in the 1990s were increasingly publishing works in a personal or autobiographical register about the highly gendered experience of cancers of the breast and ovary. Leopold suggests that the ‘literal unspeakable horror associated with breast cancer’ dating from the nineteenth century, was the result of its ‘destabilising aftermath’ and the ‘violence’ it wrought on ‘the traditional image of the nuclear family’.²⁰⁹ In line with this history, mainstream women’s cancer narratives of the late-twentieth and twenty-first century continue to operate within a framework of generational time, deriving a measure of their affective charge from the image of the children the author might leave behind.²¹⁰ Constructed as the ultimate tragedy for the family, women’s cancer diagnoses and narratives also reinforce a sense of normative generational continuity – with the legacy work of memoir oriented towards families, children, or the imagined “sisterhood” of future female cancer victims. Where does this norm position queer women who decide not to have children?

Reading against Conway’s *Ordinary Life* and Picardie’s *Before I Say Goodbye*, this chapter argues that Rose’s *Love’s Work* and Sedgwick’s *A Dialogue on Love* are representative of an alternative genealogy of cancer narratives attentive to a different kind of political collectivity. These texts invest in alternative, extrafamilial kinships, creating forms of real and imagined queer community conscious of the chronic legacies of the HIV/AIDS crisis. I situate my intervention in the 1990s as a particular moment in recent history in which the aftershocks of the HIV/AIDS crisis clash and

²⁰⁸ Ellen Leopold, *A Darker Ribbon: Breast Cancer, Women, and Their Doctors in the Twentieth Century* (Boston, Mass: Beacon Press, 1999), p. 2.

²⁰⁹ Leopold, p. 31.

²¹⁰ Early twentieth-century American cancer discourses imagined the female patient as ‘white, middle class, and part of a nuclear family...Assumptions about motherhood were embedded...Women who survived cancer tended to be mothers who could resume caring for their children. Often, the woman who did not survive seemed ambiguously unattached’. Kirsten E. Gardner, ‘Disruption and Cancer Narratives: From Awareness to Advocacy’, *Literature and Medicine*, 28.2 (2009), 333–50 (p. 337). For a further example, see narratives in Deborah Hobler Kahane, *No Less a Woman: Femininity, Sexuality & Breast Cancer* (Almeda, CA: Hunter House, 1995).

combine with the formulation of queer theory as an academic discipline, and a rising interest in the illness narrative genre within the medical humanities and in clinical practice.

Through this queer kinship claim, the writers I consider here consolidate their refusal of the linear temporalities characteristic of cancer diagnosis and treatment, and of a life lived in accordance with what Freeman names as the progression through the life course which relates 'properly temporalized bodies with narratives of movement and change'.²¹¹ Queer women's narratives offer a record of time in illness, in which waiting reveals itself as a temporality with multiple significances beyond the failure of untimely or indifferent care: waiting for Rose and Sedgwick is collective, palliative, therapeutic, spiritual and erotic. This kind of time seems to defy the linearity and progress ordinarily conceived as inherent to labour-oriented temporality. Rose and Sedgwick's approaches to temporality through form emerge in the context of a broader refusal of heteronormative (re)productivity. Running through this complex interrelation of concerns is the question of productivity and value, and how these texts offer a way to produce differently, cutting across the normative time frames that bind heterosexuality and capitalism together.

Normativity and Narrative in *Before I say Goodbye* and *Ordinary Life*

Ordinary Life and *Before I Say Goodbye* are memoirs which relate their author's experiences of breast cancer. Popular examples of the illness narrative genre written by women and emerging into the mainstream Anglosphere in the 1990s, exemplified by texts such as these, have tended to reflect and even reinforce norms around gender. Gender normativity is broadly understood as the notion that 'heterosexuality is the only "normal" sexual orientation' and the belief that a person's appearance and 'behaviours' should 'reflect their biological sex assigned at birth'.²¹² In defining the concept of 'compulsory heterosexuality', through which homosexuality, particularly the 'lesbian experience' is perceived as 'deviant... abhorrent, or simply rendered invisible', feminist scholar Adrienne Rich describes the gender norms required of

²¹¹ Freeman, *Time Binds*, p. 4.

²¹² Kristopher M. Goodrich, Melissa Luke, and Steven Kassirer, 'Entry: Heteronormativity', in *The SAGE Encyclopedia of Psychology and Gender*, ed. by Kevin L. Nadal (California: SAGE Publications, 2017).

'middle-class women'.²¹³ They are prescribed, she writes, 'to embody and preserve the sacredness of the home' and the 'romanticization of the home itself', and present in certain ways in relation to 'sexuality and motherhood': prescriptions 'fused with the requirements of industrial capitalism' itself.²¹⁴ Rich's essay, foundational for the fields of both gender studies and queer theory, tracks the ways in which norms around femininity and desirability are pervasive, rigidly maintained and very difficult to challenge or resist. I am interested initially in the ways in which Conway and Picardie's narratives reflect and affirm a particular set of classed and gendered cultural expectations of women around the value of motherhood and femininity, and how, in turn, their narratives feed into broader ideas about which kinds of narratives, temporalities and experiencing subjects have value in western industrial society.

The first chapter of *Ordinary Life* opens on what Whitehead and Woods have identified as the 'primal scene' of the medical humanities: the encounter between doctor and patient at the moment of cancer diagnosis.²¹⁵ Conway, who is a Harvard graduate and practicing psychotherapist living in the Upper West Side of Manhattan, is keen to convey something of her own identity and value to the consultant Dr Cody. Observing a painting on his wall of an older man she imagines to be his father, Conway expresses reassurance at being able to place Dr Cody within the familiar context of the family unit: 'I am glad he has a father'.²¹⁶ She imagines this will enable him to more clearly apprehend 'what matters most about possibly having breast cancer', that she is 'part of a family', with 'parents, a husband, and children' (p. 15). Wanting Dr Cody to 'know something about [her], about who [she] is and what [she] do[es]' is part of impressing upon him the high stakes of her treatment and the necessity of a high quality of care: because, as she writes 'my life is on the line' (p. 17). Later, Conway describes a similar desire for recognition and identification with her chemotherapy consultant Dr Moore, noting her 'credentials' from 'Smith College and Columbia University medical school' place her as an 'upper class...protestant' (p. 97). Dr Moore has a 'grandmotherly' appearance and treats Conway as she

²¹³ Adrienne Rich, 'Compulsory Heterosexuality and Lesbian Existence', *Signs*, 5.4 (1980), 631–60 (pp. 632, 633).

²¹⁴ Rich, p. 634.

²¹⁵ Anne Whitehead and Angela Woods, 'Introduction', in *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Sarah Atkinson and others (Edinburgh University Press, 2016), pp. 1–32 (p. 2).

²¹⁶ Kathlyn Conway, *Ordinary Life: A Memoir of Illness*, Conversations in Medicine and Society (Ann Arbor: University of Michigan Press, 2007), p. 15. Further references to this book are given in the text.

desires 'as an equal', striking her 'as someone with whom [she] could be friends' (p. 97). Conway is later pleased to note that she is mistaken and that in fact Dr Moore is also catholic, imagining her as a 'role model' in a further consolidation of her sense of identification and regard (p. 210). It is significant that this sense of identification is enacted through the imaginaries of the family and church, in ways that resemble the earlier encounter with Dr Cody.

In *Ordinary Life*, status is understood to be intimately connected with care in this way. Conway's husband David teaches history at Baruch College and their wider circle is comprised of affluent, well-educated heterosexual couples, living in socially legible relation to one another and working as medical professionals and academics (pp. 19, 38, 83, 161, 164). Being part of this social milieu affords Conway access to certain forms of economic stability and care. Anticipating her cancer diagnosis, she is able to consult with friends who are doctors (p. 7). Initially facing hostility from the hospital administrator in the billing office, Conway notes with amusement how this woman relaxes 'when she realises [Conway] is adequately insured': this amusement speaks to the stability which derives from her status as part of a heterosexual partnership underwritten economically by the legal and social privileges that attend marriage (p. 19). Unlike Boyer, a single mother, under-insured, precariously employed and therefore rushed from hospital as an outpatient following her mastectomy,²¹⁷ Conway can call on connections to place her on a 'VIP list' to secure a private room for post-surgery recovery (p. 220). On returning home to begin rehabilitation, interactions with other couples and family units constitute her principal care network in ways that continue to shore up the normative constellation of her own family, allowing them to maintain their familiar relational rhythms and structures, to go on despite the difficulties presented by her illness.

In keeping with the themes of early medical humanities research on illness narratives, the main critique within *Ordinary Life* is directed at Conway's experiences of the impersonal and depersonalising nature of medical care. While identifying with her consultants, she often notes how she feels 'ignored' by the nurses and technicians responsible for the hands-on administration of her care: a nurse taking her blood engages in 'animated and intelligent conversation with another nurse',

²¹⁷ Boyer, *The Undying*, p. 149.

thereby excluding her (p. 21); her x-ray technician is a 'scowling' man who 'doesn't want to converse' (p. 20). In fact, the dynamic of depersonalisation goes both ways. Because he does not speak to her, Conway experiences this technician as 'awkward...unattractive', and she refuses to 'think about his life' instead imagining 'he doesn't have much of one' (p. 20). Although, in the afterword of her memoir, Conway is able to reflect on the valid combination of anger and fear that shaped her illness, it is notable that she demonstrates a reduced capacity for identification with "low" status healthcare workers engaged in the everyday "drudge" work of care. Significantly this is the kind of care most often gendered as feminine – in which a "caring" maternal affect is expected – and also, historically, the most devalued. These aspects of her memoir reflect both an explicit and tacit understanding of the stratified nature of care. It internalises the logic of how existing structures of power, gender and social capital shape the expectations of different subjects to perform in certain ways, and delimits who gets to count, who is worthy of attention and ultimately who is designated as human.

For Conway, the experiences of depersonalisation which characterises cancer treatment are also connected to gender in other ways. She describes how it separates her from 'ordinary life' and her 'ordinary self', transforming her into 'a creature from a different species', like 'one of the possessed...in *Invasion of the Body Snatchers*', indicating how mastectomy and chemotherapy strip her of her normative gender embodiment leaving her as something no longer human (pp. 255–256). In its violent movement from the normative to the non-human, this imagery reflects a struggle with deeply internalised conventions about the value of femininity. The evocation of *Invasion of the Body Snatchers* is also significant, as a film in which the reproductive function of the heterosexual dyad is threatened and undermined by way of the uncanny duplication of the invading alien "pod-people". In *The Cancer Journals* Lorde famously critiques the politics of gender which demands 'other one-breasted women hide behind the mask of prosthesis or the dangerous fantasy of reconstruction'.²¹⁸ Conway herself notes that 'some women choose not to wear a wig and to appear bald in public' and that some 'decide against breast reconstruction...and let themselves be seen with one breast', acknowledging the validity of the feminist politics that inform this 'statement that breast cancer is a

²¹⁸ Audre Lorde, *The Cancer Journals*, Special ed (San Francisco: Aunt Lute Books, 1997), p. 14.

reality not to be hidden' (p. 111). However, she confesses feeling 'put off by this public movement' and the ambivalence and shame this image produces for her is clear in the language she uses to describe women who make the choice that Lorde advocates (p. 111). What Conway aspires to is to look 'as if everything is fine' (p. 111), reflecting what Frank in early scholarship identifies as an orientation towards 'restitution'. Her memoir repeatedly evokes the idea of the 'ordinary' in ways that cannot help but to shore up a normativity incurious about different expressions of gender and embodiment. Shopping for her wig post-chemotherapy, Conway seeks out what she identifies as a 'transvestite hairdresser', making a connection between wearing a wig and 'the idea of someone playing a part' (p. 137). Wigs here index for her a contrast between a "real" femininity and a femininity only pretended or assumed. Despite this tacit hierarchy of authenticity, Conway demonstrates openness to the ways in which this experience might make visible what Butler notably theorises as the accrued, durational performance that is gender.²¹⁹ Ultimately though, she finds it difficult to embrace the experience as a space of positive potential, registering her disbelief when the hairdresser 'explains that people often wear wigs, for fun, convenience, and diversity' (p. 138). Conway emerges as trapped between shame and sadness at the ways in which illness excludes her from femininity, and frustration at what this pressure to conform requires of her. When her surgeon explains that he will need to remove and reattach her nipple as part of the reconstruction surgery, she copes with her repulsion by rationalising that she would rather this than 'leave it off center' (p. 207), choosing to focus on this appearance of normality instead of the loss of sensation the intervention will cause. Conway's illness brings her directly into confrontation with the gender normativity that Rich describes, emerging from a single, culturally dominant image of male-oriented desirability rather than a self-oriented enjoyment and pleasure in the potential and eroticism of the body in its multiple and variable forms.

In the afterword, Conway reflects on the extent to which her narrative is propelled by the expression and palliation of her anger at the loss of 'normalcy' and a specifically gendered self-hood (pp. 254, 256). As a consequence, there is little that is light-hearted or humorous in *Ordinary Life*. In contrast, Picardie's *Before I Say Goodbye*

²¹⁹ Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity*, Routledge Classics (New York: Routledge, 2006), p. xv.

centres humour as its organising affect, although it addresses cancer in relation to the same themes of physical transformation and motherhood. Diedrich demonstrates that there are many examples from which to extrapolate the tonal differences between American and British illness narratives, concluding that ‘an American art of being ill...emphasizes the cultivation of an improved self, in contrast to a British art of being ill, which emphasizes the cultivation of an ironic self’.²²⁰ While this distinction is somewhat simplistic, irony does mediate how Picardie differently positions herself in relation to gender, opening up a space between the idea that the loss of markers of heteronormative femininity – i.e. hair and a particular kind of sexuality and desirability – correlate to a loss of value and humanity.

Like Conway, Picardie’s memoir is poignantly dedicated to her children. It takes an epistolary and collaborative form, comprised from Picardie’s correspondence, her columns in the *Observer*, readers’ letters, writing by her sister Justine, all bookended by a foreword and afterword by her partner Matt. Unlike Conway, Picardie’s aggressive cancer ends in her death rather than her recovery, and therefore her partner plays a significant role in its publication: the narrative emerges firstly as a testament to and product of familial relations of care. In the text, articulations of her bravery often centre on her insistence to keep writing, frankly, about her illness, in this way making her suffering legible. Like many readers, I was moved by how the narrative tangibly and compellingly conveys the terrible nature of Picardie’s illness and suffering. What is worth thinking about is how this affective impact is inseparable, as in *Ordinary Life*, from a collectively affirmed articulation of value related to normativity, productivity and class.

Before I Say Goodbye also includes numerous letters responding to Picardie’s writing on her experience from her peers, other journalists and writers, and from her wide international readership. These letters demonstrate for the reader the power of her personal narrative, and what work it performs culturally. One reader describes how she ‘picked up the Life section of the *Observer*...attracted by the picture of two beautiful children, the happy smiling couple and the tragic story of cancer’.²²¹ This image and its framing here are deeply significant, representative certainly of the

²²⁰ Diedrich, p. xx.

²²¹ Ruth Picardie, *Before I Say Goodbye* (London: Penguin, 1998), p. 40. Further references to this book are given in the text.

heteronormative ideal of the nuclear family unit, and also in ways I do not fully explore in this chapter, tacitly evoking biases related to the value of race and whiteness. The image of the ideal family and the threat of tragedy work co-constitutively, each heightening the affective impact of the other so that Picardie's story exists not only as it is but also as it symbolises the destruction of the integrity of an archetypal, collective conception of the family qua family. I see this echoed in another reader's suggestion that the death (and thus the absence) of the mother renders the family not only emotionally and materially, but also culturally and ontologically incomplete: the reader suggests it is better that Picardie's partner, like her father, should remarry someone flawed, as in her case it allowed her 'to develop more roundly than grow up "motherless"' (p. 61). As in *Ordinary Life*, something is lost in this attachment to normative gender expectations and family structures: here it might be the opportunity, for example, to reimagine and redefine the family as diverse relations of care which might not flow along conventional lines.

The gendered nature of care work for both those living with illnesses and physical disabilities is also significant to the text. Without criticising Picardie's partner specifically, rather calling attention to wider structures of gendered expectations, I note Boyer's observation that the male partners of women treated for cancer struggle in the wake of diagnosis with the pressures of caring: 'during active treatment, but particularly after it, [women] are abandoned, divorced, cheated on, abused, disabled, fired'.²²² In his afterword, Picardie's partner is frank about how cancer changes their relationship, and how challenging he finds this shift in their customary roles and dynamic. In addition to using a wheelchair, at the terminal stage of her illness and as a result of 'frontal lobe damage', Picardie begins to experience what Matt formulates as 'the insult of dementia', alongside a raft of debilitating psychiatric symptoms: 'confused ideas, thought processes blocked in repetitive cycles...lack of inhibition' (pp. 107–108). Boyer has also written about cancer's 'chronic disabling' action on the body.²²³ It is striking how much, here and in the experiences of Boyer and others, it becomes harder to draw neat lines between cancer and the lived experiences of people with physical disabilities, cognitive impairments and psychiatric illnesses. The blurring of this boundary highlights questions scholars in disability studies have

²²² Boyer, *The Undying*, p. 174.

²²³ Boyer, *The Undying*, p. 139.

raised about the socially constructed nature of the disabled identity and how the ways it is actively designated and deployed are shaped by cultural contexts. As Kafer notably argues, the line between those designated as normatively able-bodied and those designated as disabled is less rigid than is culturally allowed.²²⁴ Key here is how cancer is culturally framed as a tragedy, while the resistance to accessibility adjustments and the carceral structures of psychiatric care, especially for those experiencing psychosis, are culturally framed as a social problem. Struggling with the new role of carer – even, as he puts it, ‘gaoler’ – Picardie’s partner describes a reckoning with how the idealised ‘fantasy of terminal tendresse fell far short of the mark’ and the realisation he ‘had probably had as much love now from Ruth as [he] was going to have’ (p. 114). Her decline precipitates a ‘process of alienation [he] still bitterly regret[s]’ (p. 114). He finds it particularly difficult to come to terms with the dissolution of her agentive subjectivity: cancer ‘emptied [her] of all her fierce, headstrong will’ (p. 112). I was struck by this image he uses to describe her, a sick and disabled woman: her ‘frightened eyes’ remind him of ‘footage of a cow in the final stages of BSE’ (p. 107). Picardie has been stripped by her illness of the capacity to engage and to reciprocate in familiar – and necessarily gendered – ways, as a mother, a partner and a lover. The metaphor of the cow is reminiscent of the connection Conway tacitly makes between normative embodiment and humanity, and the dissolution of that normativity with the ungendered and non-human. In its presentation of this aspect of Picardie’s illness, intended to foreground the nature of her heroic individual struggle, the narrative uncritically appeals to, and even reproduces, an ableist conception of value in order to demonstrate the dramatic nature of her decline. However, it also raises important questions about how people are socialised to relate, care for and love those who present in non-normative ways, and the limited relational language and cultural tools an ableist society offers or makes available for this particular form of caring and loving. Her partner’s consolation is that despite this decline in her self-hood, and her ability to write, she still retains a legacy in her children: he writes, there is ‘no greater saving grace’ (p. 103).

Before I Say Goodbye also grapples with questions of gender presentation and femininity. Readers first encounter Picardie amid a process of significant physical

²²⁴ Kafer, p. 25.

changes. She writes in her email to India Knight, 'my hair is falling out with amazing rapidity – I estimate total baldness will be achieved by the weekend' (p. 1). Later, undergoing radiation for a brain metastasis, she speculates, 'I guess my left eyelashes, eyebrow and left lot of hair will fall out, which will be very attractive, not to mention the burn marks on my forehead' (p. 30). Her language here illustrates the 'cultivation of an ironic self' that Diedrich identifies as a feature of *Before I Say Goodbye* and other British illness narratives. However, it is clear that the use of humour to create and maintain distance is a coping strategy that speaks to the experience of these physical changes as a loss. This sense of loss is reaffirmed by the contrast between how Picardie is experiencing her body in the process of treatment, and how she is perceived by others before her diagnosis. Her friend Carrie describes her as,

'99% of the glamour in my life...you wear lipstick better than anyone I know and your legs are the longest of any woman outside the glossies. You could still carry off a miniskirt whilst all I can wear is tracksuit pants. Very sexy' (p. 11).

This alignment with glossy magazines is representative of a particular kind of smooth, commercialised female desirability. The intention is obviously humorously superlative and complimentary, but it is worth noting how this affirmation is framed in terms of comparison, and therefore tacitly by competition, with other women, suggesting a market-based logic in which value equates with being more beautiful than others. The examples of Picardie's writing referenced in the narrative follow similar themes of presenting in conventionally feminine ways. Her columns centre dieting, desirability, shopping and motherhood, treating these topics with a lightness and irony that winks at gendered stereotypes, yet acknowledging these socio-cultural directives still carry a modicum of weight. It is clear, from her positive reception and wide readership, that these themes resonate with her audience, part of a shared demographic who are familiar with, even invested in, the seemingly evident equation of thinness, wealth and beauty with value. In the text, her appearance is often connected with her 'sex life' and the loss of sexuality, in a kind of ironic mourning (p. 36). In her columns, physical recovery is mediated by changes in appearance: she opines 'I'll never know if the pregnancy stretchmarks on my legs would have disappeared without surgery; I haven't got time to grow my patchy, chemotherapy crop into a halo of life-before-cancer curls' (p. 58). Although Picardie's tonal

approach is very different, it is difficult not to see these statements as a rehearsal of Conway's desire to return to an 'ordinary', 'normal' form of embodiment which is itself restrictively heteronormative. As her disease progresses and she gains weight due to steroids, she focuses increasingly on 'non hair-related beauty', as a 'therapeutic strategy' to counter the loss of this aspect of her self-image, and perhaps to remain in some way aligned with culturally endorsed notions of beauty (pp. 2, 78). Describing herself gleefully, albeit sardonically, as a 'fashion bimbo', she takes pleasure and comfort in buying Agent Provocateur underwear and expensive face creams, treatments and consultations with beauticians (p. 24). This conspicuous display of consumption suggests class privilege might be one of the things Picardie feels she can hold on to in the upheaval of her identity. It is significant that this also constitutes a strategy of maintaining a relationship with India, who, as another writer, is both peer and friend. By modelling their exchanges around the conventionally assumed themes of female friendship – sexuality, appearance, motherhood – Picardie is able to remain in contact with an idea of normalcy.

In Conway and Picardie's cancer narratives, an investment in the normative expression of gender is reflected in a similar investment in a normative conception of temporality, specifically the idea that time moves forward in a linear direction and that a movement through time is characterised by progression, broadly speaking.

Although *Before I Say Goodbye* begins in media res, with Picardie's second round of chemotherapy and hair loss rather than at the moment of diagnosis, the material of the narrative is organised in a way that represents the linear passing of time.

Imposing this temporal discipline on the narrative aligns with what Kleinman, Cassell and Charon have identified as the medium's sense-making, or rationalising function. This orientation to time seems natural and self-evident, though I suggest that there are important ways in which it reflects a wider view of history as a record of human progress, privileging ideals of order and reason which have their origin in the humanism of the Enlightenment. Clearly the narrative is not explicitly situating itself in relation to this intellectual tradition, but equally clear, in my view, is the way in which its orientation to time makes the influence of this humanist tradition implicitly felt through theme and structure.

The emphasis on linearity is reinforced by the foreword and afterword Picardie's partner includes in his role as co-producer of the narrative. These passages describe

Picardie before and after diagnosis respectively, positioning her subjective experience of cancer between them as an interruption and redirection of her progression through life's expected stages. Their shared production of the narrative is echoed in their shared experience of reproduction. Describing the experience, Picardie's husband notes their initial optimism about the endeavour: 'we believed a little too much in our luck, that we somehow deserved a providentially good life...things seemed always to fall more or less into place' (p. 100). His observation speaks to a culturally affirmed outlook in which children follow an established career and a successful monogamous partnership as part of a logical progression forward. In describing their difficulties conceiving and the eventual birth of their twins via in vitro fertilisation (IVF), Matt conveys something of the tenuousness of this ideal of the 'good life', its fragility, and how its existence is reified by sociocultural and biomedical structures (pp. 100–101). One of the key themes of the narrative, reiterated by those in Picardie's social circle, is the idea of the 'wrongness' of the situation: that Picardie's death is particularly 'tragic' because of the interruption of her trajectory as a new mother and a successful journalist just coming into the height of her career (pp. 40, 56). What this notion of tragedy does not make explicit is how assumptions around class and race are central to its workings.

Ordinary Life represents a similar orientation to temporality, tracing Conway's experiences of illness from diagnosis, through treatment to recovery. Echoing themes that Hawkins positively, and Sontag negatively, associates with the illness narrative genre, Conway frames her experience of cancer metaphorically as a journey to the depths, each chapter evoking a progressive stage or aspect: 'on the verge', 'the descent', 'the second and third cycles', 'despair', 'the journey back', returning finally to 'ordinary life' (p. xi). In this schema, cancer is conceived as a time of crisis, other to the flow of 'ordinary life'. I have already endeavoured to highlight the cultural work her use of the word 'ordinary' is doing in this narrative to maintain certain kinds of normativity and privilege. This work also has a temporal dimension, resembling Baraitser's reading of the dynamic operative in Janet Roitman's theory of crisis and anti-crisis. Baraitser notes that in this dynamic crisis 'functions as a narrative device to raise certain political questions and foreclose others', thereby, as Alex Khasnabish has observed, also functioning as 'a discursive tool for the defense

of the status quo'.²²⁵ Throughout this period of crisis and rupture, Conway offers a granular accounting of time, in which the forms of delay and unproductive periods of waiting encountered in treatment are particularly difficult to tolerate. Her critique of the dehumanising nature of medical care settings extends to what she perceives as their indifferent temporalities. During a pre-operative EKG, Conway notes that the uncommunicative technician has a picture of her daughter on the wall:

It's the end of the day and I'm sure she wants to hurry to see her. This is her job. It's routine for her. I want to get home to my daughter, too, and to my son. But the hospital personnel don't seem to care about that really. I am just a body, at their disposal for as long as it takes them (p. 20).

Here, Conway sets up a contrast between labour time, specifically clinical time, and the temporality of the domestic sphere and the nuclear family. This suggestion overlooks what Freeman, citing the work of Julia Kristeva and Dana Luciano, has identified as a complicity between labour time and 'domestic' time, with each sustaining and making possible the conditions for the other.²²⁶ Conway seems to suggest that these two temporalities are fundamentally at odds with one another, and this disjunction precipitates the ultimate failure of the project of care. However, on closer reading, what seems to be a clear statement about how time should flow stumbles upon itself in contradiction: does Conway appreciate the technician's efficiency, or does she require more time for care? More than her dissatisfaction then, this passage emphasises Conway's ambivalence. This ambivalence can be felt in the many other examples of Conway's fierce critique of medical time on an institutional level, and her critique of what Frank describes as the 'restitution' timeline on a narrative level, and yet her alignment with both the timelines and distinct telos of biomedical temporality and the recovery arc.

Conway and Picardie align with Freeman's analysis of a heteronormative temporal progression through the life course.²²⁷ The 'narratives of movement and change' Freeman describes are central to the temporalities of heteronormativity and capitalism, including medical institutions. In *Ordinary Life* and *Before I Say Goodbye*, cancer appears as a rupturing event within an otherwise linear

²²⁵ Baraitser, p. 5; Alex Khasnabish, 'Anti-Crisis by Janet Roitman', *Anthropological Quarterly*, 87.2 (2014), 569–77 (p. 569).

²²⁶ Freeman, *Time Binds*, pp. 5–6.

²²⁷ Freeman, *Time Binds*, p. 4.

progression through such milestones, emphasising a conventional orientation to temporality even as they mourn its disruption. In contrast, Rose's memoir *Love's Work* and Sedgwick's *A Dialogue on Love* demonstrate a different relation to time, exploring what Sedgwick identifies as the kinds of temporal incommensurability, even time travel, characteristic of queer life, exemplified by the strange propensities for accelerations, alongside forms of stasis, that she reads in the work of Proust.²²⁸

Articulating Queerness in *Love's Work* and *A Dialogue on Love*

Rose and Sedgwick share a non-normative expression or relation to gender and sexuality which can be conceptualised as queer. Queer time is but another channel for the expression of the contradictions, extremes and impossibilities Sedgwick articulates first as part of queerness. Unlike and outside of normativity, queerness is not a single or fixed concept or location at which to arrive, and as Sedgwick and others have made clear, there is no single way to define it. I am interested in how Sedgwick and Rose differently approach and/or embody queerness, leaving openings in their work for a variety of queer readings, and how that in turn influences their representations of time in illness and at the prospect of death. Underpinning the queering of time in their narratives is a queerness that challenges gender expectations and places value on relationships outside of the nuclear family and heterosexual relational constellations. In their alterity, these relations both exceed and fall short of heterosexual norms, creating space to explore the pleasures of forms of non-reproductive sexuality – whether homoerotic, sado-masochistic or autoerotic. I argue that in this they can be situated within an alternative genealogy of queer women's cancer narratives, overlooked or under engaged in the life writing landscape of the 1990s, a genealogy which can be traced back to Lorde's *The Cancer Journals* and Sontag's critique of the gendered use of metaphor.

This queerness manifests in atypical modes of erotic investment and sexual expression. For Sedgwick, queerness goes beyond the dichotomy of 'homo-hetero' sexuality – in *Tendencies*, she devotes over two pages to detailing the 'very important dimensions...along which sexuality varies from one person to another.'²²⁹ In

²²⁸ Sedgwick, *Touching Feeling*, p. 148.

²²⁹ Sedgwick, *Tendencies*, p. 7.

A Dialogue on Love, it becomes clear these variations apply to Sedgwick herself in the ways that she subverts relational and sexual norms. She is ostensibly in a heterosexual partnership, married at nineteen to her teenage boyfriend Hal (p. 19). While he is her 'fella', they have had an arrangement 'for decades' where they do not cohabit but 'only see each other on weekends' (p. 24). She describes her growing dread at the expectation of intimacy at the outset of their relationship, feeling 'disappointed/scared' when Hal finally initiates sex '5–6 mo. Into their rel.' connecting this with a discomfort with her own gendered embodiment which originates in the imaginary of a judgemental 'maternal gaze' (p. 56). She is relieved to find that extramarital affairs – 'falling in love with T...unrequited...then having a five-year affair with K.C' – did not mean 'los[ing] Hal in the process', but rather allowed her to feel less 'trapped in the marriage' and work towards a unique constellation of relationships which held different kinds of meaning (p. 57).

In *A Dialogue on Love*, something else emerges around atypical sexuality in the centrality of masturbation and auto-eroticism as Sedgwick's primary mode of sexual expression, her fantasies about scenes of erotic punishment along sado-masochistic lines, and her ambiguity around her own same-sex desire. A queer orientation to sexuality allows for the fact that 'many people have their richest mental and emotional involvement with sexual acts they don't do, or don't even want to do',²³⁰ and that 'some people's sexual orientation is intensely marked by autoerotic pleasure and histories – sometimes more so than by any aspect of allo-erotic object choice'.²³¹ Sedgwick's commitment to troubling particular 'hetero-homo' alignments is useful because it makes space for the same opacities and potential conflicts in Rose's disclosures about her sexuality, providing a language that holds both moments of alignment with and divergence from heteronormativity.

In *Love's Work*, Rose catalogues a series of unhappy loves – her affair for example with the priest Father Gorman is explicitly this, and explicitly a sexual relationship. This is less clear in the other loves the text chronicles, including Rose's relationship to a 65-year old woman named Yvette. Rose describes Yvette as an archetypal 'lover': lustful, 'inexhaustible, but at the same time 'dowdy' and 'grandmotherly' (pp. 24, 25, 30). Sedgwick's formulation of the contradictions inherent in queerness helps

²³⁰ Eve Kosofsky Sedgwick, *The Weather in Proust*, Series Q (Durham [NC]: Duke University Press, 2012), p. 198.

²³¹ Sedgwick, *Tendencies*, p. 8.

reconcile Yvette's 'grandmotherly identity with her prodigious sexuality': her 'heavy veneered chest of drawers with a pride of family photos jostling on top', with 'the three bottom compartments of this tallboy... jammed full of pornographic material...almost entirely of women' (p. 29). While Rose is markedly coy regarding the sexual aspect of their relationship, clearly their dynamic is defined by a deep attraction, admiration, respect and love. When Rose 'first noticed and watched her...at Preston Park Station in Brighton' she notes Yvette's 'green tights...shapeless dark skirt, and...mop of nondescript grey hair' yet somehow also understands that Yvette is also 'a superior being', that her appearance was 'but transparent media for the piercing intelligence in evident amused communication with itself' and that Yvette's 'dowdy and unselfconscious bearing was unable to conceal her visceral vocation as the Lover' (pp. 18, 20). Their courtship, in its earliest stages, is played out in public, through the language of the gaze. Rose writes, 'this lucid apparition came to me many times – crossing the Level in Brighton, in the corridors of the School of European Studies, as well as frequently at the same station platform' (p. 18). This tension between the public and private dimensions of same-sex attraction has a precedent: describing the poetics of cruising in the albeit different context of a male-oriented gay scene, Jack Parlett notes that the street has long been an 'erotic and aesthetic site', a staging for the 'desiring look shared between strangers'.²³² Cruising, Parlett argues, is a 'profoundly optical phenomena, a perceptual arena where acts of looking are intensified and eroticised'.²³³ Both contexts evoke particular histories of a male same-sex love that in the immortal words of Lord Alfred Douglas 'dare not speak its name',²³⁴ or in the case of female same-sex love remains, as Rich has observed, culturally invisible.

This ambivalence about visibility can be felt in the way Rose frames herself in relation to Yvette. While she is explicit about Yvette's proclivities, her own are opaque. When they part in the hospice in which Yvette is dying of cancer, she invites the reader into a rare scene of intimacy. She writes 'I bent over her and kissed her on the lips several times, her lips reaching mine each time before mine touched hers (p. 29). Yvette, 'in her own way', gives Rose her blessing: 'you know how I feel. You

²³² Jack Parlett, *The Poetics of Cruising: Queer Visual Culture from Whitman to Grindr* (Minneapolis: University of Minnesota Press, 2022), pp. 2, 5.

²³³ Parlett, p. 2.

²³⁴ Lord Alfred Douglas, 'Two Loves', *Poets.Org* <<https://poets.org/poem/two-loves>> [accessed 31 May 2023].

know how I feel. Nothing has changed. Nothing has changed. All the very best. All the very best' (p. 29). The question of whether they are lovers remains indeterminate, perhaps queerly so, offering a picture of a different kind of romantic relationship which need not centre on a heterosexually defined consummation as the focal point.

Beyond their sexuality, Rose and Sedgwick challenge norms around gender in that both are childless women. Examples of queer and feminist western literature up to that point had long sought to offer radical challenge to western culture's natality fetish.²³⁵ Rose and Sedgwick's narratives demonstrate how, as Edelman and Sophie Lewis have theorised, the figure of the biological child continues to occupy a central position in white heteronormative imaginaries and 'collective narratives of meaning', in addition to functioning as the means by which this dominant imaginary seeks to discipline and regulate the individual and social body.²³⁶ In *Love's Work*, Rose reflects on the specifically gendered stigmas that accompany women's cancers, assembling an ironic 'anthology of aetiologies', or catalysts, for her own ovarian cancer. Two of these speculative aetiologies connect cancer in women to childlessness. Scholar Camille Paglia's acerbic verdict is that cancer is 'nature's revenge on the ambitious, childless woman', giving voice to assumptions that centre motherhood as a "natural" or essential aspect of womanhood, but position ambition, particularly intellectual ambition, as a perversion of this natural order (p. 84). Ian Florian, principle of the College of Acupuncture, suggests similarly, and with more sincerity, that illness originates in an 'imbalance of energies necessary for a woman to sustain success in the world', here tacitly aligning 'success' with adherence to unspecified gendered norms (p. 84). Both perspectives echo scholar Jackie Stacey's encounter with an alternative healer, who states that Stacey's 'lesbian relationship and lifestyle meant that [she] had denied [her]self the "natural" harmony between masculine and feminine guaranteed by heterosexuality'.²³⁷ In this context, Stacey's grapefruit sized ovarian teratoma, a kind of tumour that sometimes has hair and

²³⁵ 'I decided that if I got pregnant again, I'd stick a broken hanger up my cunt. I didn't care if I died as long as the baby died'. Kathy Acker, *Blood and Guts in High School* (London: Penguin, 1978). Acker's *Don Quixote* also opens with an abortion. Kathy Acker, *Don Quixote: Which Was a Dream; [a Novel]* (New York, NY: Grove Press, 1986).

²³⁶ Lee Edelman, *No Future: Queer Theory and the Death Drive* (Durham: Duke University Press, 2004), pp. 2, 11; Sophie Lewis, *Full Surrogacy Now: Feminism Against Family* (New York: Verso, 2021), pp. 14, 16, 33–34.

²³⁷ Jackie Stacey, *Teratologies: A Cultural Study of Cancer* (London; New York: Routledge, 1997), p. 40.

teeth, signifies as a 'monstrous' birth, and is read homophobically as evidence of her perversion, inversion and subversion of feminine sexual and reproductive norms.²³⁸ Rose's cancer of the reproductive system might signify similarly within a register of normativity. Through this 'anthology of aetiologies' then, Rose connects with critiques of the reductive rhetoric of gender essentialism that underpin both the field of alternative medicine and a wider set of misogynistic and homophobic discourses that function to curtail the scope of women's lives. Following Sontag's argument in *Illness as Metaphor*, Rose exposes the idea of a "cancer personality" as the product of 'junk literature', a cluster of often contradictory stigmas that describe 'everyone and no one', but particularly women who transgress or fall short of a fecund, compliant femininity: childless women who indulge in 'the philosophy of Hegel and Adorno', 'the wrong kinds of relationship with men', 'too much whiskification', and who present with 'obesity, anorexia, depression, elation (manic depression), lack of confidence...poor relationships' (p. 84–85).

In contrast to the idealised image of the nuclear family in *Ordinary Life* and *Before I Say Goodbye* – exemplified in all its symmetry and homeostatic balance – Rose and Sedgwick's narratives explore the family as a focal point of relations of violence and libidinal drive. In *Love's Work*, the care victims of the Holocaust have for their children is exploited as a form of torture: Rose reflects on scenes of horror 'in the beech forests outside Tarnów, where 800 children...were shot' (p. 10), and the 'fifty members of [Rose's] Grandma's family...killed – the children bayoneted first in front of their parents' (p. 15). Rose describes Julius Carlebach's account of standing in a school hall 'on 10 November 1938, the day after Kristallnacht, when the Gestapo came and told the children they had four weeks to leave Germany' and wonders 'what happened to those children?' (p. 20). Rose also notes her changing patriarchal family names as a form of gendered assimilation: "Stone" to "Rose", from my father's name to my stepfather's name...one heteronym to another... Stone...for the Polish-Jewish "Riddell", then "Rose", English Rose, masked German-Jewish "Rosenthal" (p. 36). What Rose demonstrates is the ways in which the family is turned against the marginalised as a tool of gendered power, white supremacy, and in the context of the Holocaust, antisemitism. As examples of Nazi propaganda demonstrate, the "Aryan" ideal of the family was often presented in contradistinction

²³⁸ Stacey, p. 91.

to anti-Semitic imagery that constructed people of Jewish heritage as a threat.²³⁹ As Butler observes, reflecting on the active practice of family dis-unification at the US border, the concept of the biological family cannot be disentangled from such histories, that ‘slavery or forced migration’ and ‘the loss of a name’ are a crucial part of its story.²⁴⁰ *Love’s Work* frames cancer within a reckoning with the ‘transgenerational haunting and possession’ and the ‘ancient, unacknowledged and unmourned dead’ left in the wake of family as a site of gender conflict and racist aspirations towards “purity” (p. 84). Rose captures the reality that, far from an unambivalent site of care, the family institution is a ‘double-edged sword...a racial — or racializing — project as well as a national’ and heteronormative one.²⁴¹

As a product of the psychoanalytic encounter, *A Dialogue on Love* is interested in the family not as a sanitised space of idealised affect, but as a ground for the emergence of complex psychosexual dynamics. Sedgwick explains to Shannon that she ‘never, ever wanted to have children of [her] own’, connecting this certainty with her persistent feelings of resentment at being born, and her uneasy position within her family (p. 17). Sedgwick’s parents viewed her as ‘uncanny or a changeling’, somehow already queer (in the sense of strange), a precocious child who they struggled to perceive and treat as childlike (pp. 146–147). This image conflicts with the innocence and dependence ascribed to the figure of the child in the social ideal of the family. In this reflection, Sedgwick’s father emerges as very different from a traditionally authoritative patriarch, is ‘allusive and fragmented’, missing ‘the bright incisiveness of his wife’ (p. 146). Sedgwick’s mother, in turn, does not present as conventionally maternal and there is a strong sense of her ‘fear’ and ‘intimidation’ in relation to Sedgwick’s brilliance. These dynamics are further complicated by what Shannon, as a therapist, reads as how ‘sexuality got expressed in the family’: Sedgwick’s mother presenting ‘a desired and oft-spoken-about picture of prepubescent girlhood for her father in her slight stature and girlish figure’ (p. 78).

²³⁹ Menachem Wecker, ‘How the Nazis “Normalized” Anti-Semitism by Appealing to Children’, *Smithsonian Magazine*, 27 June 2016 <<https://www.smithsonianmag.com/history/how-nazi-normalized-anti-semitism-appealing-children-180959539/>> [accessed 31 May 2023]; ‘Propaganda Slide Showing the Opportunity Cost of Feeding a Person with a Hereditary Disease (1936)’, *United States Holocaust Memorial Museum Encyclopedia* <<https://encyclopedia.ushmm.org/content/en/photo/propaganda-slide-showing-the-opportunity-cost-of-feeding-a-person-with-a-hereditary-disease>> [accessed 31 May 2023].

²⁴⁰ Judith Butler, ‘Kinship Beyond the Bloodline’, in *Queer Kinship*, ed. by Tyler Bradway and Elizabeth Freeman (Duke University Press, 2022), pp. 25–47 (p. 33).

²⁴¹ Butler, ‘Kinship Beyond the Bloodline’, p. 34.

Sedgwick does not and cannot emulate this model of femininity, and is instead ‘a dorkily fat, pink, boneless middle child...nickname[d] “Marshmallow” in a family that is ‘good-looking / all Mediterranean / all with fine brown frames’ (p. 19)

Remembering a poem her mother used to recite, which begins “oh fat white woman whom nobody loves”, Sedgwick describes feeling this poem ‘was pointed at her and implied that she would be like this, unloved as she matured into a woman’ (p. 193). Shannon also hears that Sedgwick’s mother ‘always wondered why [Sedgwick] & Hal didn’t have children’ (p. 147). Her family is the ground in which her ‘rage and damage around fat issues’ are established (p. 85), leading her therapist to speculate how Sedgwick herself might have disrupted this ‘stable, pre-adolescent parental picture’, inclining Sedgwick to ‘the fragmentation which she has in her own sexuality’ (p. 78). In keeping with this sense of a family unmoored from the conventions and dynamics of the normative expectations of their roles, there is a sense that the missing or absent child at the centre of the narrative, and her marriage with Hal, is Sedgwick herself. Eve the ‘four year old girl’ is among the shared ‘repertoire of images’ that Sedgwick and Shannon repeatedly revisit (p. 116).

For Rose and Sedgwick, queerness, begins with or comes to rest around the extent to which they identify away from femininity and towards a more fluid relation to gender. Jack Halberstam writes that forms of female masculinity go beyond an ‘imitation of maleness’, and instead afford ‘a glimpse of how [certain heroic] masculinitie[s] are constructed’.²⁴² In *Love’s Work*, Rose describes early conflicts with gender norms in her obsession with the cowboy western star Roy Rogers: ‘my desire to possess Roy Rogers for my love was inseparable from my equally unshakeable desire to be him’ (p. 61). Scholar and former British Film Institute (BFI) executive Edward Buscombe writes that, as a child, he was similarly ‘passionate about Roy Rogers’, identifying Rogers as one of the ‘singing cowboys’, whose films adopted the aesthetics but not the politics of the typical western narrative, eschewing notions of ‘Manifest Destiny’, the winning of the west, [and] the conflict of civilisation and savagery’ in favour of a ‘genial, friendly’ masculinity rooted in a modern context replete with radio, telephones, cars and even airplanes’.²⁴³ In her early doctoral work, scholar Elizabeth Abele notes that ‘Rogers was [a] flamboyantly dressed,

²⁴² J Halberstam, *Female Masculinity* (Durham: Duke University Press, 1998), p. 1.

²⁴³ Edward Buscombe, ‘Gene Autry and Roy Rogers: The Light of Western Stars’, in *What Dreams Were Made Of: Movie Stars of the 1940s*, ed. by Sean Griffin (Rutgers University Press, 2011), pp. 33–49 (pp. 34, 37, 39).

happily married cowboy'.²⁴⁴ He emerges as a camper, more contemporary and more stylized foil to brooding 'psychological' western heroes such as John Wayne.²⁴⁵ It is interesting that Rose is drawn to this particular manifestation of the cowboy archetype which already, as Abele points out, undermined or 'resisted society's constructions' of a particular kind of masculinity.²⁴⁶

Rose's mother gives into her demands for a 'cowboy outfit' and goes to purchase one from Harrods but is 'stopped in her tracks when the toy department assistant routinely enquired, "How old is your little boy?"'. Rose, far from 'daunted' at the inappropriateness of her aspirations, describes 'training [her]self to urinate from a standing position' (pp. 61, 62). For 'fear of [Rose's] burgeoning gender proclivities', her mother 'put an end to the affair'. Rose is told instead: 'as an English female, the closest aspiration I could entertain to my ambition...was to become a milkmaid' (p. 62). Interestingly, both cowboy and milkmaid constitute gendered archetypes of either exaggerated masculinity or femininity. Both typologies emerge out of a western industrial society invested in a particular mythology of male virility that needs feminine beauty as its counterpart. Freeman has identified 'cowboy culture', as one of many bastions of homosocial nationalism which fostered 'erotic contact between men',²⁴⁷ Rose's identification with that aesthetic highlights a queering of her own gender moorings. Her aspiration to perform what is already a *performance* of heroic masculinity – a kind of drag – suggests an attunement to the arbitrary politics of gender, even as she apparently disregards them. Elsewhere in *Love's Work*, the poems Yvette recommends to Rose evoke a decidedly pastoral vision of love, where girls are pretty and lads are lively in a way that resonates, however distantly, with the aesthetic of the singing westerns: 'what shall I do for pretty girls/ now my old bawd is dead?' (p. 21) 'lively lad most pleasures me / of all that with me lay' (p. 25) These literary figures, reanimated in the relationship between Rose and Yvette, seem to emerge from Freeman's historical queer pastoral, fertile ground for the notion of

²⁴⁴ Elizabeth Abele, 'Happy Trails, Hans: Roy Rogers as the New Heroic Ideal', *Images Journal*, 3, 1997, p. 2 <<http://www.imagesjournal.com/issue03/features/diehard1.htm>> [accessed 17 May 2023].

²⁴⁵ Buscombe, pp. 39, 42.

²⁴⁶ Abele, p. 2.

²⁴⁷ Freeman, *Time Binds*.

'temporal drag' which describes the pull of the past on the present, and the aestheticization of anachronism.²⁴⁸ These are key themes in *Love's Work*.

In *A Dialogue on Love*, tensions around gender manifest for Sedgwick as a persistent sense of a dichotomy between herself as valuable or as 'spoilage/wastage/ruin' (p. 193). Sedgwick, being 'fat', saw herself as neither 'intelligibly masculine [nor] feminine', connecting this sense of spoilage with a perceived failure to express a proper gender identity (pp. 19, 193). Again, the figure of the mother appears central in policing gender normativity: the poem that Sedgwick's mother recites, which Sedgwick is convinced is about her, results in a sense that 'the gender area is poisoned against her, before she ever gets to try her hand at it' (p. 193). Sedgwick consequently perceives herself as one who 'refuse[s] or fail[s] gender categories' (p. 193). Strikingly, in her therapeutic sessions, Sedgwick makes a connection between this "gender failure" and physical pathology in a way that resonates with how Conway and Picardie experience their bodies post-diagnosis. For Sedgwick, 'fatness' has been experienced as 'a totalizing matter of a ruined, sick, or offensive body' (p. 85), her feeling, she expresses to Shannon is that 'I've ruined my body or it's ruined me. Nothing is going to work', it will 'never be a comfortable body to inhabit, never moving easily, wrong temperature' (p. 193). What emerges instead from their sessions is how Sedgwick turns to the 'personal, intellectual [and] spiritual' as differently articulated markers of value distinct from normativity 'physically and gender-wise' (p. 193). Prioritising this different notion of value, Sedgwick and Rose's narratives speak to a wider refusal to reproduce certain roles and identities required for a particular articulation of the social body. Instead of biological reproductivity, they aspire both to a "life of the mind" and a "room of their own", in a sustained philosophical, critical and artistic engagement with culture that up to, and indeed beyond, the feminist movements of the 1960s was still understood to be the phallogocentric reserve of the male public intellectual. However, this positions them within the scope of illness writing from an almost exclusively white, 'liberal class fraction of journalists and intellectuals', although they endeavour to go beyond the interiority and individual heroism that Luckhurst observes as

²⁴⁸ Freeman, *Time Binds*, p. 62.

characteristic of this movement,²⁴⁹ and which is evident in *Ordinary Life* and *Before I Say Goodbye*.

Cancer, AIDS and the Temporality of the Other

While Conway and Picardie's texts follow a linear temporality, the queer cancer narratives of Rose and Sedgwick demonstrate a willingness to enfold multiple temporalities and illness experiences beyond their own, moving within them in non-linear ways not oriented to obvious ends. Their writing on cancer is fragmented and dispersed, often digressive. Sedgwick's experiences of cancer must be assembled from scraps of information in *A Dialogue on Love* and her well-known essay 'White Glasses' in *Tendencies*. *Love's Work* is notable for withholding the revelation of Rose's cancer diagnosis until the mid-point of the narrative. Their work can be situated alongside other cancer writing by queer women emerging at the time, such as Kathy Acker's article 'The Gift of Disease' and Stacey's *Teratologies*,²⁵⁰ which interpolated theoretical and historical reflections, operating in the register of poetry and at times the political manifesto. In this way, I suggest Rose and Sedgwick demonstrate a willingness to dwell in the temporality of the Other, in an act of what Salisbury has thought through as 'waiting *with*': a relational 'attitude of presence and patience'.²⁵¹

By contrast, Conway and Picardie, threatened by a sense of depersonalisation arising from their treatment, insist on cancer as an emphatically individual experience. *Ordinary Life* distances itself from the experiences of other women with cancer, only returning in the foreword and epilogue to acknowledge these women in the wake of Conway's own recovery. Like Conway, Picardie's survival strategies also include resisting identification with what Johanna Hedva has theorised as the 'sick woman',²⁵² through a similar kind of distancing expressed in more assertive terms.

²⁴⁹ Luckhurst, *The Trauma Question*, p. 130.

²⁵⁰ Kathy Acker, 'The Gift of Disease', *The Guardian (1959-2003)* (London (UK), 18 January 1997), p. 5, ProQuest Historical Newspapers: The Guardian and The Observer, 187922295; Stacey.

²⁵¹ Laura Salisbury, "'Between-Time Stories": Waiting, War and the Temporalities of Care', *Medical Humanities*, 46.2 (2020), 96–106 (pp. 100, 104).

²⁵² Johanna Hedva, 'Sick Woman Theory', *Topical Cream*, 12 March 2022

<<https://topicalcream.org/features/sick-woman-theory/>> [accessed 31 May 2023]. This article was originally published in the now-closed *Mask Magazine* in 2016.

She calls the other women being simultaneously treated ‘sad old ladies’ and ‘sad, bald fucks’, characterising breast cancer patients as ‘old ladies in wigs’ (pp. 62, 22, 38).

The 1990s marked the aftermath of the height of the HIV/AIDS crisis, as HAART (Highly Active Antiretroviral Therapy) becomes widely available, transforming HIV diagnosis from a death sentence to a manageable chronic condition. Sontag’s work is helpful here in thinking through how the abjection of cancer was at this time in the process of shifting, becoming distinct from the abjection of AIDS. In *AIDS and its Metaphors*, AIDS replaces cancer as the unspeakable disease: ‘for several generations now, the generic idea of death has been a death from cancer, and cancer is experienced as a generic defeat. Now the generic rebuke to life and to hope is AIDS’.²⁵³ In terms resonant with the nineteenth century discourses around breast cancer Leopold has described, Sontag states that ‘the very names of such diseases...have magic power[s]’ and are unspeakable.²⁵⁴

Ordinary Life and *Before I Say Goodbye*, like many of the cancer narratives emerging at this time, do not envision themselves in relation to the crisis. Conway’s narrative does not address HIV/AIDS – even obliquely. Picardie’s text is even more complexly situated, pitting cancer and HIV/AIDS against one another in its articulation of her resentment about ‘the amount of money that goes into HIV research’ (p. 38). In contrast, Rose and Sedgwick stake a bold kinship claim with those effected by the AIDS epidemic of the 1980s and 1990s, discursively constructing the victims of the crisis as homosexual men, echoing discourses in the wider culture. However, as other texts amply demonstrate, the AIDS epidemic did not just affect gay men: Amy Hoffman’s *Hospital Time* (1997) and Rebecca Brown’s quasi-autobiographical book *The Gifts of the Body* (1994), are just two other examples of how the virus was experienced across a range of identifications, in addition to how queer women and lesbians constructed a role for themselves within the circulating discourses of AIDS.²⁵⁵ Derek Jarman’s decision to speak openly about

²⁵³ Sontag, p. 112.

²⁵⁴ Sontag, p. 6.

²⁵⁵ Amy Hoffman, *Hospital Time* (Durham, N.C: Duke University Press, 1997); Rebecca Brown, *The Gifts of the Body* (New York: Harper Collins, 1995). See also Kate Lister, ‘The Lesbian “blood Sisters” Who Cared for Gay Men When Doctors Were Too Scared To’, *The i Newspaper*, 2018 <<https://inews.co.uk/opinion/comment/the-lesbian-blood-sisters-who-helped-save-gay-mens-lives/>> [accessed 7 May 2019].

living with AIDS in the press, and through his published diaries *Modern Nature* (1991) and autobiographical lyric film *Blue* (1993) created significant impact that still culturally resonates today, a testament to the heightened atmosphere of fear.²⁵⁶ Across the Atlantic, clothing brand United Colours of Benetton used Therese Frare's image of dying AIDS activist David Kirby for a poster, provoking even more controversy.²⁵⁷ As Stacey highlights, AIDS was often characterised in the conservative "self-health" movement as a manifestation of self-hatred, guilt and even as punishment for failed masculinity among gay men.²⁵⁸ The significance of Rose's conscious decision to devote a meaningful proportion of her own cancer memoir – already a slender volume – to illustrating the paucity and discrimination that characterised HIV/AIDS medical care, must be understood in this context. As should Sedgwick's refusal, in her own words, to 'feel [the] form of contempt that... society says [she] ought to feel' (p. 24). In 'White Glasses', Sedgwick is particularly disgusted by attempts within her hospital breast cancer support group to disavow any sympathies or connections with AIDS and instead forge a breast cancer sorority of which identifies itself instead as 'that-disease-that-is-not-aids'.²⁵⁹ Rose and Sedgwick's own investments in and identifications with modes of queer, or atypical, gender and sexual expression are an important part of this gesture of kinship.

Queer Kinship

In *Queer Kinship: Race, Sex, Belonging, Form* (2022), Freeman and Tyler Bradway cite Kath Weston's *Families We Choose: Lesbians, Gays, Kinship* (1991) as an iconic formulation of queer kinship that constructs it, in ways that I continue to employ in this chapter, as a movement 'toward alternative structures of belonging that may offer intimacy, care, eroticism, and dependency in other forms'.²⁶⁰ This vision of kinship, queered, encompasses the kinds of relationality that Rose and

²⁵⁶ Alastair Curtis, 'The Relevance of Derek Jarman's "Blue" Now', *Frieze*, 2023

<<https://www.frieze.com/article/derek-jarman-blue-now-2023>> [accessed 1 June 2023].

²⁵⁷ Alexandra Genova, 'The Story Behind the Colorization of a Controversial Benetton AIDS Ad', *Time Magazine* (New York, 14 December 2016) <<https://time.com/4592061/colorization-benetton-aids-ad/>> [accessed 1 June 2023].

²⁵⁸ Stacey, p. 43.

²⁵⁹ Sedgwick, *Tendencies*, p. 262.

²⁶⁰ *Queer Kinship: Race, Sex, Belonging, Form*, ed. by Tyler Bradway and Elizabeth Freeman, Theory Q (Durham: Duke University Press, 2022), p. 13.

Sedgwick represent in their narratives: dynamics such as ‘throuples, friendships, cousins, mentors, companionate marriages, nesting partners, roommates, queer platonic partnerships, fuck buddies’, or the “house” system in queer ballroom culture, that exceed the legible relational categories of heteronormativity.²⁶¹ However, as Weston argues, laying claim to a gay family in no way depends upon a break with one's family of origin’, suggesting the chosen family is something more than ‘a surrogate for kinship lost’.²⁶² This bears out in *Love's Work* and *A Dialogue on Love*, where queer kinship structures appear in addition to, rather than in replacement of, the importance of the biological family. What is significant is how Rose and Sedgwick's queer friendships hold a place of equal, if not greater, importance in their relational constellations and consequently their negotiation of the impact of illness. As Freeman and Bradley state, it is not a simple question of ‘either/or’, or a straightforward dichotomy between queer kinship and families of origin. Rather, ‘queer experiments in belonging’ maintain ‘complex relationships to the historical, ontological, and epistemological violence that kinship engenders’.²⁶³ While wary then of ‘kinship idealism’, they demonstrate how structural conditions of capitalism highlight that many ‘assumptions about heteronormative kinship thus no longer hold’.²⁶⁴ Following this thinking, I suggest that the constraints of normativity evident in Conway and Picardie's narratives open up a space ‘for imagining the politics of belonging more queerly’,²⁶⁵ one that makes a radical commitment to be co-present with the other in the absence of the social expectations of biological or heteronormative ties.

As their titles intimate, *Love's Work* and *A Dialogue on Love* attempt to explore illness in the context of a radical ethic of love which exceeds and confounds conventional partnership or familial structures. Within this ethic, queer kinship emerges from an investment in what Sedgwick's therapist calls a ‘border-crossing position’ (p. 179). I read this as a position of shared identification and recognition of discriminatory super-structures, from which Rose and Sedgwick demonstrate a willingness to remain in contact with forms of abjection experienced by ailing and

²⁶¹ Bradway and Freeman, pp. 10, 13.

²⁶² Kath Weston, *Families We Choose: Lesbians, Gays, Kinship* (New York: Columbia University Press, 1997), p. 117.

²⁶³ Bradway and Freeman, p. 2.

²⁶⁴ Bradway and Freeman, pp. 5, 9.

²⁶⁵ Bradway and Freeman, p. 10.

queer bodies, challenging the basis of ‘compulsory heterosexuality’ and ‘compulsory able-bodiedness’.²⁶⁶ In their work, gestures of queer kinship work to close the temporal gap which separates the historic stigma of cancer from the more immediate social stigmas associated with HIV/AIDS. In these texts, the failure of medical institutions to foster spaces and affects of care becomes the ground for the different forms of inventive, improvised strategies and allegiances of what I have named as fugitive care, employed by the ‘black people, indigenous peoples, queers and poor people’ that Jack Halberstam recognises as part of Moten’s fugitive ‘undercommons’.²⁶⁷ As such, queer kinship arises as a political gesture of solidarity against shared experiences of discrimination within the medical establishment and in society more widely. As discussed, both queer men and women are subject to gendered stigmas associated with non-reproductive sex-acts and the failure to produce a heteronormative identity.

For Rose and Sedgwick, claiming queer kinship has the more personal motivation, in the form of friendship. Both wrote about intense and mercurial friendships with men living and dying with AIDS, tacitly if not explicitly identified as gay, that are hard to define as either straightforwardly platonic or even romantic, exceeding culturally available relational categories. Instead, their friendships appear by turns collegial, emphatically platonic, infused with erotic charge, or replete with the familiar and familial rhythm of the mother-child dyad. Through this practice, they offer a provocation to Rich’s notion of ‘compulsory heterosexuality’, taking up her challenge to the assumption that intimacy and romance can only occur within a specific heterosexual formulation.²⁶⁸

In *Love’s Work* this relational dynamic is played out between Rose and her friend Jim. There is an argument that Rose’s relationship with Jim can be understood as among the ‘unhappy loves’ in the text. After all, Jim’s homosexuality dooms it to “failure” by the standards of heteronormative romance, and yet their connection is clearly potent and enduring in many other ways. Their first meeting in 1970 announces a turning point in Rose’s life. She arrives that year in New York, still recovering from the ‘stupidity of reading philosophy at university’ (p. 120), her

²⁶⁶ Rich, p. 632; McRuer, *Crip Theory*, pp. 1-2.

²⁶⁷ Halberstam, ‘The Wild Beyond: With and for the Undercommons’, p. 6.

²⁶⁸ Rich, p. 632.

passion for the subject 'almost completely expunged' by three years at Oxford (p. 102). Three days into her trip she meets Jim, and decides to extend her stay from three weeks to a full year:

'What did I discover in that year? Jim, continental philosophy (Kant, Hegel, Nietzsche, Husserl, Heidegger), the Second Vienna School (Schoenberg, Webern, Berg), Abstract Expressionism (Clyfford Still, Mark Rothko, Barnett Newman, Morris Louis), cooking (out of Craig Clairborne and Alice B. Toklas), hashish, LSD, popular music (Grateful Dead, Bob Dylan, Rolling Stones – yes, in New York!), homosexuality, Jim, Häagen-Dazs ice-cream, the German language, Harlem (where I taught black teenage delinquents to read, two afternoons a week), Adorno, Jim' (p. 110).

Jim's name punctuates and organises every one of these new experiences, conveying a sense of his heady influence. He revitalises her interest in philosophy and through him Rose becomes acquainted with the phenomenologists who become so important for the analysis of time and death elsewhere in her work.²⁶⁹ Rose describes this year as a *Lehrjahr* – an educational year – positioning them also as colleagues and intellectual peers. Rose traces with close attention his thick 'mane of blue-black hair', his height ('well over six foot'), his 'leopard walk' and his large 'majestic hands', crafted as though 'from the workshop of Henry Moore, with immense, broad, flat fingers' (p. 110). This language generates a lingering sense of charisma that is physical, intimate, even erotic. In *Vamps and Tramps*, Paglia, characteristically crass, reduces their connection to something more familiar, claiming Rose was the last female Jim ever dated.²⁷⁰ Rose however carefully cultivates and maintains the ambiguity of their relationship, which in turn sustains the queerness of their entanglement.

Love's Work moves a-temporally between events in his life, and thus refuses the offices of biography (p. 117). He eventually leaves Bennington in disgrace 'on the charge of corruption of students' (p. 112), a 'fiasco' that saw him give up philosophy as a profession (p. 116). This sense of circumscribed promise pervades his characterisation, suggesting in turn why Rose's description of Jim is so persistently hagiographic – an 'icon of AIDS' (p. 5), he symbolises a generation of young men bereft of a third act. In *Love's Work*, Jim's intellectual importance, charisma,

²⁶⁹ Gillian Rose, *Mourning Becomes the Law: Philosophy and Representation* (Cambridge; New York: Cambridge University Press, 1996).

²⁷⁰ Camille Paglia, *Vamps & Tramps: New Essays*, 1st ed (New York: Vintage Books, 1994), p. 228.

circumscribed future and legacy failure are taken up and woven together in the work of memory-keeping and in what Mary K DeShazer has called an ethics of commemoration: a mode of compassionate witness that is not voyeuristic.²⁷¹ He is introduced in chapter one, visibly deteriorating due to AIDS related illnesses, only to disappear again until its penultimate chapter. The effect is to suggest the whole of Rose's life as narrated in the text is inexplicably (according to the ordinary workings of time) held within the temporality of Jim's dying, such is its paradigmatic importance. Her past is re-lived in the context of an event that is both happening and hasn't happened yet. Interposed thus with Rose's memoirs, Jim's death itself also takes on a far more extended duration.

Sedgwick's politicisation around AIDS begins with her meeting with AIDS activist and academic Michael Lynch at the annual MLA Conference. Her 1993 work *Tendencies* is dedicated to Lynch: the essay 'White Glasses' commemorates him explicitly, bringing together cancer and AIDS to suggest a 'dialectical epistemology' between the two diseases.²⁷² There is an intensity to the relationship: his charisma and influence upon her are unmistakable. In her memoir, Sedgwick insists on the integrity of this formulation of queer kinship, as a gesture that begins in the personal: 'it isn't that I like or love all gay men – naturally I don't. I love the particular people I love' (p. 24). Here she is referring to Michael Moon, her housemate and friend. Their bond although 'passionate' and 'physical' is not sexual, although Sedgwick admits 'I'm in love with him' (p. 24).

After Michael's death, or perhaps because of it, Sedgwick becomes involved in the project of organising and editing the writing of 'Gary Fisher, [her] former student', as well as visiting and emotionally supporting him. The sense of alignment between them is more complex (p. 92). Her language establishes an intense, mercurial dynamic: 'Gary is a quicksilver young black writer who won't show his ravishing stories and won't tell anyone – won't let me tell anyone – about the HIV that is working its way through his incandescent body' (p. 92). As in *Love's Work*, the lexical choices are telling – 'ravishing', 'incandescent' – replete with quasi-erotic charge.

²⁷¹ Mary K. DeShazer, *Mammographies: The Cultural Discourses of Breast Cancer Narratives* (Ann Arbor: The University of Michigan Press, 2013), p. 174.

²⁷² Sedgwick, *Tendencies*, p. 15.

Sedgwick articulates a strong connection between them; she later describes having 'fallen in deep again' with him.

Here, the AIDS-cancer 'dialectic' across which *A Dialogue on Love* moves so fluently becomes more difficult to navigate. She writes that 'she is the wrong person to be promoting this material. It is about a black man and she is white; he is gay and she is not; the material has considerable angry racial material as well as being about sex and about master-slave sexual relationships; finally there is a long "colonial" history of white women patronising black writers' (p. 179). Nevertheless, Sedgwick has an investment in making this 'border-crossing position' work. It is a practice that, like Rose's legacy work on behalf of Jim, has a temporal dimension. Taking care of Gary invokes spoken and unspoken histories of racialised dynamics which include the objectification of the Black male body by white women. When Sedgwick assumes the 'responsibility' of navigating these dynamics, Shannon also warns her that she must be 'in for the duration' (p. 92). While the time and intentionality required for care often remains hidden in nuclear family structures, due to the highly gendered nature of care, it paradoxically becomes hyper-visible in queer relations where roles are neither clear nor fixed. The process of coming to terms with the literal and symbolic significance of Gary's death subtends *A Dialogue on Love*. His bedside is part of the imaginary Sedgwick and her therapist Shannon return to repeatedly. When Gary dies midway through the narrative, Sedgwick allows Shannon to "tell" this part through his therapist's notes: she seems to struggle to find language for her grief. Gary's death is thus a transformative event within the timeline of their therapeutic relationship, a threshold they cross together into greater mutual trust and a deeper transference.

'Waiting With' Abjection

Through the construction of queer kinship ties imagined and materially maintained across time, Rose and Sedgwick enter into the fugitive space of possibility that Emejulu describes, in which the act of imagining otherwise takes on a heightened importance.²⁷³ Both Rose and Jim die what sociologist Julia Lawton in her ethnography of hospice care has called 'dirty deaths': dyings that involve abjection

²⁷³ Emejulu, p. 11, 35, 36, 38.

and disintegration of the body.²⁷⁴ Abject bodies are often cast out, expelled as excess and thus condemned to isolation. Sedgwick too experiences in the possibility of remission and her own death, a feeling of deep isolation and psychological abjection. As such, both Sedgwick and Rose rely on the claiming of queer kinship as a way of remaining in contact with something beyond the self and as an acknowledgement of the need for care. Closing the temporal gap between cancer and AIDS through the representation of shared, mirrored and entangled abjection is therefore more than an act of solidarity, but also a recognition and revelation of vulnerability. In Rose's and Sedgwick's narratives, bodies conceived as socially abject join together in kinship across time. Through shared identification and intersubjective contact, the time of living in prognosis produces resonances beyond abandonment.

After unsuccessful treatment, Rose's ovarian cancer metastasises to her bowel, necessitating a colostomy bag. Rose observes dryly that nowhere in the endless romance of world literature does she find an account of living with a colostomy (p. 93). She rectifies this with a frank assessment of her own bodily processes: 'deep brown, burnished shit is extruded from the bright, proud infoliation in a steady paste-like stream in front of you: uniform, sweet-smelling fruit of the body, fertile medium, not negative substance' (p. 95). Rose describes her cancer itself as 'seedlings' which spread in the bowel linings and 'a thin, flat cake of tumour...attache[s] to the greater curvature of the stomach and the old wound' (p. 98). She is informed of the risk of leakage, and of fistula, in which the bowel would begin to digest the abdominal wall. This lexical field – 'seedlings', 'cake' and digestion – draw out one of the particularities of the abject Kristeva foregrounds: that capacity to simultaneously both draw in and revolt, uncomfortably mixing the act of tasting and expelling. 'Seedlings' too, suggest something about the characteristics of cancer: improper propagation and natural processes perverted.

This imagery of the abject, the sense of, as Sedgwick puts it, 'matter out of place', is echoed in Rose's description of the apartment where Jim spends his final days. 'Scored with dirt, infested with cockroaches, stale with dust and debris' it represents the home not as a sanctuary of care but as a space of abandonment, anticipating the

²⁷⁴ Lawton, pp. 122, 145.

rejection AIDS patients could routinely expect from the medical establishment (p. 118). Jim spends 'his last hours in the triage ward of a city hospital for people without health insurance...speechless for days, shrunken and orange with death, his breathing shallow and laboured' (p. 119). When his lover Lance falls ill with AIDS, he contracts a particularly visible 'Kaposi's sarcoma that ravaged his ballerina face' (p. 115). Lance's fate is similarly abject in the original Kristevan sense of being cast out: his body sits in a refrigerator for the first few days after he dies, before being 'removed and sent to Potter's Field...where the unclaimed bodies of the murdered, the intestate, the unidentified and unidentifiable, are buried' (p. 115). These diseased, dying and dead bodies are abandoned as excessive, surplus to the social body, which it expels in order to "live", and for its inward logic and economy to persist.

While Sedgwick's cancer is in a stage of remission in *A Dialogue on Love*, she recognises feeling increasingly 'withdrawn' (p. 197), which Shannon interprets as her turning away from the world, 'shutting down some affects...trying to relate to the future of her own death' (p. 216). In this rehearsal of death, Sedgwick becomes more isolated from the 'living' and closer in thought to the dead and dying. Sedgwick identifies that her withdrawal and work on Gary's legacy results in a 'present way of moving between the living and the dead' which she experiences as 'obscene, dirty (dirt as matter out of place)' (p. 198). She speaks with Shannon about 'being attracted to the dying and the dead... [and] identification with disease' (p. 160). Desire appears in an abject mood in her fantasy life: she imagines 'taking [Shannon's] socked foot and masturbating with it' (p. 182), and states that 'genital desire without a structure to satisfy it...[is] like walking through the world with a gaping wound' – this wound, bound up in her adolescent and nascent sexual desire is an 'open-secreting-smelly thing' (p. 183). Importantly though, while Sedgwick is solitary in this fringe position, she is not alone. The dead and dying – her friends Gary Fisher and Michael Lynch, and the poet James Merrill – keep her company. Indeed, in her life and dreams, everyone around her is dying. She is part of a community of the dying reaching across identifications; she dreams of an 'exam by her oncologist and an older MD. Her oncologist has cancer and now the older MD has had it, has shirt off (sic) and scars on his torso' (p. 209). Her husband Hal tells her that 'their doctor in NY...turns out to have an AIDS related infection' (p. 198).

Later in the narrative Shannon notes that ‘E got a call from woman (sic) she has known here who just found out she too has breast cancer’ (p. 220). Gary is admitted to hospital with ‘CMV in the gut’, which ‘makes people with AIDS go blind’, and he is ‘very sick, still hacking [cough], very weak. Says it’s been gruelling’ (p. 127). Like Rose, Sedgwick’s increasing sense of the abject seems to specifically mirror the decline and suffering of her friends. Editing Gary’s papers involves a sharing of subjectivity and abjection: ‘I plunge into the vat of his unmakings. Including, intensely: abyssal, glazed-over boredom’. A boredom that ‘means overstimulation, stimulation of wrong or dangerous kinds; hell; rape; dissolution’ (p. 160). She is ‘immersed, morning till night, in Gary’s book. The archaic fragrance of profanation around the project only gets more insistent’ (p. 198).

While there is a measurable contrast between the care Rose and Sedgwick can access as white middle-class women presenting with cancer as a less stigmatised disease, through echoing imagery, their narratives reach across the temporal gap which separates discourses of cancer from HIV/AIDS. Rather than turning away from the bodily and emotional proximity to abjection which follows in the progression of their illness, seeking to mask or obscure, their narratives turn towards that which in a normative register might generate the same repulsion Conway expresses at the thought of the breastless women appearing without wigs or prosthesis. In this way the prospect of the declining of the body is not only represented as solely destructive – through the loss of valued femininity – but rather as constitutive, as a ground for curiosity and the potential for shared identification with the other. In being co-present with these others, they re-assert the significance of queer kinship. Simultaneous to her own experience, Rose abides in the abjection of Jim’s dying; Sedgwick does the same for Gary.

As Kafer and Lochlann Jain suggest, living in prognosis is a temporality which has multiple significances.²⁷⁵ In *Love’s Work* and *A Dialogue on Love*, this time of waiting makes available something more than the indifference and alienation that Conway and Picardie record in their linear accounting of time. Through form and language, they are able to queer waiting, subverting its normative associations with failure and inefficiency in order to tap into its transcendent and even erotic potential. As Michael

²⁷⁵ Kafer, p. 37; Jain, p. 103.

Wood observes in his introduction to the 2011 edition, *Love's Work* seems to be organised around an injunction to 'keep [one's] mind in hell and despair not': the words of the nineteenth century Russian Monk and mystic, Staretz Silouan (p. xiii). For Woods the phrase has two layers of meaning: in Silouan's original sense, it might mean something like 'if you can weather hell, and not despair in the process, you will be saved' (p. xiii). For Rose, hell itself is transformed to mean the staunch refusal of despair: 'to inhabit hell, to keep one's mind there, is to find the hope that is not the opposite of devastation but its complement' (p. xiii). The maxim also retains the flavour of ascetic discipline as religious ecstasy. The ascetic nature of this discipline comes from the conditions of discomfort or pain in which it takes place throughout the text – for example, the extended period in which Rose is living with a colostomy. It suggests a strategy of inhabiting states of psychic or physiological discomfort yet finding ways in which to subvert the meanings attached to 'hell' in order to produce something other than despair. Far from unproductive or contentless, waiting in *Love's Work* brings together a range of contradictory states and affects in ways that articulate a different kind of value. The patience required in the work of love is a reoccurring refrain: Father Patrick, for example 'knows the long travail and discipline of love' (p. 67). On their first meeting he 'immediately gripped [Rose's] hand and, looking [her] straight in the eye, did not release the tension between [their] clasped hands and locked eyes for the duration of the telephone call' he is making when she arrives (p. 66). Indeed, it is waiting that produces the tension which is the source of the erotic. Yvette helps Rose to develop this discipline of erotic attention – 'the universal and sacred spirit of lust' (p. 29) – paradoxically as a kind of spiritual ascetic practice. Love and lust involve a mix of pain, longing and discipline; waiting to die is a practice that is an extension of Rose's life's work of advancing this sacred and universal spirit, and adhering to the difficulty, perversity and beauty of a queer life.

Waiting is linked with discipline in *A Dialogue on Love*, but in a more overtly fetishised character. Sedgwick's dreams and sexual fantasies take place against a backdrop of 'quasi-medical' 'punishment spaces' (p. 48). These 'fantasies always have an institutional pretext – almost a bureaucratic one. They take place in a girls' school, a prison, or a spy agency – always, always places with waiting rooms' (pp. 47 – 48). Sedgwick describes the 'slant, withdrawn fellowship of waiting patients at

the cancer clinic, the specific gravity of each thickened by dread: it's like the way people wait, about to be punished, in my fantasies' (p. 48). 'Certain rhythms' are central to these scenes: 'spanking rhythms most obviously. Waiting – waiting with dread' (p. 172). These fantasies produce a warm 'at home' pleasurable affect 'different from the anxious way you'd talk about actual childhood scenes of punishment, waiting, masturbation' (p. 172). Later, she feels the touching of 'the two, utterly separate worlds' [of sexual fantasy and cancer treatment] on an occasion where a nurse is trying to take blood: 'I could hear the moment when the nurse relaxed. When she realised that she'd never get blood out of me unless she could step away from the assembly line of her own temporality and simply stop' (p. 49). Waiting is a space in which Sedgwick becomes aware of the other as a potential erotic interlocutor. These scenes of sexual discipline become a way of managing – of waiting through – health anxieties and grief. She remarks to Shannon: 'curious that I'm willing or able to focus on this instead of (in place of? In any relation to? I can't tell) the loss of Gary...talking about this stuff seems more bearable in the face of huge, unaddressed loss' (p. 174). Ostensibly opposed, there are unexpected queer commonalities to be found within the transcendence of ascetic religious practices, and the kinds of sexual ecstasy that Rose and Sedgwick explore.

Conclusion

These queer women's narratives chart the waiting that accompanies living in prognosis. They suggest that, rather than the content-less suspension of time, waiting is richly associative, affirming spiritual and erotic preoccupations as well as producing communities of the dying who might 'wait with' one another.²⁷⁶ Waiting is a space of attention that develops parallel to, but distinct from the regulatory agent of clock time. In waiting, other kinds of productivity become apparent and indeed available, in a temporality that runs queerly counter to the market logic of neoliberal capitalism. The queer kinship gesture which grounds and differentiates these cancer narratives from their mainstream counterparts, seems to emerge from a willingness to abide, dwell and endure in the suffering of abject others, to enfold their temporalities into one's own. In contrast, placing the nuclear family at the centre of

²⁷⁶ Salisbury, "Between-Time Stories", p. 100.

their narratives, *Ordinary Life* and *Before I Say Goodbye* represent cancer narratives as they are often positioned: as neutral, or else not distinctly political, demonstrative of universal experiences of illness that transcend social and economic stratifications. Focused on the individual experience, both to an extent take for granted the ways in which status and care are intimately connected. While compelling and affectively potent, these narratives are constrained by the conventions and norms of their form. They constitute the false neutral against which I argue in subsequent chapters of this thesis for a wider, more expansive understanding of cancer and illness narratives: in what other formal containers might other, more marginal experiences of sickness and death, be recognised and drawn out?

Chapter Two: Black Death, Narrative and Poetic Form

‘This is the afterlife of slavery – skewed life chances, limited access to health and education, premature death, incarceration, and impoverishment’²⁷⁷

– Saidiya Hartman, *Lose Your Mother: A Journey along the Atlantic Slave Route*

Much has been theorised about the afterlives of slavery, particularly in relation to health and increased mortality for those racialised as Black. Research findings, quantitative and qualitative, give an account of the higher rates of illness and death across the Black diaspora.²⁷⁸ These narratives are sympathetic to a particular thread of anti-humanist thought running through contemporary Black studies – Afro-pessimism – which theorises the ontological condition of blackness as an abiding form of social death, born of the enduring temporalities of transatlantic slavery. While Afro-pessimism and its adjacent thinking offer a helpful framework for understanding the related workings of time, race and illness, I also consider the limitations of this school of thought.

In the context of this research, the absence of illness narratives related from this perspective is particularly striking. This chapter, then, thinks through the relations of narrative to the Black experience of death, illness and what Jaspir Puar has termed ‘debility’ – a concept used ‘to rethink disability through, against, and across the disabled/non-disabled binary’.²⁷⁹ What might it mean to locate and identify the formal containers for these experiences: where are these narratives held? This question is the point of departure in the process of locating a missing, invisible archive. For the experiences of racialised illness and death to reveal themselves, we need to, as readers, be open and attentive to different formal containers. One analogue to this practice might be found in Hartman’s reading strategies, which work towards, rather than in frustration with, the absences and breaks of the archive. What is particularly interesting is the connection Hartman makes between visibility and coercion in the archives of Black life. There, records and ‘photographs coerced the black poor into

²⁷⁷ Hartman, p. 25.

²⁷⁸ Tina K. Sacks, *Invisible Visits: Black Middle Class Women in the American Healthcare System* (New York, NY: Oxford University Press, 2019), p. 6.

²⁷⁹ Puar, p. 2.

visibility' while testifying to everyday poverty and violence.²⁸⁰ There is a similar paradox at work in the narrative representations of the end-of-life from a Black perspective, which hazard the trap of visibility as part of the condition of the possibility of legibility and, more distantly, change.

To develop this line of argument I examine a selection of contemporary autobiography and poetry, focusing on two memoirs, Edwidge Danticat's *Brother, I'm Dying* and Jesmyn Ward's *Men We Reaped*, and two poems: Harryette Mullen's 'All She Wrote' from the collection *Sleeping with the Dictionary*, and Claudia Rankine's *Citizen*. My argument is that Black illness and end-of-life experiences are occluded from the medical humanities canon and must be "mined" from within other kinds of texts. This occlusion foregrounds the way in which blackness constitutes a state of both hypervisibility and, paradoxically, illegibility, within a logocentric, capitalist system which centres whiteness as a condition of narrativity. Key to this dynamic is the question of temporality, specifically chronicity: the chronic, durational legacies of transatlantic slavery and western imperialism which perpetuate chronic, generationally-compounded experiences of illness and dying across the Black diaspora. As Jennifer C. Nash points out in her recent monograph *Black Feminism Reimagined*, critical theory has arrived at 'an intellectual moment where black studies is preoccupied with death—social and material'.²⁸¹ This idea of death as fundamental to Black studies and woven into Black existence as the paradigm of "deathly life" is a key point of resonance between these literary texts and the Afro-pessimist tradition. It is difficult to surpass, although one of the ways to do this is through form, specifically formal experimentation. I suggest poetry as an alternative representational strategy for exploring Black illness and end-of-life experiences, one that functions importantly as a formal and temporal *break* with both narrative and history.

On the face of it, the texts selected for analysis in this chapter are not obviously or solely about illness. However, this apparent incommensurability is one of the most compelling arguments for granting them sustained attention. These texts expose the conditions that produce chronic sickness, poor health outcomes and death in its

²⁸⁰ Hartman, *Lose Your Mother*, p. 21.

²⁸¹ Jennifer C. Nash, *Black Feminism Reimagined: After Intersectionality*, Next Wave New Directions in Women's Studies (Durham: Duke University Press, 2019), p. 20.

most violent and untimely forms. Using close reading as a method compels each text to yield insights about Black illness and end-of-life experiences, while inviting a wider consideration of how and why the accounts of such experiences might be expressed opaquely or be decentred or simply missing in both the texts themselves and the culture more broadly. Here I draw on Édouard Glissant's conception of 'opacity', which is an argument for the irreducible difference of the other against the threat of their assimilation or annihilation.²⁸²

It is telling then what gets to "count" as an illness narrative. The following chapter engages with the implications of cultural occlusions as a key theme, considering the tension between speech and silence. Who is permitted a voice, in what form is that voice expressed, and how do differences in form themselves speak to asymmetries of power over time? In the context of the cancer narratives of the previous chapter, which offer a picture of illness and care in excess of the family in the shadow of the AIDS crisis, illness functions as an incitement to writing. For Rose as a philosopher, illness occasions a deep immersion into language through the process of situating herself and writing in relation to a tradition of western continental philosophy. The texts selected for this chapter focus on different intellectual lineages and evidence a vexed relationship with this kind of legibility.

Legibility, Temporality, History

Throughout this chapter, I return again and again to this question of what it means to speak or remain silent under emotional or political duress: to be required to give account of oneself and to be, or to fail to be, accounted for. I am also interested, as stated, in related questions of legibility. These terms and phrases can be drawn together into a unified semantic field, to gesture to the ways in which conceptions of narrative, readability, and textuality share resonances with conceptions of fiscal value and record-making. I see this in King's granular reading of colonial surveyor William Gerard De Brahm's '1757 Map of the Coast of South Carolina and Parts of Georgia'. The map's legend – significantly 'placed in the exact bottom center [sic] of the map as the anchor' – contains a ledger of the names of and titles of the

²⁸² Glissant and Wing, p. 49.

proprietors of newly colonised land and enslaved people.²⁸³ These white settlers, King argues, are signified as human through the inscription of name and title, through ‘a series of symbolic representations that are largely logocentric’.²⁸⁴ These include the legend of the map, and, more abstractly, the western literary canon itself. Again here, complex connections between subjectivity, narrative and value present themselves and suggest certain kinds of legibility are required as a condition of being recognised as human.

The idea that there is an inherent tension between blackness and the Human as ontological categories has been differently expressed by leading thinkers within Black studies and critical race theory. It is worth returning to how that tension is formulated by Franz Fanon, as a relation of painful and involuntary attachment. Writing in *Black Skin, White Masks*, Fanon describes a particular type of bind,

There is a fact: White men consider themselves superior to black men. There is another fact: Black men want to prove to white men, at all costs, the richness of their thought, the equal value of their intellect. How do we extricate ourselves?²⁸⁵

The remainder of Fanon’s text is taken up with analysing the nature of such aspirations to “progress” which harm even as they “uplift”. Under such conditions, certain memories, social relations and even a persistent and hopeful orientation to the future take on the character of ‘cruel optimism’, working counterintuitively even as they sustain.

This term, coined by queer theorist Lauren Berlant, describes a relation to an object or desire imbricated with, or simultaneously existing as an ‘obstacle to your flourishing’.²⁸⁶ Berlant writes that cruel optimism ‘might involve food, or a kind of love...a fantasy of the good life, or a political project’.²⁸⁷ The last two of these examples stand out as particularly relevant to the concerns of this chapter. Ward, for example, tries to reclaim an attachment to a good, or at least a better life, beyond or perhaps in spite of anti-blackness, as the ‘greatest gift’ her mother passes on. She writes, ‘without my mother’s legacy, I would never have been able to look at this history of loss, this future where I will surely lose more, and write the narrative that

²⁸³ King, p. 82.

²⁸⁴ King, p. 88.

²⁸⁵ Frantz Fanon, *Black skin, white masks* (London: Pluto, 2008), p. 3.

²⁸⁶ Lauren Berlant, *Cruel Optimism* (Durham: Duke University Press, 2011), p. 1.

²⁸⁷ *Ibid.*

remembers...that says: *Hello, We are here. Listen*'.²⁸⁸ Ward's articulation of the ways in which the legacies of slavery are felt generationally is reminiscent of another narrative of death and "passing on": Toni Morrison's *Beloved*.²⁸⁹ However, in that text, attachments to life are ambivalently negotiated. Protagonist Sethe and her real-world analogue, Margaret Garner, resolve to kill their own children rather than allow them to be re-enslaved. In many ways, Sethe-Margaret's decision to turn away, to sever the attachment to life is consistent with the Afro-pessimism of Wilderson, which dictates that the Black subject experiences the world in something akin to the genre of horror. Within the conventions of both frameworks, Afro-pessimism and the horror genre, the experience of the subject is overdetermined, and any sense of reprieve or escape is temporary. I suggest there is another position beyond the foreclosure of horror as articulated by Wilderson, and the allure of writing the Black subject into narratives of progress.

The answer might be approached by framing the problem as a question of time in addition to form. In Fanon's own words, 'the architecture of this work is rooted in the temporal. Every human problem must be considered from the standpoint of time'.²⁹⁰ In archetypal narratives, illness and death have been presented as moments of rupture, as intrusions within the ordinary flow of a life, even a life that refuses a normative progression through certain milestones. By contrast, in the texts that form the focus of this current chapter, illness and death are approached as fundamentally intertwined with life, embedded in the *longue durée* of racism. I take my cue here from the ways in which *longue durée*, as a temporal model, has been more recently mobilised by thinkers in the Afro-pessimist tradition, following Fernand Braudel's original usage, in which *longue durée* describes deep history and the aggregation of historical forces over time.²⁹¹ In this context, a break, or blockage in the ordinary "flow" of time has a very different significance as an interruption of the chronic and repetitive workings of anti-blackness. A break functions here as a kind of closing which allows space for temporally-contingent forms of care: healing, grieving and bringing things to the relief of ending. These moments must be snatched in between

²⁸⁸ Jesmyn Ward, *Men We Reaped: A Memoir* (London: Bloomsbury, 2013), pp. 250–51. Further references to this book are in the text.

⁷ Toni Morrison, *Beloved*, Vintage Classics (London: Vintage, 2007), p. 324.

²⁹⁰ Fanon, p. 5.

²⁹¹ 'Entry: Longue Durée', in *A Dictionary of Critical Theory*, ed. by Ian Buchanan, 1st edn (Oxford University Press, 2010) <<https://doi.org/10.1093/acref/9780199532919.001.0001>>.

the daily labour of going-on, which aligns them with the notion of fugitivity which appears in Moten's thinking. A fugitive mode or frame, animated by the spirit and desire of the runaway formerly enslaved, prioritises refusal 'of the proper and the proposed...[as] a desire for the outside'.²⁹² Fugitive acts of care might run counter to sanctioned clinical pathways, might seem makeshift or janky from a normative perspective, and are likely to involve kinship networks and relations that confound the insularity of the nuclear family. The suspension of time itself might also function as a kind of opening onto, or caring for, the future, creating an aperture which generates the possibility of imagining and 'existing otherwise'.²⁹³

Inspired by the ways in which the grammar and phenomenology of rupture has been formulated by Moten and Giorgio Agamben, it is possible to think about different formulations of the break in Black avant-garde poetry, perhaps notably: Harryette Mullen's 'All She Wrote' and Claudia Rankine's *Citizen*. Throwing into relief the limits of narrative, poetry presents itself as a literary form appropriate for holding or conveying that experience of rupture. Narrative is typically bound to the sequential progress through a beginning, middle and end. Illness narratives marry this progression with a movement through diagnosis, treatment and ideally rehabilitation and recovery, promoting a structure and temporality that tends to affirm what Le Guin identifies as the story of the 'Hero'.²⁹⁴ Poetry, so often non-sequential and taking place in a kind of non-space/non-time, seems to be able to sustain a different set of temporalities, more sympathetic to the (sometimes radically) decontextualised, suspended time of rupture, blockage or break. My analysis of these two poems focuses on how they take up the painful themes of Danticat and Ward's narrative and reformulate them. I am attentive to their exploration of blockage, formal breaks and as well as breaking-down (as an integral part of breaking through).

Both temporalities – the continuity (the continuous line of anti-black violence and racism) of what Sharpe theorises as living 'in the wake' on one hand,²⁹⁵ and the suspended time of the break, the block or rupture on the other – represent a challenge to the concept of "timeliness" used to dictate the shape and value of (the good) life. While I will consider Sharpe's intervention in more detail subsequently, I

²⁹² Fred Moten, *Stolen Life*, (Durham; London: Duke University Press, 2018), p. 131.

²⁹³ Hartman, *Wayward Lives, Beautiful Experiments*, p. xv.

²⁹⁴ Le Guin.

²⁹⁵ Sharpe, *In the Wake*.

want to focus on this conventional notion of “timeliness” in relation to what Mills has theorised as ‘white time’. ‘White time’, consolidated by settler-colonialism, functions as both a ‘Euro-centered periodization...[and] a demarcator of the appropriate use of time, conceptions of daily rhythms of work and leisure, as opposed to the general misuse of time Europeans found elsewhere’.²⁹⁶

In his article, Mills also conceptualises racism as a kind of forceful redistribution of time, a set of practices which takes time away from those subject to racialisation. This “taking away” has many functions and implications. It can function by extending work hours or circumscribing time available for maintenance and care, the implications of which are felt as shortened or abbreviated life spans. In Mills’ terms, throughout history and into the present,

racial regime[s] (racial slavery, colonial forced labor, Jim Crow, or apartheid polities) imposes, inter alia, particular dispositions and allocations of time that are differentiated by race: working times, eating and sleeping times, free times, commuting times, waiting times, and ultimately, of course, living and dying times.²⁹⁷

I note that these are the conditions described by Sharpe’s formulation of the ‘weather’ in her influential work *In the Wake: Blackness and Being*. Part memoir, part theory, literary criticism and historiography, *In the Wake* bends genre in ways that call to mind Hartman’s influential body of work, particularly *Lose Your Mother: A Journey along the Atlantic Slave Route*. *In the Wake* is taken up here as a useful critical in-road to discourses of health, temporality and racism in Black studies. The text itself opens with an illness narrative in the plural, a record of recurring waves of chronic illness and death within Sharpe’s extended family.

Sharpe reflects on the accrual of losses after her sister’s death in May 2013:

I had no idea, then, that two more members of my family would also die within the next ten months. This would be the second time in my life when three immediate family members died in close succession. In the first instance, between February 2, 1997, January 19, 1998, and July 4, 1999, we survived the deaths of my nephew Jason Phillip Sharpe; my mother, Ida Wright Sharpe; and my eldest brother, Van Buren Sharpe III.²⁹⁸

²⁹⁶ Mills, p. 31.

²⁹⁷ Mills, p. 28.

²⁹⁸ Sharpe, *In the Wake*, p. 1.

I am struck by the resonances between this first chapter of *In the Wake* and how Ward frames her memoir *Men We Reaped*. The latter inhabits the contexts Sharpe lays out to frame her critical intervention, but in a deeper, more extended way. The losses Sharpe relates briefly in this first chapter of her book include the death of her father during childhood, which plunges Sharpe's family down from 'lower-middle-class straitened circumstances into straight-up working poor'.²⁹⁹ They are followed and compounded by the death of her adopted nephew Caleb Williams and finally, of her brother Stephen. Stephen is diagnosed with malignant mesothelioma, a cancer with a ten-to-fifteen-year dormancy period, which painfully demonstrates the endless present of racism and poverty: 'In the wake, the past that is not past reappears, always, to rupture the present'.³⁰⁰

Both Sharpe and Ward's texts offer representations of early life experiences of striving towards "better", modulated by kinship and careful maternal cultivation of 'joy' and 'livable moments'.³⁰¹ These experiences are nevertheless overridden, in Sharpe's words, by the 'engine of US racism [which] cut through my family's ambitions and desires'.³⁰² This is the 'weather': an 'orthography', or grammar, which 'registers and produces the conventions of anti-blackness in the present and into the future'.³⁰³ It works effectively as a form of deep metaphor that evokes both the temporal and (in a sense more tangential to my argument) environmental, even ecological, dimensions of racism.

Sharpe's argument is that the deathly repetition of illness and violence is one unnegotiable dimension of living in the temporality of 'the wake': a term that borrows some sense of Hartman's conceptualisation of the 'afterlives of slavery'. The wake describes 'the track left on the water's surface by a ship' and the impact of a disturbance of water (the ship and the disturbed waters of the Atlantic constituting a potent symbol in the history and material idiom of chattel slavery).³⁰⁴ Sharpe's notion of the wake also expands to refer to states of 'wakefulness' as a particular kind of

²⁹⁹ Sharpe, p. 4.

³⁰⁰ Sharpe, p. 9.

³⁰¹ Sharpe, p. 4.

³⁰² Sharpe, p. 3.

³⁰³ Sharpe, p. 21.

³⁰⁴ Sharpe, p. 3.

consciousness of race and its effects.³⁰⁵ Wakes also enfold rituals and processes of the mourning and celebration of life.³⁰⁶

In the book, Sharpe states her intention to ‘think care as a problem for thought’.³⁰⁷ She does so in a way that foregrounds the rehabilitative aspiration of a certain kind of work within Black studies which maintains contact with painful legacies, while working through relations between Black studies as a discipline and the wider body of western philosophical thought: a form of taking care of history.³⁰⁸

I enter into dialogue with Sharpe here in order to build on her conception of the wake specifically as a temporality, and her construction of the ‘weather’ as a metaphor of the unescapable nature of this extension of time, and its quality as something that must be endured, waited-through, even as the wake and the weather are framed as temporalities without end. Drawing out the metaphor, I suggest that finding moments and modes of relationality, particularly through form, which offer temporary reprieve or, even “shelter” from the weather, constitute a different, but equally instrumental kind of care for and as Black diasporic survival.

Foregrounding Illness and Death in *Brother I’m Dying*

While it tracks the movement of her family between Haiti and the United States, Edwidge Danticat’s *Brother, I’m Dying* is filled with narratives and micro-narratives of the chronically ill and the terminal. Tellingly, this fact alone does not qualify the text for admittance into the corpus of illness narratives. Following trends in the text’s reception, Aline Lo reads the memoir as a refugee narrative.³⁰⁹ Myriam Chancy’s chapter in *The Bloomsbury Handbook to Edwidge Danticat* (2021) also reads the text through the lens of racialised immigration discourses, in this following April Shemak’s landmark book *Asylum Speakers: Caribbean Refugees and Testimonial Discourse* (2010). Illness narrative critique is hobbled by the same tendencies of the market which produces them: a tendency to privilege narratives of ostensibly more universal

³⁰⁵ Sharpe, p. 4.

³⁰⁶ Sharpe, p. 21.

³⁰⁷ Sharpe, p. 5.

³⁰⁸ Baraitser, p. 14.

³⁰⁹ Aline Lo, ‘Locating the Refugee’s Place in Edwidge Danticat’s *Brother, I’m Dying*’, *Lit: Literature Interpretation Theory*, 29.1 (2018), 45–59 <<https://doi.org/10.1080/10436928.2018.1425958>>.

or “neutral” experiences of illness, uncomplicated by the legacies and histories of colonialism and racialisation. This tendency also expresses itself in the way that meditations and memoirs containing Black illness experiences are categorised in the first instance by their relation to blackness and silo-ed off from the genre canon.

Brother, I'm Dying, is subject to these genre distinctions, unfolding as it does in the context of Haiti's troubled history and America's hostile immigration policy in the late 1990s and early 2000s. Marlene Daut, a prolific scholar of Haitian revolutionary history, foregrounds the ways in which scholarship on the revolution configures it exclusively in terms of colourism, as ‘a “mulatto/a vengeance narrative”’ on a mixed race elite class with proximity to enslavers, rather than recognising ‘a desire for liberty and equality’.³¹⁰ In *Haiti: The Aftershocks of History* (2012), Laurent Dubois highlights the way in which Haiti has historically been judged by the world as ‘a hopeless and absurd place with no future’, its capital city ‘Port-au-Prince [is] dirty and unpleasant and full of beggars’, its citizens deems ‘lazy and “ashamed” of work, which is why they [are] so poor’.³¹¹ However as Dubois's historiography shows, such judgements obscure the ways in which Haiti's struggles with economic instability, infrastructure and civil war are a direct result of colonial interference, US occupation and violent civil wars.³¹² Environmental turmoil in the form of periodic earthquakes compounds this instability, with ‘entire neighbourhoods...levelled, as if by a bombing raid. In schools, shops, hospitals, and homes, falling concrete slabs...killed or trapped hundreds of thousands of hapless victims and left a million people homeless’.³¹³ As Michel-Rolph Trouillot observes, Europeans see in the political grammars of the “developing world” ‘proof of the inferiority of non-whites’, but ‘as befits comparisons between the West and the many subaltern others it created for itself, the field was uneven from the start’.³¹⁴ Against such odds it is difficult to see how any other country would have had a chance. A sense of Haiti's end and decline was thereby temporally encompassed in its very beginnings as a state. In *Brother*,

³¹⁰ Marlene L. Daut, *Tropics of Haiti: Race and the Literary History of the Haitian Revolution in the Atlantic World, 1789-1865* (Liverpool University Press, 2015), p. 1.

³¹¹ Laurent Dubois, *Haiti: The Aftershocks of History*, First Picador edition (New York: Picador, 2013), pp. 2, 1.

³¹² Dubois, pp. 4, 9.

³¹³ Philippe R. Girard, *Haiti: The Tumultuous History--from Pearl of the Caribbean to Broken Nation*, 1st Palgrave Macmillan pbk. ed (New York: Palgrave Macmillan, 2010), p. 2.

³¹⁴ Michel-Rolph Trouillot and Hazel V. Carby, *Silencing the Past: Power and the Production of History* (Boston, Massachusetts: Beacon Press, 2015), p. 7.

I'm Dying, the sense of foreclosure and accretive histories are rightly present and immediate.

This said, it is possible to read *Brother, I'm Dying*, as an illness narrative in the more conventional sense, in as much as it is the story of two brothers as they approach the end of life. The narrative culminates in the death of Danticat's Uncle Joseph – who she sees as her second father – in custody, in an immigration detention centre at the age of 81, due to chronic illness. Simultaneously, the narrative is also tracking the advancing illness of Danticat's father, Mira. Mira's framing of chronic illness in the text suggest it manifests as a kind of deathly life: he states, 'when a person is sick, either you're getting better or you're dying'.³¹⁵ The text opens on Mira's diagnosis of incurable pulmonary fibrosis, in the wake of his chronic shortness of breath, coughing and weight loss. Treatment seems as challenging as the illness – the codeine he is given causes him to lose his job, and the narrative sees him relying instead on medicines from his US based traditional herbalist. Uncle Joseph experiences of chronic illness start sometime before this, as a young man, when he starts to lose his voice and experience throat pain. He travels to the south of Haiti to consult the visiting American doctors in the hospital, who diagnose a large tumour sitting at the top of his larynx as cancerous. The American doctors in Haiti cannot help him: the tumour 'was too large and they didn't have the right equipment for the procedure' (p. 39). He is advised to travel abroad for "proper" treatment. His illness shifts suddenly from chronic to acute after he arrives in New York: the tumour has grown to such a size that it obstructs his breathing. The result is an emergency tracheotomy and the permanent loss of his ability to speak, something, I will argue, deeply impacts his ability to give account of himself: to be legible to the systems of capitalist imperialism with which he becomes entangled.

A conventional illness narrative might be said to focus on the trajectory of one "main character", charting the dynamic progress of their illness over time. In this way, through familiar form and structure, they contribute to an imaginary of illness as exceptional, individual, moving in predictable ways through a trajectory of diagnosis, treatment and recovery. Such narratives of heroism are organised around the ill person's capacity to "resist" their illness, using strategies such as humour, in a

³¹⁵ Edwidge Danticat, *Brother, I'm Dying*, 1st Vantage books ed (New York: Vantage Books, 2008), p. 19. Further references to this book are given in the text.

display of proper socialisation, and physical and psychological discipline. What unfolds instead in *Brother, I'm Dying*, through Danticat's parallel narrative of her Uncle Joseph and father Mira's chronic illnesses and end of life experiences, is a sense of illness as shared and as messily social, commonplace and collectively lived, even though the embodied experience of illness takes place, to an extent, apart. What is more, the text is stippled with a many other, shorter, seemingly incidental micro-illness-narratives, which do not fit the conventional shape and trajectory of the illness narrative genre, but contribute to the broader meanings *Brother, I'm Dying* makes of the character of illness. For example Danticat writes of her auntie, Tante Zi, who has dressed in 'all-white outfits...since 1999', to commemorate her 'oldest son, Marius, [who] died of AIDS in Miami at the age of thirty' (p. 194). This sentence contains a whole, compacted micro-narrative of suffering, illness, death and grief, which speaks to the wider cataclysm of the HIV/AIDS crisis, while still being held within the narrative.

Medical waiting rooms and spaces appear early and often in *Brother, I'm Dying*, emphasising the failures of care perpetuated by the American state, while simultaneously highlighting instances of solidarity and accord in disenfranchised communities across time. The narrative begins with a visit to Brooklyn's Coney Island Hospital, to a consultation with a pulmonologist about Danticat's father's 'rapid weight loss and chronic shortness of breath' (p. 3). Readers will come to understand that sites of medical care are key to the structure and meaning of this text, which returns to them frequently in the elaboration of its themes. They constitute striking representations of America's systems of stratified care and establish a familiar context in which medical institutions, far from being neutral or a-political, are the main stage on which chronic socio-economic hierarchies play out.

The waiting room of the pulmonologist Dr. Padman is described as a 'sad and desperate place', a 'gray and dingy room' with 'stale and stuffy smells', 'peeling beige paint' and 'anti-smoking posters' (p. 7). The latter in this context seem didactic and redundant, placing the onus of illness back onto patients themselves, without acknowledging the inescapable mitigating factors of work and environment. In its reproduction of precise textures of material discomfort, this early scene establishes a connection between under-resourced provision of care and particular racial identities; the room is peopled by 'mostly Caribbean, African, and Eastern European

immigrants' and Dr. Padman himself is a 'South Asian man' with a 'trace of an accent' (pp. 7 – 8). The connotative symbolism of Coney Island might assert itself here. Coney Island has enduring significance as an melting pot (although to a lesser extent than its sister Ellis Island), and as a reminder that although the US has been characterised as a country of immigrants, it becomes what it is by making stringent distinctions between the 'tired...poor... huddled masses' and 'wretched refuse' of Emma Lazarus' famous sonnet, seeking some character of freedom or reprieve.³¹⁶ What comes into view instead is a picture of the medical treatment of people of colour as siloed-off from that of white Americans. However, in spite of its shortcomings, Dr. Padman's waiting room is a place where the possibility of identification and even solidarity emerges: here Mira can 'cough without being embarrassed, because others were coughing too...more vociferously' (p. 7). He is part of a community of 'skeletal faces and winded voices' (p. 7).

There is a parallel between this scene, and the narrative flashback to Danticat's uncle's experience of seeking treatment for his then undiagnosed throat cancer. Uncle Joseph hears through a local radio station that American doctors are coming to a hospital in Southern Haiti to offer open consultation as part of some charitable initiative or philanthropic care. The hospital is some distance away, the trip takes several days. On arrival he faces 'a long wait' outside in the yard. 'Hundreds' have made the same trip, a testament to Haiti's pressurised healthcare system (p. 37). Their complaints too, draw a stark picture of the national standard of health in Haiti 'tuberculosis, malaria, typhoid fever and other not so easily recognisable afflictions' (p. 37). Elsewhere, Danticat and her brother Bob are referred for chest X-rays as part of the 'physical' examination that will allow them to join their parents in the US. She describes the 'small windowless waiting room in the public hospital's radiography department... filled with many more patients than it could hold comfortably' (p. 98). Another narrative flashback to Danticat's birth offers a further picture of reproductive health injustice in Haiti: 'my mother...was one of nearly a dozen women who were doubled over and wailing in the yard. There were too many of them and not enough doctors. No one even examined them until their babies crowned' (p. 253). These waiting rooms seem to be connected across time and

³¹⁶ Emma Lazarus, *The New Colossus, The Poems Of Emma Lazarus*, Literature Online - American Poetry Literature Online - American Drama 1714–1915 (Cambridge, 1889), p. 203.

space. It is important to acknowledge the ways in which they demonstrate a chronic demand for services that exceed provision, an under-resourcing of care for Black populations that points to larger structural issues.

In contrast, the herbalist recommended by Mira's pastor is able to see them immediately, although they do not have an appointment (p. 6). This contrast illustrates the ways in which care within minority communities, is, historically and by necessity, inventive, improvised and endlessly challenging, taking place in excess of sanctioned clinical and social pathways. Care appears in such spaces as a set of fugitive, liminal practices at odds with institutional mandates and systems. Tensions between Haiti's medical system – including traditional Haitian herbal medicines – and US medical practices crop up time and time again within the narrative to play out this contrast.

Throughout the text, sites of medical care double as sites of compromise between Haitian citizens and western medical practices. In the narrative, these citizens recognise their necessity, and even their efficacy, but seem latently aware of how these spaces and practices unavoidably seem to construct them as Other-than, even on Haitian soil, in a kind of persistence of the logics of the colonial, or as a manifestation of what philosopher Achille Mbembe defines as 'the postcolony'.³¹⁷ 'The postcolony' is 'a given historical trajectory...of societies recently emerging from the experience of colonization and the violence which the colonial relationship involves': it is 'chaotically pluralistic', characterised by 'political improvisation'.³¹⁸ By extension, healthcare spaces in Haiti are also repeatedly configured as sites of transition and socialisation. Danticat describes, for example 'a doctor whose clinic had the feel of a transitional middle world between our parents' and ours', who speaks to her in French 'then repeated himself in English' in an attempt to prepare her for the impending migration (p. 98). Many of the illnesses that the characters in *Brother, I'm Dying* suffer from have been "cured" or otherwise "resolved" by modern medicine, but chronically persist as health threats in Haiti as a result of its "underdevelopment". In Haiti, TB is still a very present illness which continues to carry stigma. Danticat writes about the experience of Meline, another member of her

³¹⁷ Achille Mbembe, *On the Postcolony*, Studies on the History of Society and Culture, 41 (Berkeley: University of California Press, 2001), p. 102.

³¹⁸ Ibid.

expanded childhood kinship network: '[Meline] was eventually sent to a sanatorium and died a few weeks after her seventeenth birthday' (pp. 99 –100). 'Sleeping on the top bunk above Liline and her, those times she'd spent the night, I'd probably caught the tuberculosis from her and passed it on to my brother. Or maybe Bob had caught it from a kid at school, a kid who didn't even know he had it, and had passed it on to me' (p. 100). The differences between the global north and south are evident here. It can be thought of again as a question of time: America is a post-TB society, Haiti is not. The two systems are often brought into direct contrast, and sometimes conflict, with one another in a way that unavoidably consolidates hierarchies of global development.

Even the aforementioned visit from the American doctors who diagnose Uncle Joseph's cancer, who form part of an ostensibly benevolent care initiative, seems to function in this way. To communicate their diagnosis, they relegate a Haitian doctor to the position of their translator. The narrative represents this translation and equivocation as constant: both Haitian doctors and, later, Haitian dollars (p. 200) are translated into an American value system in order to become legible both in a diegetic sense between characters within the text, and in an extra-diegetic sense for the reader. Both Uncle Joseph's biopsy and cancer are constructed as a specifically western experience of disease and treatment: 'None of our relatives knew what a radical laryngectomy was. We didn't even know anyone who'd had cancer...it almost appeared to be a curse that...only American doctors could cross an ocean to put on you' (p. 40). This highlights the ways in which idioms of cancer diagnosis and treatment are taken for granted as definitively curative in a western context, as well as the dominance of western medicine definitions of what constitutes health and cure. Reframing cancer diagnosis and treatment as the workings of a peculiarly western form of curse productively interrupts their established discursive significances.

In the context of such structures, a preference for traditional Haitian herbal remedies is unsurprising; the hesitancy and scepticism towards biomedicine within Black and minority ethnic communities across the diaspora over time can likewise be storied beyond narratives of blame and contempt. Uncle Joseph's wife, Tante Denise, for example refuses to consider migration to the US despite the rising levels of violence in Haiti's Bel Air, purely because 'she relies [so] heavily on her herbs' (p. 129). In so

doing, she latently suggests something about the incommensurability between care as formulated within a western industrial context and a traditional Haitian context. However, this juxtaposition between established American medicine and traditional Haitian health practices does not translate as an invitation to “return” to more holistic practices racialised as ethnic and indigenous, which has gripped the western wellness economy and that reeks of primitivism. Instead, the co-presence of these “alternative” (itself a troubling descriptor which might re-inscribe hierarchies) medicines and therapies, serves to destabilise the dominance and authority of particular ways of knowing and caring embedded into whiteness and/as capitalism.

The Politics of Chronicity

Illness in *Brother, I'm Dying* is not only social in the sense that it brings into relief networks of expanded kinship; it also arises from and is entirely intertwined with socio-political and socio-economic realities. This seems to bear out in Tante Denise's assessment of Marie Micheline's death: 'Before she was buried, a coroner had determined that Marie Micheline died from a heart attack. But when I spoke to Tante Denise...no one could convince her of [anything other than] a simpler truth: that watching the bullets fly, the violence of her neighbourhood, the rapid unravelling of her country, Marie Micheline had been frightened to death' (p. 137). Later, Tante Denise herself goes into a chronic decline of her own. 'Her glamour, her elegant dresses, her pretty face, her wigs, her gloves now seemed very far in the past. She, like those buildings, had been disassembled while I was gone': she dies at 81 from a massive stroke (p. 142). Danticat writes 'in death, she'd regained a hint of the elegance and glamour of her youth, before the diabetes, before the high blood pressure, before the strokes, the departures and unbearable losses...' (p. 154). Chronicity is key: a sense of ailments and the weakening effect of racially contingent psychosocial stressors accruing over time. It is important to note that this form of chronicity exceeds the individual; its effects resonate inter-generationally.

This seems to be true of all characters experiencing and managing the effects of chronic illness. Danticat reflects on the possible aetiology of her father's illness: 'What causes an illness like this? I wondered as Dr. Padman and I waited for my father to return from his pulmonary function test. Could it be the persistent car fumes

from the twenty-five-plus years my father had worked as a cabdriver? Carcinogens from the twenty-plus years he smoked as a young man, even though he hadn't smoked in more than twenty-five years?' (p. 11). This assessment inadvertently discounts the specificity of her father's position as a Haitian migrant. The subtextual argument *Brother, I'm Dying* continues to make is that it is not just cab fumes or toxic effects of tobacco, but another kind of exposure working to wear out the body and mind over time. In this context, blackness emerges as a form of morbidity in and of itself, reflected in the way certain illnesses have been recognised as disproportionately affecting Black people. Here other micronarratives are a key corroborative: the stories of near escape from racial violence which Mira presents for prayer and thanksgiving at his local church. When Danticat's family learn Mira is dying, her brother asks him tearily 'Have you enjoyed your life?' (p. 20). Almost an echo of another moment years before, when a young, school age Danticat asks her father 'Do you ever wish you could do something other than drive your cab?' (p. 123) Both questions, which cannot have anything other than difficult answers, foreground the hardship that must be endured as part of the Haitian migrant experience under America's hostile immigration policies and systems.

Time, particularly temporalities of endurance and long duration, completely shapes the representations of illness and the end of life in *Brother, I'm Dying*. The narrative is interwoven with Haiti's history as a third world country troubled by poverty, unrest and climate crisis. The legacies of transatlantic slavery and US imperialism contribute to a chronic, durational instability, strategically instigated and maintained over time in service of various western economic powers. Sites of medicine and medical institutions are where these legacies can be felt, these spaces materialise time in histories of power, imperialism, asymmetry and enslavement. The violence of transatlantic slavery, for example, is embedded into the very soil: 'the hill in Bel Air on which [Uncle Joseph's] house was built had been the site of a famous battle between mulatto abolitionists and French colonist who'd controlled most of the island since 1697 and had imported black Africans to labor on coffee and sugar plantations as slaves' (p. 29). This violence is reiterated in US occupation: 'the Americans had reinstated forced labor to build bridges and roads and had snatched able-bodied men like his father and boys like himself from their homes. They were lucky to have been spared' (p. 36). This violence of relocation and forced labour has characterised

many narratives of enslavement and thus represents history repeating itself, ad infinitum, in a long unbroken line of domination.

Civil unrest in the form of 'police raids and gang wars' leads to an omnipresent sense of threat. Mira reflects that, 'in the end, it was the experience of bending [fake leather] shoes all day and worrying about being shot that started him thinking about leaving Haiti' (p. 52). Haiti, here and in the wider post-colonial imaginary, comes to represent promise abbreviated by enduring structures of power and violence. It is a site of precarious life – life lived in close proximity to death. This is something Danticat communicates using the words of NY Journalist, Howell, who makes one of Danticat's relatives the focus of a political profile: 'Marie Micheline, wrote Howell, was in many ways "a reflection of Haiti and its potential, a flicker of light frustrated in its attempts to shine"' (p. 135). The impact of these extractive politics is also felt environmentally and has resonances in deep time, with climate change evidenced in Haiti more and more intensely. Danticat writes: 'that night we discussed Tropical Storm Jeanne, which had struck Gonaives, Haiti's fourth-largest city, the week Uncle Joseph had left for New York. Jeanne has displaced more than a quarter of a million people and left five thousand dead' (p. 166). I find it striking that this narrative of illness and death, like *Men We Reaped* and *Citizen*, takes time to place natural disasters and tropical storms in relation to systems of racism, labour and western industrial capitalism.

The main legacies of transatlantic slavery and western imperialism can be articulated as an unbroken line of violence connecting the temporalities of the French occupation of Haiti in the seventeenth century, the first US occupation of Haiti in the early twentieth century, the intermittent periods of civil unrest in-between, and the US interference in the 1990s and at the turn of the millennia (pp. 24, 29). Danticat's memoir presents the reality of Haitians caught in this extended temporality of extraction and domination. The only options seem either to endure, waiting upon the possibility of a different future, or to migrate elsewhere to actively pursue such a future on different terms.

The defining factor of this violence is its routine, everyday character and its omnipresence, both at home and abroad. Moving into the 1990s, the violence in Haiti grows steadily, Danticat recounts reports from her uncle of protests and

demonstrations brutally quashed: ‘the army raided and torched houses and killed hundreds of my uncle’s neighbours’ and ‘bloody corpses...dotted the street corners and alleys of Bel Air’ (p. 139). Danticat’s uncle begins to keep a morbid death record: ‘the names of the victims, when he knew them, the condition of their bodies and the times they were picked up, either by family members or by the sanitation service...’ (p. 139).

Eventually the violence is such that Danticat’s uncle is forced to consider leaving Haiti. Even so, strikingly, he considers the move a temporary one and is determined to return. This is a feature of the narrative and other forms of life writing that this chapter also considers: the idea of attachments that seem to exceed logic. Danticat’s father and perhaps the reader also, struggles to understand, why Uncle Joseph and Tante Denise never leave Haiti, and particularly Bel Air, for good. The clue might lie in how Uncle Joseph configures the move to New York as a kind of exile: ‘exile is not for everyone. Someone has to stay behind, to receive the letters and greet family members when they come back’ (p. 140). I think Uncle Joseph’s words communicate an understanding that even in flight, the continuities of Haiti’s antebellum history are not easily escaped, as demonstrated by the text’s comprehensive representations of Danticat’s father’s experiences of omnipresent racialised violence in New York. The migrant experience represented in this narrative form seems to extend these deep temporalities of violence and asymmetry into the present, rather than offer anything approaching a break with them.

Much of this violence is overt: the blunt force trauma sustained in the clash between individuals and a specific set of material conditions. For example, Danticat relates an incident in which her father, ‘while working very early on a Saturday morning... cut in front of some teenagers in a stolen van and they shot three bullets at his car’ (p. 121). On a separate occasion, ‘three men held a gun to his head and forced him to drive to the Brooklyn Navy Yard, where they asked him to give them all of the money he had in the car’ (p. 121). These incidents seem to reflect economic as well as racial tensions. However, they do materialise the ontological proximity to danger and a risk of death that are part of the exposure to the selvedge of capitalism, a space, or even a temporality marked out for certain racialized identities.

Some of this violence is insidious. It is about withholding belonging and elongating a sense of exile, illustrated acutely in an incident Danticat relates of her father's cabdriving: 'another time my father picked up a woman who, when he asked her to repeat her address, shouted at the top of her voice, "No one who drives a cab speaks English anymore"' (p. 122). The 'another time' is a minor but significant modifier here which gestures to the accrual of this time onto other times. This incident seems to relate to the wider theme in the text of speaking, understanding and being understood within the structures and constraints of racialised inequality, which reach their apex in the narrative's concluding chapters. These varied types of violence are significant here because their impact on racially differentiated health outcomes is among the many kinds of harm they cause.

Sites of Care, Sites of Violence

Considered as a whole, it is the final chapters of *Brother, I'm Dying* that most closely resemble an end-of-life narrative. As this narrative unfolds, the focus shifts from the tensions created by asymmetries between Haitian and American medical care models, to the active complicity between US medical institutions and the state. What emerges most strongly from the painfully intertwined end-of-life narratives of Danticat's father Mira and her Uncle Joseph is the collusion between what passes as care for racialized minorities, and the logics of the border and of the carceral. Here themes the narrative elaborates crystallise and solidify: how the legacies of slavery and imperialism contribute to everyday violence, to chronic stress and illness and racially stratified hierarchies of care, in ways that render the humanity of Black people illegible at critical, life affecting moments. In this section of the narrative, the *longue durée* of racialised capitalism makes itself felt and extends its reach to circumscribe the conditions of possibility that represent the future.

Mira and Joseph's experiences, thus far related in parallel, suddenly converge dramatically. Mira is hospitalised as his pulmonary fibrosis enters its palliative stage. Mira arrives at US customs, ostensibly healthy. However, instead of using his visa, he honestly yet ultimately mistakenly states the intention to claim temporary asylum. In this pivotal moment he fails to use the language of the system, which sets in motion the events that ultimately lead to his death. He is imprisoned at Krome

detention centre, where medical care is characterised by extreme neglect, or violently dehumanising practices. At Krome, number stands in for nomenclature – Uncle Joseph is renamed alien 27041999 (p. 214). This is a process which has a dehumanising and familiar antecedent in Holocaust history, although it is important to note *Brother, I'm Dying* is preoccupied by a different history of genocidal imperialism – one which extends into the present in the form of the using, abusing and “letting die” of bio-politics. This horror has a deeply historical aspect: ‘the lawyer answered that their ages were determined by examining their teeth. I couldn’t escape this agonising reminder of slavery auction blocks, where mouths were pried open to determine worth and state of health’ (p. 212). Life at Krome is lived then in constant proximity, and under the possibility of death: one of the detainees ‘had his back broken by a guard and was deported before he could get medical attention’ (p. 212).

The whole chapter, from the first misstep at the border, seems to constitute a failure to give account of oneself, to render oneself properly legible. Uncle Joseph can’t seem to make himself understood or advocate for his own needs. Actually, what is going on instead, or simultaneously, is the failure of the state itself to properly account for Black, and specifically Black Haitian migrant life. Both Uncle Joseph’s trauma as an asylum-seeker and his chronic ill-health are excluded from the picture: “‘What is your purpose in entering the United States today?’” asked Officer Reyes. “‘Because a group that is causing trouble in Haiti wants to kill me,’” my uncle answered. According to the transcript, Officer Reyes did not ask for further explanation or details’ (p. 217). Furthermore, ‘the transcript has neither my uncle nor the interviewer mentioning two rum bottles filled with herbal medicine, one for himself and one for my father, as well as the smaller bottles of prescription pills he was taking for his blood pressure and inflamed prostate’ (p. 218). ‘In spite of my uncle’s eighty-one years and his being a survivor of throat cancer, which was obvious from his voice box and tracheotomy, when answering whether there were age and health factors to be taken into considerations, Officer Reyes checked No’ (p. 223). The border guards remove his medication – the immigration officer claims it is a substitution – but there is no record of it. ‘The medications were indeed taken away...in accordance with the facility’s regulations, and others were substituted for them’ (p. 234). This seems to be a wilful and malicious form of neglect which is about

maintaining those hierarchies between American medical care and “foreign” healthcare practices previously discussed.

When he falls ill the neglect continues and the complicity between medical institutions and border logics become more pronounced. His lawyer and the border officer are disgusted by his ‘spreading vomit’ (p. 232), and respond in ways that deny his humanity, even as the vomit constitutes and represents a very human kind of bodily (dys)function. The callousness of this reaction is heightened in its contrast with his son Maxo’s reaction on his arrival: ‘the first thing Maxo wanted to do was clean the vomit from his face’ (p. 234). Even at this point, the medic’s instinct is to criminalise Uncle Joseph: “I think he’s faking,” the medic said, cutting Pratt off’ (p. 233). Danticat describes how the medic ‘grabbed [her] uncle’s head and moved it up and down’ (p. 233). Then, ‘he [is] transported to Miami’s Jackson Memorial Hospital with shackles on his feet’ (p. 236). His status as a seriously ill patient needing medical care does not at any point supersede his status as a Black Haitian migrant—there is no break with the policies of hostility, criminalisation and contempt that are used to frame him and other migrants across generations. After being ‘found pulseless and unresponsive by an immigration guard at 8:30pm’ Danticat’s uncle is subject to a “code” (p. 239), a violent resuscitation protocol generally considered the antithesis to a “Good Death”. Strikingly, in the parallel narrative, Danticat’s father Mira expresses his desire to sign a Do Not Resuscitate (DNR), again framing resuscitation as suffering compounded rather than avoided.

Significantly, Danticat’s account focuses mostly on details of her uncle’s medical care. His short illness and death are not framed affectively, and the sense of institutional mediation is very keen in this passage. ‘The records indicate that my uncle appeared to be having a seizure’ (p. 232). She uses logs and invokes precise timestamps. This contributes to the formal argument that, although the law cannot acknowledge it, some kind of crime has been committed here. There is no insight into Uncle Joseph’s feelings, instead the report-like tone of the account produces a sense that he is alone and beyond reach. The effect is to reproduce the distance and bureaucracy that separate Danticat from her uncle and preclude her from being with him at the end of life.

Danticat's father dies at home sometime later. His death is expected: his medical care team at Columbia Presbyterian assisted in making several adjustments in preparation, including the provision of oxygen and a hospital bed to take home and the suggestion to put a DNR in place. Despite this careful preparation, Mira also receives a 'code': 'the paramedics removed my father's clothes, laid him on the wooden floor in his room naked and pounded at his chest for an hour' (p. 264). Although the lack of DNR on file reflects Danticat and her brothers' inability to acknowledge he is dying and thereby release him from painful and ongoing attachment to life, the language she uses here frames the treatment as punitive rather than curative. While the paramedics do so, the whole family is interviewed by a policeman: 'a measure to make sure there was no foul play, no euthanasia involved' (p. 264). Again, a complicity between medical institution and harsh policing is established and a Black grieving family is criminalised amid their loss, while Mira's death also foregrounds the counterintuitive workings of attachment, even under the conditions of life the narrative describes.

Danticat's account of her uncle's death represents an aspiration to speak up for him as a corrective to the time in detention when he was unable to speak for himself, and as a response to his death which places him beyond speech. *Brother, I'm Dying* is constantly trying to work through this tension between speech and silence. After Uncle Joseph loses his voice in Danticat's childhood, for example, she becomes accustomed to speaking for him. In many ways, the writers at the focus of this chapter are engaged in the same act of "speaking-for" as a form of gendered memory keeping that preoccupied Rose and Sedgwick in the previous chapter of this thesis.

Illness and Debility in *Men We Reaped*

To read *Men We Reaped* as an illness narrative requires a more expansive definition of this prescriptive and circumscribed category. Ward's memoir takes its title from Harriet Tubman's account of the defeat of the Black 54th Massachusetts Volunteer Infantry by the Confederate side in 1863. Tubman's words are inscribed before the contents page as an epigram: 'we heard the rain falling and that was the blood falling; and when we came to get in the crops, it was dead men that we reaped'.

The narrative concerns ‘five Black young men [Ward] grew up with’, who ‘died, all violently, in seemingly unrelated deaths’ between 2000 and 2004 (p. 7). The text establishes continuity with Tubman’s articulation of gendered work of gathering in and elegising the Black (male) dead. Although the text is replete with experiences of poverty and poor physiological and psychological health, set against the backdrop of the 1990s crack epidemic, no one character in *Men We Reaped* has a definitive diagnosis of a condition of any kind. Their experiences trace the same shape as the historical and ethnographic data considered in the early part of this chapter: stories of medical neglect and under-treatment, lack of access to services caused by an interpolation of poverty, racism and lack of faith in institutions and systems. *Men We Reaped* therefore also offers an occasion to reflect on the ways in which illness is defined, and who is allowed to occupy the paradigmatic sick role theorised within the medical humanities, to qualify for consideration and care as an ill person. Puar’s deployment of the term ‘debility’ is useful to consider here as a way to attend to illness experiences positioned differently or at a remove from medical institutions and diagnostic models.³¹⁹ What is more, in tracking the demise of what is, really, a whole generation of young Black people, Ward generates support for the idea that some Black chronic illness or cancer narratives simply do not materialise because members of this demographic simply do not live long enough to develop such diseases of the mid- and late- life.

Lorde’s oft-cited line from her poem *A Litany for Survival* – ‘we were never meant to survive’ – resonates particularly keenly in the context of Ward’s memoir.³²⁰ Although much of the narrative focuses on the untimely deaths of Ward’s male relatives and friends, an early chapter opens with an extended meditation on Ward’s own chronic childhood illness: ‘when I was born, I weighed two pounds and four ounces and the doctors told my parents I would die’ (p. 42). As a dangerously premature baby, her prognosis includes ‘severe developmental problems’: doctors are surprised that her lungs and heart are able to function (p. 43). Ward develops blood tumours which will last until she is four years old and leave her body covered in ‘mottled scars’ (p. 42). It is a serious illness, but like the micro-narratives in *Brother, I’m Dying*, this episode recedes from the foreground into the pattern of a text in which illness, debility and

³¹⁹ Puar, p. 2.

³²⁰ Audre Lorde, ‘A Litany for Survival’, *Poetry Foundation*

<<https://www.poetryfoundation.org/poems/147275/a-litany-for-survival>> [Accessed 31 July 2023].

death are intertwined with living, rather than experienced as exceptional moments of rupture. This is expressed structurally, as well as thematically: *Men We Reaped* alternates between a chronological progression through Ward's memoirs in chapters titled 'We are Born', 'We Are Wounded' etc, (emphasising collectivity rather than "rugged individualism") and chapters titled simply with the full names of the dead in reverse chronology: first 'Roger Eric Daniels III', 'Demond Cook', 'Charles Joseph Martin', 'Ronald Wayne Lizana', and finally 'Joshua Adam Dedeaux'.

Puar observes that while ableism within minority communities is also common, 'disabilities and debilities are not nonnormative, even if the capacitating use of the category disabled may be tenuous'.³²¹ This observation might invite those reading *Men We Reaped* from a medical humanities disciplinary orientation to look again at the unfolding of death within the text and recognise narratives of illness, chronic pain and decline both masked and caused by structures of racialisation. Framed in both of these ways, Roger Eric Daniels III's death is a cogent example. The narrative acknowledges his history as a chronic cocaine user and initially there is an easy equivocation to be made between this and his death. However additional details emerge over the chapter that disrupt or complicate this causality: 'the seed of a bad heart that had killed his father' caused his heart attack (p. 36), 'he died by his own hand' (p. 38), or this from an ex-boyfriend of Ward, "'they picking us off, one by one'" (p. 38). These four narratives sit alongside each other: the first is an old story of drug addiction in a minority demographic, the second speaks to literatures which make connections between genetic predisposition to heart failure and certain ethnic groups, the third opens up a dialogue about self-medicating with controlled substances, as well as about mental illness and suicidal ideation that resonates in the subsequent narrative of Ronald Wayne Lizana's death by suicide as a result of chronic depression (p. 177). The fourth and final suggestion from Ward's ex-boyfriend gestures to wider structural factors at work in the ubiquity of untimely Black death, ventriloquising Puar and Berlant's theories of the 'slow wearing down of populations instead of the event of becoming disabled'.³²² In the same way, death in this context cannot be conceptualised as a singular "event", but something that is instead endured daily, inseparable from the work of living.

³²¹ Puar, p. 16.

³²² Puar, p. xiii.

A reoccurring concept within these narratives is the double bind of attachments which are painful or harmful, but which for important reasons are part of this work of living and therefore cannot be dispensed with. This plays out in both Danticat and Ward's prose texts in particular ways but is arguably most evident in *Men We Reaped*. Towards the end of the text, after attempting to break with the South, attend College and look for work in New York, Ward acknowledges, 'yet I've returned home, to this place that birthed me and kills me at once. I've turned down more lucrative jobs, with more potential for advancement, to move back to Mississippi' (p. 240). She wakes up every morning, 'hoping to have dreamed of [her] brother' (p. 240), who numbers among the rollcall of the dead.

This attachment dynamic presents itself in the text prior to this point. Part of Ward's journey to break the hold of generational poverty is to accept and make the best of an opportunity to attend a private, fee-paying Episcopal school. Her place is secured by the wealthy white southern family whose house her mother cleans (p. 201). Unsurprisingly, as the only Black girl at the school, Ward is the subject of various degrees of racial abuse. She recounts one occasion on which a group of male classmates surround her, joking 'you know what we do to your kind'. Readers do not need the ensuing clarification, but Ward offers it anyway: 'whatever the joke, it involved a Black person, hands bound, and a choking rope at the neck, a picnic. Lynching' (p. 187). Her classmates regularly use the n-word in her hearing to indirectly address her. In public school, 'there were so many Black kids that [Ward] could rely on someone else to fight'. As it is, she is alone: 'sometimes I wanted to leave that school. But how could I tell my mother that I didn't want to take advantage of the opportunity she was working herself ragged to provide...?' (p. 195). For so many young Black women who have internalised narratives about their worthlessness, "opportunities" often go hand in hand with traumatising exposure to violent racialisation. An attachment to "progress" reduces the likelihood of ever truly being free of the self-regulating mechanisms of race. Through the workings of wider structures, it becomes, in Berlant's terms an 'obstacle to...flourishing'.³²³

Berlant's thinking is helpful in elucidating the endemic attachment to unhealthy or even actively harmful practices within Ward's Mississippi community. In the wake of

³²³ Berlant, *Cruel Optimism*, p. 1.

her friend Demond's death by shooting, Ward reflects on whether the previous generation 'lived with the dead as we did...Had they quaffed shine the way we did beer and weed and pills' (p. 68)? At the more extreme end of the spectrum, the 1990s marked 'the beginning of the crack epidemic', which 'with its low prices and quick, searing high, was eating away at the soul of neighbourhoods and communities...its consumption driven by those desperate for escape' (p. 199). The long ranging impact of racism on health makes itself felt. Controlled substances here might function in the way that Berlant describes 'sugar, fat, salt, and caffeine': although they produce 'morbidity', they also have an 'ongoing familial and cultural lure'.³²⁴ The 'slow death' they engender constitutes 'what there is of the good life for the vast majority of American workers'.³²⁵ Counterintuitively then, these substances provide the conditions under which "going-on" is both possible, but ultimately unsustainable.

Ultimately, the most difficult kind of attachment to navigate in *Men We Reaped*, are those that bind the characters to each other. These mirror the relation to home earlier described and might be articulated and analysed best in the second epigram Ward chooses to preface the narrative, an extract from A. R. Ammons' 'Easter Morning':

'I stand on the stump
Of a child, whether myself
Or my little brother who died, and
Yell as far as I can, I cannot leave this place, for
For me it is the dearest and the worst,
It is life nearest to life which is
Life lost: it is my place where
I must stand... ' (p. i)

This extract speaks to the tension within the responsibility to hold vigil with grief, to commemorate and account for those who have died. This very much resonates with

³²⁴ Lauren Berlant, 'Slow Death (Sovereignty, Obesity, Lateral Agency)', *Critical Inquiry*, 33.4 (2007), 754–80 (p. 774).

³²⁵ *Ibid.*

one version of vigil keeping formulated by Sharpe, while reflecting at the bedside with her brother Stephen as his cancer enters its final, palliative stage.³²⁶ Sharpe describes the perseverance necessitated by taking up that station at the bedside; a vigil that involves a more stringent kind of vigilance, as she and her family worked against discrepancies in medical care which see Black patients denied parity in pain-relief. Stephen's bedside however, is also in its own way the 'dearest and worst' place: there Sharpe and her family share wine, stories and play songs in a gesture of witness to the fact Stephen has lived, as he dies. The epigram Ward chooses seems to register a similar impulse, but is also, I suggest, evidence of a compulsion of a more fraught nature. The epigraph's central image of being fixed at the site of pain and death suggests something about the deathly life of Black subjectivity 'in the wake' for those both living and dead. It also conjures the precise textures of the pathology of grief that cannot be grieved, and is instead replayed, recursively narrativised. This grief, a form and expression of care, fixes Ward to the temporal, psychological site of her brother's death as a way of bearing witness to his life, ensuring he is not forgotten. However, it also evokes a kind of impossible waiting for a reunion with the dead which attests to the unpalliated distress of living.

Ward formulates this notion as a compulsion, a responsibility to speak on behalf of those who have died. However, I wonder if this compulsion to narrativise life in linear ways, and attachment to certain forms, might represent another kind of complex, freighted attachment. It represents an aspiration and a struggle towards legibility, particularly significant given the ways in which the deaths of the five young men that Ward relates come as a result of their failure to be seen or "read" at critical moments, a failure that echoes Uncle Joseph's death in *Brother, I'm Dying*. For Ward and Danticat, narrativising these experiences holds out the posthumous possibility of becoming legible within a historic, logocentric system of white supremacy, without addressing or undoing the structures of that system itself.

In *Citizen*, Rankine meditates on how racism in language does not, or does not solely, function through denigration and erasure. Instead, language acts to create Black subjects who are 'rendered hypervisible', hyper-exposed. They '[exploit] all the ways that you are present. Your alertness, your openness and your desire to engage'

³²⁶ Sharpe, *In the Wake*, p. 10.

and ultimately the desire to be accounted for and to be recognised.³²⁷ Rankine alights on a tension for Black subjects between being exposed as spectacle and being readable which seems to take on increased significance in the context of illness and debility, particularly against the backdrop of medical institutions which depend on taking “histories” as an integral part of the diagnosis model.

Break, Block, Ellipsis – Interruptions and Suspensions of Time

In their different ways, Agamben and Moten offer arguments for the significance of temporal breaks, with Moten making explicit connections to Black radical and Avant-garde traditions and practices. Temporal breaks in the context of language, meaning-making and race are significant for all sorts of reasons. My argument, following the theoretical interventions here, is that such breaks offer an interruption of what has gone before, loosening the hold of continuity on the future.

Agamben’s essay takes as his starting point ‘Deleuze’s text, which...bears the title “Immanence: A Life ... ” (“Immanence: Une vie ... ”).³²⁸ The essay makes a clear, intuitive argument for the significance of breaks and pauses in the making of meaning. It is useful here because of how it opens up new ways to understand their presence in literary texts. It is striking that Agamben emphasises that “‘Immanence: A Life ... ” appeared in the journal *Philosophie* two months before [Deleuze]’s death’.³²⁹ In doing so, I suggest he invites a consideration of the link between syntactic breaks – punctuation – and the phenomenological experience of the end of life. Agamben suggests that the colon in the title functions as opening marks do: ‘between immanence and a life there is a kind of crossing with neither distance nor identification, something like a passage without spatial movement’.³³⁰ This is an interesting intellectual metaphor which suggests something about the affective and phenomenological space of the colon as (he terms it) a ‘pause value’, and what it is then possible to infer about ‘pause values’ in general.³³¹ This ‘passage without

³²⁷ Claudia Rankine, *Citizen: An American Lyric* (London: Penguin Books, 2015), p. 49. Further references for this book are in the text.

³²⁸ Giorgio Agamben and Daniel Heller-Roazen, *Potentialities: Collected Essays in Philosophy*, Meridian: Crossing Aesthetics (Stanford, Calif: Stanford University Press, 1999), p. 221.

³²⁹ *Ibid.*

³³⁰ Agamben and Heller-Roazen, p. 223.

³³¹ Agamben and Heller-Roazen, p. 222.

spatial movement' is static yet dynamic, evoking nothing so much as the workings of time.

Agamben states that ellipsis in the title works similarly to both close and leave open. His subsequent analysis of their function and philosophical meaning however is more opaque: he notes Deleuze's observation that 'Celine's use of ellipsis dots deposes the power of syntactical ties'.³³² A reading might start to emerge that leads to an understanding of the elliptical as a break or 'pause value' that might loosen rigid meanings and 'make words dance outside all syntactic hierarchy'.³³³ Agamben is particularly interested in the ability of this ellipsis to 'transform the very status of the word "life," from which the ...dots become inseparable' in Deleuze's title.³³⁴ What this demonstrates is that elliptical breaks (or perhaps, break-downs) work to catalyse an openness to a radical changing of valance. Agamben's argument is that, in this context, the ellipsis emphasises the indefinite and indeterminate: not incompleteness or lack, but rather a radical opening out of possible meanings.

It is possible to make connections between the ontological conditions that Agamben uses the ellipsis to evoke and the ways in which Moten characterises 'the break', 'the cut' and 'the crack' all as productive intervals which are 'full' in different ways.³³⁵ Moten formulates this concept of the break in the context of Amiri Baraka's poetry. Its meaning takes shape around Baraka's page breaks. However, Moten also describes Baraka's work itself as in a kind of 'break'; that is, simultaneously *at* and *as* the opening of a field – that of Black radicalism – and as a kind of abundant refusal of closure. What follows is a discursive journey through landmark works and genres of the Black avant-garde tradition. Moten alights on Miles Davis' paradigm shifting jazz, which evidences a kind of 'musical caesura that demands precisely that immersive lingering that, according to Ralph Ellison, is a necessary preface to action'.³³⁶ Here, Moten seems to offer, through the epistemological dimensions of jazz, a rethinking of the interval: that space between stopping and beginning again anew.

³³² Agamben and Heller-Roazen, p. 223.

³³³ Ibid.

³³⁴ Ibid.

³³⁵ Fred Moten, *In the Break: The Aesthetics of the Black Radical Tradition* (Minneapolis: University of Minnesota Press, 2003), p. 85, 89, 107.

³³⁶ Moten, p. 117.

He also considers another kind of ‘break’, this time as the ‘crack’ in Billie Holiday’s voice, which becomes so much a feature of her idiosyncratic style. Holiday’s album *Lady In Satin* – itself a showcase of her late style, as her penultimate album – is ‘the record of a wonderfully articulate body in pain’, which ‘uses the crack in the voice, [the] extremity of the instrument, [as a] willingness to fail reconfigured as a willingness to go past’.³³⁷ The radical, transformative and truly exciting semantic possibilities of breaking (-off, -down) start to establish themselves. Moten adds to this an analysis of ‘the cut’, a structuring element of the montage form. Montage, he writes, compels the viewer to ‘linger in the cut between ...a generative space that fills and erases itself’, a space that mimics Derrida’s deconstructive analysis of the sign.³³⁸ Moten also seems to be suggesting something about a gap between perception and cognition, elaborating the ways in which the interruption of habitual pathways between the two (as for example, in the habitual process of racialisation) might be useful, essential even. As a poet himself, Moten sees poetry as central in the working-through of this emergent strand of thought.³³⁹

Race, Illness and the Temporality of the Poem

Both Mullen and Rankine differently make use of the aesthetics of the ellipsis and the break to loosen the hold of totalising histories and make way for alternative representational strategies that allow something different to become possible. The remainder of this chapter turns from a focus on prose to poetry, and therefore away from the former as a medium which privileges linear, sequential temporal modalities, and one deeply imbricated in the maintenance of the *longue durée* of racialised violence. The turn to poetry both builds on and elaborates the themes of illness, cultural occlusion and Black legibility offered thus far, while presenting poetry as a form which might challenge the linear temporalities of prose through various kinds of play with time: broken temporalities and a-temporalities.

A large body of Mullen’s writing appears in relation to traditions of restraint as incitements to write, ‘All She Wrote’ follows in this pattern, the first entry in the

³³⁷ Moten, p. 107.

³³⁸ Moten, p. 89.

³³⁹ Moten, p. 90.

abecedarian collection *Sleeping with the Dictionary*. Mullen's prose poem 'All She Wrote' scans as a litany of excuses for the failure to be productive. 'Writing about not writing is one way to break through writer's block',³⁴⁰ she states elsewhere, and the poem centres around the concept of block or breakdown, the interval between past states of flow and the anticipation of that flow's resumption. The block or breakdown might re-present itself as a way back into speech, out of silence.

Mullen is known for her use of recycled language, idioms, puns and wordplay. These are evident in the title 'All She Wrote' and in the poem's selected phrases: 'wash your wet hair' / 'By the way, my computer was stolen. Now I'm unable to process words'.³⁴¹ This use of cliché and wordplay contributes to a sense of temporal circularity and stasis. The reader spends the poem waiting for something to happen but nothing, or nearly nothing, does.

Mullen is known also for her interventions into the Black avant-garde tradition. However, unlike her other poems, the speaker of 'All She Wrote' is never explicitly racialised as Black. I am tempted to read into the speaker's pronouncement – 'I can't write back' (line 1) – an evocative of a tradition of intellectual resistance by people of colour.³⁴² The reference to Oprah too seems significant, evoking a specific set of expectations around commercially successful Black women. The speaker's identity, however, remains ambiguous.

'All She Wrote' as a whole is characterised by an extension of this avoidance and refusal, particularly in response to bureaucratic, quasi-institutional practices and expectations. The speaker's excuses are comical, wide ranging, inventive and richly allusive. They vary from the playful half-rhyme of 'I can't say I got your note. I haven't had the strength to open the envelope' (lines 2–3) to the quasi-tautological 'Wash your wet hair?' (lines 3–4), which reads as a contortion of the kind of market-driven

³⁴⁰ Harryette Mullen and Barbara Henning, 'Conversation with Harryette Mullen: From A to B | Naropa University', *Not Enough Night*, 2010
<<https://www.naropa.edu/academics/jks/publications/notenoughnight/spring-10/conversation-with-harryette-mullen.php>> [accessed 30 January 2021].

³⁴¹ Harryette Mullen, *Sleeping with the Dictionary*, 1st edn (University of California Press, 2002), p. 3. Further references to this poem are given in the text with line numbers.

³⁴² Anke Bartels and others, 'Interlude: Writing Back', in *Postcolonial Literatures in English*, by Anke Bartels and others (Stuttgart: J.B. Metzler, 2019), pp. 189–90.

imperative that one might find written on a shampoo bottle, but invites an inference of difficulties around self-care.

The speaker's excuses, on the surface trivial, amount to more than the sum of their parts. 'Writer's cramp' sounds like an idiomatic complaint analogous to writer's block, but might actually align with a more serious physical complaint, e.g. something like focal hand dystonia, a disorder characterized by abnormal posturing. The poem overall then is pervaded by a lingering sense of pathology, which reads as possibly depressive, as in expressive of a depressed mental state. It also might bear hallmarks of late-stage illness – debility, incapacity, difficulty with cognitive function. I want to suggest that the poem represents a kind of illness narrative, an argument supported by the explicit statement, 'I can't get out the door to work, so I called in sick' (lines 16–17). Or, a more liberated reading might take the speaker, positioned as beyond language and agency, as haunting the static domestic scene of the poem: either deathly or already dead. In this way, and by maintaining a ludic tone, 'All She Wrote' uses the concept of the break or block to both represent and springboard out of the totality of illness.

Claudia Rankine's *Citizen* has become a definitive text of the Black Lives Matter (BLM) movement. Responding in part to endemic police brutality in the US, it presents a similar set of material conditions to those that animate *Brother, I'm Dying*. The title, 'Citizen', for example, conjures up the same idiom and atmosphere of the border so central to those final chapters of Danticat's text, although Rankine gives the raw material of institutionalised violence a very different treatment in her novel approach to form. The text meditates on points of continuity and collapse between past and present, chronic low-grade pathology and illness, speech and silence, death and survival. *Citizen* then, is thematically, if not formally, consistent with the illness narrative genre. Housing this experience of chronic illness and stress in an atypical container allows the text to accomplish something subtly different from narrative and bypass some of the limitations of its characteristically linear form.

The text resonates with others under discussion here by focusing on the difficulty of giving account of oneself in the face of systematic demands to do so. In one example, the speaker/Rankine meets someone in person she has only ever spoken to on the phone, in order to sign a form. On arrival this person 'blurts out, I didn't

know you were black!’ (p. 44). Another incident: a friend sees a photo of her on the internet: ‘he wants to know why you look so angry...this unsmiling image of you makes him uncomfortable, and he needs you to account for that’ (p. 46). It doesn’t seem to matter that in the speaker/Rankine’s perception, this image was ‘the most relaxed’. Each of these examples can be reduced to demands to ‘fit the description’ (‘because there is only one [Black person] who is always the [Black person] fitting the description’, p. 105). The subtext here seems to suggest that the speaker/Rankine does not align with the associations this man has formed around blackness. But the incident also suggests blackness is an anomaly which creates discomfort and must always be explained, punishing deviations from racialised conventions and expectations around behaviour. The incidents the speaker/Rankine describes function a bit like the litany of demands the speaker of ‘All She Wrote’ contends with: demands to ‘write back’, to ‘read your letter’, to ‘open the envelope’, to read the ‘document you meant to send’, to ‘reply to your unexpressed desires’ (‘All She Wrote’, lines 1–3, 7). These demands, initially seeming routine (e.g. ‘stand where you are’ *Citizen* p. 70), become more urgent, more illogical and suggestive of violence (‘get on the ground. Get on the ground now.’ *Citizen* p. 105).

In ‘All She Wrote’, the speaker’s solution to these mounting expectations to *comply* is to respond with avoidance and refusal. For the speaker of *Citizen*, the solution is to offer a partial, incomplete account of the self and of incidents and other individuals affected by racism. Rankine writes of an occasion when ‘the woman with the multiple degrees says, I didn’t know black women could get cancer’ (p. 45). The incident unfolds within a single sentence on a page. The reader infers from the specificity of the article ‘the’ (as opposed to “a”) that this woman is known to the speaker and is likely to be a provider of care, a doctor. Possibly, this fragment is related to another on a following page: ‘despite the fact that you have the same sabbatical schedule as everyone else, he says, you are always on sabbatical’ (p. 47). In both cases, important context is missing. It changes things to know, for example, that Rankine underwent chemotherapy for cancer around the time *Citizen* was published.³⁴³ The

³⁴³ See Sarah Galo, ‘Poet Claudia Rankine Says next Book Will Be on Culture of Cancer’, *The Guardian*, 10 September 2015 <<http://www.theguardian.com/books/2015/sep/10/claudia-rankine-book-cancer-culture>> [accessed 24 January 2021]; Neil Munshi, ‘Poet Claudia Rankine on Studying Whiteness, and the Age of Protest’, *FT Magazine*, 24 February 2017 <<https://www.ft.com/content/176feb54-f8f8-11e6-9516-2d969e0d3b65>> [accessed 24 January 2021]; Elias Rodriques, ‘Claudia Rankine’s Dialogue With America’, 6

second fragment, seemingly unconnected to the first, takes on a different significance alongside the knowledge that Lorde and June Jordan ‘were respectively denied a reduced teaching load and medical leave from their institutions...despite their documented battles with breast cancer’.³⁴⁴ The reader could situate these fragments in a wider structural context in which Black women’s health outcomes are influenced by racial bias, or where Black women are constructed, even in extremis, as undeserving of the same workplace privileges enjoyed by colleagues.

Although *Citizen* seems to be more overtly reflecting on the sudden deaths and lives circumscribed by institutional violence, it is important to acknowledge that these recurring violences provide the conditions for unspecified physical complaints that surface and resurface at certain points in the poem. ‘Confrontation is headache producing’ (p. 10). Abuse literally causes sickness: ‘the wrong words enter your day like a bad egg...and puke runs down your blouse’ (p. 8). The headaches multiply: ‘sighing is a worrying exhale of an ache’, although ‘over the years you lose the melodrama of seeing yourself as a patient’ (p. 62). Yet among the many “cast” members of the poem, there is no competent healthcare provider to gather these symptoms together into a history (literal or metaphorical), to ensure the major complaint which haunts the poem is not overlooked, and instead cared for and cared about. Ultimately, *Citizen* redacts the cancer narrative contained within it: readers see only the racist disavowal of Rankine’s experience, which must stand in for what might have been the narrative (p. 45). This displacement functions as a more eloquent picture of the nature of Black women’s experiences of serious, potentially terminal illness.

Rankine often plays in the slippage between the indeterminate identity of the speaker (‘you’) and a more explicitly autobiographical mode. The choice of second person to relate this and other accounts is also significant. At a remove from both the false neutrality of third person and the voyeurism of first person, writing in the second person is an established strategy for simultaneously implicating the reader in the

October 2020 <<https://www.thenation.com/article/culture/claudia-rankine-just-us-review/>> [accessed 24 January 2021].

³⁴⁴ Alexis Pauline Gumbs, ‘The Shape of My Impact’, *The Feminist Wire* <<https://thefeministwire.com/2012/10/the-shape-of-my-impact/>> [accessed 24 January 2021], referenced in Jina B Kim, ‘Toward a Crip-of-Color Critique: Thinking with Minich’s “Enabling Whom?”’, *Lateral*, 6.1 (2017) <<https://doi.org/10.25158/L6.1.14>>.

text's unfolding and cultivating a quasi-Brechtian sense of alienation. As an uncommon stylistic choice, it also further formally distinguishes *Citizen* – a lyric prose poem – from a conventional narrative form. Collectively, these accounts of racism, often radically decontextualized and temporally ambiguous, are full of redactions and omissions. They are thus able to acknowledge and bear witness to violence without reproducing it in the ways that more explicitly mimetic forms tend to do.

Alongside the struggle to give account of the racialised self, *Citizen* also addresses the ethical responsibility to register those unaccounted for within a system where Black life is routinely constructed as less valuable. This concern becomes visible in the section in which *Citizen* engages with the framing of Hurricane Katrina. An unnamed victim says, 'we never reached out to anyone to tell our story, because there's no ending to our story' (p. 84). Temporality is central to this difficulty: how is it possible to tell a story or make out an account that does not and cannot end? Time then is another key theme. *Citizen* represents the temporalities of race through form in its dependence on fragments, which are seemingly unconnected, or absolutely bound together in continuity, depending on the reader's positioning and understanding of race relations in America.

Citizen represents the endless presen(t)(ce) of racism. This becomes visible in the ways times collapse into each other at significant moments of violence. Rankine is under to pressure to ignore each new iteration of violence and behave instead as if it 'hasn't happened before, and the before isn't part of the now as the night darkens and the time shortens between where we are and where we are going' (p. 10). Through the indeterminacy of the speaker, the all-times (of racism) collapse into a no-time, an a-temporality, which produces the effect of stasis, or suspended time. This is the way in which *Citizen* manages to tell a story with no end, something Ward and Danticat struggle to do. The narrative form forces them to adhere to the structure of beginning, middle and end, resolving their critique of systemic racialisation with a return to the individual.

Ultimately, *Citizen* is formally organised by many different kinds of breaks: line breaks, page breaks, breaking-off and breaking down. The flow of the text is broken up by page breaks which make use of varied forms of artwork which follow Rankine's

strategy of non-mimetic reflection on racism. It is filled with examples of breaking off elliptically, mid-sentence, using line breaks which suppress or draw out the significance of certain words and images. It is filled too with examples of breaking down, syntactically, in its more overtly poetic sections, where meaning is hard to excavate from the morass of lexis (pp. 75 -76). These breaks function by creating openings in the text which make alternatives possible. It is an important, non-syntactical representation strategy relevant to the non-narrative presentation of the chronicity, illness and death that the literature constructs as part of Black life across diasporas. Caesura might metaphorically index the kind of pause which allows grieving, important in the context of theorisation of Black death and suffering as painfully and violently ungrievable. Notably, in Freud's *Mourning and Melancholia*, the distinction between a pathological melancholic response and a healthy mourning response is a distinction of timing.³⁴⁵ The latter refuses to or is prevented by certain structures from finding the relief of ending. Poetry presents itself as a site of integration which reasserts and reconfigures an attachment to life under conditions of un-livability.

Conclusion

Ultimately, Ward and Danticat's narratives are caught up in a temporality that both predates them and threatens to outlast them. They are enmeshed in the enduring temporalities of the transatlantic slave trade and colonial capitalism. Trying to make meanings of death seems to be bound up with trying to make meanings of blackness for Ward and Danticat. However, the restrictions of narrative assert themselves in the attempt, and *Brother, I'm Dying* and *Men We Reaped* struggle to negotiate the need to gather and account for the dead and the desire to break with the epistemological structures which make death so much a part of Black life. The texts are caught in the same dynamic of foreclosure which has become a defining characteristic of that first,

³⁴⁵ Sigmund Freud, James Strachey, and Sigmund Freud, *On the History of the Psycho-Analytic Movement: Papers on Metapsychology and Other Works ; (1913-1914)*, The Standard Edition of the Complete Psychological Works of Sigmund Freud, transl. from the German under the general editorship of James Strachey; Vol. 14 (London: Vintage, 2001), p. 244.

hyper-masculinist wave of Afro-pessimism, focused exclusively on blackness as deathly life.

For Rankine and Mullen that equivocation is mediated by an experimental approach to form which is at home with a post-structuralist-inflected deferral, or even refusal, of meaning. Poetry presents itself as a form flexible enough to evoke the suspended time of the break, which – following Agamben – in its indeterminacy, can both close and leave open/unfinished:³⁴⁶ acknowledging and grieving what is, while holding out the possibility of interruption and difference. The aesthetics of poetry make for a non-mimetic form of elegy that bears witness to lasting violence without exactly reproducing it.

While closely attending to both narrative and poetry as distinctive forms, the picture still emerges of illness and death in these texts as interminable. Against such a ground, the failures of institutional care appear stark, especially in Danticat and Ward's narratives. However, breaking off – representationally, linguistically, formally – in Mullen's 'All She Wrote' and Rankine's *Citizen* are temporal interventions that might constitute fugitive forms of care.

³⁴⁶ Agamben and Heller-Roazen, pp. 223–24.

Chapter Three: Un/Dying in Narratives of Environmentalism

There is an industrial corridor between New Orleans and Baton Rouge widely known as 'Cancer Alley'.³⁴⁷ It is home to a cluster of majority Black working-class communities living and dying with the effects of industrial pollution. In Reserve, Louisiana, the risk of cancer is 50 times higher than anywhere else in the United States; one resident, Mary Hampton, has lost two brothers, a sister-in-law and a neighbour to cancer. Thirty-five miles east, residents of Gordon Plaza are locked in a legal struggle with the city of New Orleans.³⁴⁸ In the 1990s, local authorities built their low-income housing development on top of a former toxic landfill site. Before the full extent of contamination was revealed, Marilyn Amar and her son ate homegrown tomatoes from her garden, which she links to her cancer and her son's mysterious childhood illnesses.

Hampton and Amar's stories were published for the first time in 'Cancer Town', a year-long online series of investigative reports by *The Guardian*. The experiences of poor Black, immigrant communities living in areas of toxic environmental pollution are largely absent from the growing body of cancer and illness narratives published over the last 25 years. The following chapter looks for these stories and probes their form and politics as part of the overarching questions of this thesis: why has the medical humanities illness narrative canon, and certain other canons of literature, historically struggled to capture and recognise certain experiences? There is a question of scale worth considering here: as I suggest in previous chapters of this thesis, canonical illness narratives have tended to focus on the individual life course without always acknowledging the wider intergenerational and collective – both human and non-human – temporalities that exceed the individual. What might an enriched and expanded canon look like? And how might such a canon bring to light the atypical forms of care that palliate processes of disease and dying?

³⁴⁷ Jamiles Lartey and Oliver Laughland, "Almost Every Household Has Someone That Has Died from Cancer", *The Guardian*, 6 May 2019 <<https://www.theguardian.com/us-news/ng-interactive/2019/may/06/cancertown-louisiana-reserve-special-report>> [accessed 19 April 2023].

³⁴⁸ Lauren Zanolli, "'We're Just Waiting to Die': The Black Residents Living on Top of a Toxic Landfill Site", *The Guardian*, 11 December 2019 <<https://www.theguardian.com/us-news/2019/dec/11/gordon-plaza-louisiana-toxic-landfill-site>> [accessed 19 April 2023].

The objective of this chapter is to track legacies of harm that go unrecognised by the state but are nevertheless registered on the bodies of individuals living and dying within these abandoned communities. The chapter demonstrates how illness and untimely death are bound up not only with questions of gender and race, as argued in previous chapters, but more and more urgently with the exploitation of the natural environment. Through readings of Antonetta's *Body Toxic* and Ward's *Salvage the Bones*, I explore what I identify as the proto-apocalyptic environments produced by toxicity, pollution, and the increasingly extreme weather events driven by climate change.

Citing Hans Baer in the introduction to the edited collection *Waiting*, Ghassan Hage formulates the temporalities of climate change as an articulation of modes of waiting: 'waiting for ecological disaster, waiting for governments to acknowledge climate change and act to counter it and finally waiting for a more popular awakening to the imminent dangers constituted by climate change'.³⁴⁹ He stresses the saliency of Baer's assertion that the intensity of waiting in the time of climate change is mediated by 'the degree of power that each group has within the social and political structure'.³⁵⁰ This chapter builds on this assertion, exploring how race and poverty affect the temporal experience of climate change and environmental pollution, and how these experiences are implicated in the disproportionate rates of illness and death in certain communities.

My analysis is further shaped by a set of themes that includes form, (un)death and the notion of fugitive care. With reference to these themes, I argue for the inclusion of *Body Toxic* and *Salvage the Bones* in an expanded understanding of illness narratives that recognises the ongoing work in fields such as environmental studies and disability studies, as well as critical race theory and queer theory. At a time when the critical medical humanities has established itself and approaches the end of its first decade of scholarship, I argue that the field is positioned to go beyond the prescriptive definitions created by "first-wave" medical humanities scholars such as Couser and Hawkins, discussed in the introduction to this thesis.³⁵¹

³⁴⁹ *Waiting*, ed. by Ghassan Hage (Carlton: Melbourne University Publishing, 2009), p. 8.

³⁵⁰ Hage, p. 8.

³⁵¹ Hawkins, p. xiv.

Experimenting with Form and Genre

Boyer's *The Undying* (2019) is an example of a text that "counts" as a cancer memoir in the illness narrative tradition, while challenging and expanding past and existing definitions of the form. As such, it has quickly become a keystone text for the medical humanities. Since the early 2010's, scholarship in the field has challenged previous claims about narrative and called for a criticality that recognises how illness and narrative are not privileged sites exempt from racial, sexual, economic and environmental politics, often instead creating intensifications of these power imbalances.³⁵² I argue that many of the emerging debates within the field meet in *The Undying*, which is in many ways a culmination of that line of critical enquiry. The text therefore continues the conversation initiated by key thinkers in the critical medical humanities, while moving the conversation on and creating a context in which *Body Toxic* and *Salvage the Bones* become freshly legible as literatures of illness and death.

The Undying follows convention in that it tracks Boyer's personal journey through diagnosis, treatment and recovery. Yet it also looks outwards to claim collectivity with others outside of her own lived experience, while using her own experiences as the basis for a sharp analysis of the politics of illness. To offer a few examples, Boyer is firm about the role of environmental toxicity in producing and shaping illness, railing at 'Superfund sites', locations contaminated by toxic materials and identified as candidates for the Superfund United States federal environmental remediation program.³⁵³ Boyer cites Diane Di Prima's poem 'Revolutionary Letter #9': '1. kill head of Dow Chemical / 2. destroy plant / 3. MAKE IT UNPROFITABLE FOR THEM TO BUILD AGAIN'.³⁵⁴ Throughout *The Undying*, she critiques the conditions of neoliberal capitalism through a reflection on her position as a working single mother, who must continue to work through her mastectomy recovery period and during her chemotherapy treatments. Her care networks offer a challenge to norms around gender and sexuality by foregrounding the importance of friendship, pleasure and sexual freedom, in defiance of expectations that the primary unit of care should be

³⁵² *The Edinburgh Companion to the Critical Medical Humanities*, ed. by Anne Whitehead and others (Edinburgh: Edinburgh University Press, 2016), p. 2.

³⁵³ Boyer, p. 48.

³⁵⁴ Boyer, p. 124.

the nuclear or biological family. Boyer is also cognizant of how race matters, thinking beyond her own position as a white American to acknowledge the higher rate of breast cancer mortality in Black women, and the fact that Black women are disproportionately affected by the triple negative breast cancer with which she is diagnosed.³⁵⁵ She evokes Lorde, returning to *The Cancer Journals* to highlight the often-overlooked debt subsequent cancer narratives owe to the Black feminist tradition that Lorde helped to shape. In its radical broken-up-ness, *The Undying* celebrates the potential of experimenting with form, subverting the linear temporality of conventional cancer and illness narratives in its fragments, historical and critical digressions and second person reader address. In reference to the latter, its most important achievement is to use language to evoke a sense of collectivity, a chorus of 'undying' individuals gathered together across time and immortalised in prose, to argue that the condition of the survivor is a condition of limbo and that living on means living with death. In the last pages of *The Undying*, Boyer laments that cancer narratives are judged by '[their] veracity or [their] utility or [their] depth of feeling but rarely by [their] form', and that it is in their form that they obtain their 'motor' and capacity for transformative 'fury'.³⁵⁶ This statement reads as an explicit call to take up form as a weapon.

Form is also central to the workings of *Body Toxic*, a memoir in which Antonetta explores the experiences of her immigrant family, who come from Barbados on her maternal grandfather's side and Italy on her paternal grandfather's side to settle in New Jersey in pursuit of a better life. The memoir centers around the symbol of this aspiration: a summer cottage built by her maternal grandfather Cassill in the Pine Barrens, amid New Jersey's coastal boglands. The family gather there at weekends and over holidays to escape industrial suburbia, to swim, fish and pick wild berries. Gradually, it emerges that the area has been compromised by radiation from a nearby nuclear plant, while the river, coastal and drinking waters have been poisoned by the historic dumping of toxic industrial waste chemicals. Like Mary Hampton in 'Cancer Town', aspiring to a version of the American Dream and living in relation to the land and environments they have made their homes, residents of the Pine Barrens find themselves impacted by institutions and corporations who have

³⁵⁵ Boyer, p. 172.

³⁵⁶ Boyer, p. 285.

already laid powerful, destructive and extractive claims on these same environments and their resources, treating them and the communities who must live there as disposable refuse.

Beyond Jurecic's insightful engagement with the text in *Illness as Narrative*, scholarship and reviews of *Body Toxic* read it appropriately as an environmental memoir, focusing their critique on the tragedy of the destruction of natural landscapes.³⁵⁷ Yet ending this analysis here misses the ways in which *Body Toxic* is also an important text for both disability studies and end-of-life literatures within the context of the medical humanities. Exploring the diseased bodies of its subjects, the text offers insights into what it means to live with chronic illness and the likelihood of early death. The privileging of *Body Toxic* as an environmental memoir focuses on planetary deep time, and this default tendency towards "big picture" analysis demonstrates the difficulty and unwieldiness of understanding such temporalities in relation to human experience, mirroring the problem of scale which pervades the discourse around climate change. This problem of temporal scale, I argue, is what makes *Body Toxic* difficult to conceptualise as a conventional illness narrative. Unlike narratives of cancer and terminal illness, the temporalities of the text are extended, causality is diffuse, and both are complicated by Antonetta's use of a surreal, fragmented non-linear formal structure.

Form is also significant in Ward's *Salvage the Bones*, which differs from the texts examined in this thesis in that it is the only novel I have chosen to include in my analysis. *Salvage the Bones* is a story about Hurricane Katrina which focuses on the 15-year-old narrator Esch, her father and her three brothers Randall, aged 17, Skeeter, aged 16 and Junior, aged only seven. The novel is set in the Pit, which is the name the characters give their home in the fictional town of Bois Sauvage, Mississippi. Esch's mother died giving birth to Junior and Ward builds the novel around her as the absent centre, exploring how the children and their father struggle to live on in the wake of her death and as the storm approaches. I include *Salvage the Bones* in this chapter because the novel is in many ways a transmutation of

³⁵⁷ Christine Flanagan, 'The Superfund Gothic: Suzanne Antonetta's "Body Toxic: An Environmental Memoir"', in *New Directions in Ecofeminist Criticism*, ed. by Andrea Campbell (Newcastle upon Tyne: Cambridge Scholars Publishing), pp. 44–61; Yanoula Athanassakis, 'Bodies Interrupted', in *Environmental Justice in Contemporary US Narratives* (Routledge, 2017); Victoria Kamsler, 'Review of The Body Toxic: An Environmental Memoir', *Ethics and the Environment*, 7.2 (2002), 194–96.

Ward's own experiences of Hurricane Katrina, as well as her parents' memories of Hurricane Camille of 1969, another destructive Category 5 storm.³⁵⁸ The love between Skeeter and his pitbull China reflects the complexity of Ward's father's relationships with the pitbulls he owned and fought in dog fights. The characters flee their flooding house at the climax of the novel in a parallel of Ward's family's decision to go out into Hurricane Katrina to avoid drowning in their own attic. While many writers draw from lived experiences for their work, I am interested in Ward's decision to turn towards fiction as a vehicle for representing this particular set of experiences. Ward has utilised memoir as a form before, as the previous chapter on *Men We Reaped* demonstrates. However, it is worth considering what the novel form closes down and opens up for both Ward and the reader. Memoir presents itself as appropriate for the elegiac mode of *Men We Reaped*, closer perhaps to the rawness of her grief. *Salvage the Bones* offers a different kind of truth. It is a novel, a form historically associated with leisure and enjoyment, yet its content and the real-life tragedy it gestures towards complicate the readers experience of their own consumption and enjoyment. *Salvage the Bones* sidesteps the problem of Black death as spectacle, a very real issue in the context of accusations of exploitation and voyeurism surrounding Hurricane Katrina news coverage and documentary.³⁵⁹ I argue that Ward employs fiction in a similar way here to the poetry I discussed in the previous chapter. It offers a measure of opacity, allowing *Salvage the Bones* to stand as both a work of art and a narrative of death and environmental devastation. It is a representational strategy that both acknowledges and avoids reproducing the violence, prurient curiosity and ultimately the neglect endured by Katrina's victims. In place of the unidentifiable Black dead, their bodies 'lying all over the city, bloated and discoloured',³⁶⁰ Ward offers readers the palpable liveness of Esch and her family.

Another representational strategy at work in *Salvage the Bones* worth touching on briefly is its distinctive temporal structure. In an inversion of the diffuse, extended temporalities Antonetta weaves into her memoir, the novel's constitutive events take place over a compact twelve-day period, contracting telescopically until all that

³⁵⁸ Jesmyn Ward, *Salvage the Bones* (London ; Oxford ; New York ; New Delhi ; Sydney: Bloomsbury Publishing, 2017), p. 261.

³⁵⁹ Anna Hartnell, 'Katrina Tourism and a Tale of Two Cities: Visualizing Race and Class in New Orleans', *American Quarterly*, 61.3 (2009), 723–47 (p. 735).

³⁶⁰ David Denby, 'Disasters', *The New Yorker*, 27 August 2006
<<https://www.newyorker.com/magazine/2006/09/04/disasters>> [accessed 19 April 2023].

remains is the storm and the stark question of survival. Literary criticism has long been interested in the question of the scale of the novel. In *Darwin's Plots: Evolutionary Narrative in Darwin, George Eliot and Nineteenth-Century Fiction* (1983), Gillian Beer intervenes in such standing debates, noting that while 'George Eliot's ...and Dickens's novels, tend to include death, rather than end with death, [Thomas] Hardy's texts pay homage to human scale by ceasing as the hero or heroine dies'.³⁶¹ Beer highlights a dynamic in which the classic nineteenth-century novel tended to adopt an expansive view beyond the individual, whereas Hardy's work initiated a return to the individual. Caroline Levine builds on this insight, thinking through the temporalities sustained by the contemporary novel. She contrasts a yearning towards closure with fragmentation and indeterminacy in canonical works of literature, concluding that 'happy endings not only falsify, then; they also train us into docile submission to the status quo, encouraging us to accept ongoing injustice and violence'.³⁶² Yet, the indeterminate ending is also curiously politically evacuated and Levine suggests that in an 'age of acute precarity', the insistence of an aesthetic of openness 'has reached its limit', becoming 'eerily consonant with domination and exploitation'.³⁶³ *Salvage the Bones*, like *Body Toxic*, is able to mediate between the time-senses Beer and Levine describe, attending to the scale of both the individual and temporalities which exceed them. It ends by suggesting care is the means by which its characters might continue to go on, its telescopic focus ultimately retracting to reflect the complex and ongoing significance of Hurricane Katrina.

The storm acts as a literal sign that, for many, climate change has already arrived. In 2005, the Gulf Coast of the US saw three Category 5 Hurricanes including Katrina – more than any other year in recorded history – creating an impact that was cruelly accretive. A recently published study tracks this increase in the rate of hurricanes affecting the Gulf Coast over the last 40 years, linking the intensification to climate change and predicting that the socioeconomic impact on the low-lying coastal communities will only increase in subsequent years.³⁶⁴ In this way, the storm and its

³⁶¹ Gillian Beer, *Darwin's Plots: Evolutionary Narrative in Darwin, George Eliot, and Nineteenth-Century Fiction*, 2nd ed (Cambridge ; New York: Cambridge University Press, 2000), p. 223.

³⁶² Caroline Levine, 'In Praise of Happy Endings: Precarity, Sustainability, and the Novel', *Novel*, 55.3 (2022), 388–405 (p. 388) <<https://doi.org/10.1215/00295132-10007438>>.

³⁶³ Levine, p. 390.

³⁶⁴ Karthik Balaguru and others, 'Increasing Hurricane Intensification Rate Near the US Atlantic Coast', *Geophysical Research Letters*, 49.20 (2022), <<https://doi.org/10.1029/2022GL099793>>.

impending arrival also functions more symbolically as a metaphor for the growing likelihood of climate change experienced on a wider i.e. global scale, in a reflection of the total apocalypticism routinely represented in the disaster films of Hollywood's blockbuster imaginary. This is a strange temporality of the disaster which has both arrived and is nevertheless experienced by much of the Global North as yet-to-come. Drawing on Black feminist theory, including the critical work of Hartman and the fiction of N. K. Jemisin, Yusoff has detailed the ways in which white geology and the periodicity of the Anthropocene has ignored 'how the end of this world has already happened for some subjects'.³⁶⁵ These realities underscore more clearly than ever the ways in which impoverished people and their relationships with the environment are not legitimised and signals the need for deeper engagement with such experiences within an analysis of health and care in the medical humanities.

Salvage the Bones describes a landscape subject to an ongoing legacy of harm, which in a kind of vicious circularity produces a sense that the landscape and its people can be legitimately abandoned without care. It is significant that the towns at the heart of *Salvage the Bones* and 'Cancer Town' are located in the former slave states of Louisiana and Mississippi, where Black working-class communities are often situated on or nearby sites of former plantations and sharecropping farms.³⁶⁶ There, the toxicity of the past is layered over the toxicity of the present in a kind of palimpsest. In *Body Toxic* the Pine Barrens are subject to a similar sort of abandonment. Before the region's cheap land was purchased by immigrants such as Antonetta's grandparents in the 1920s, the Barrens were historically a haven for fugitives, 'where for centuries people have fled to hide, smugglers...traitors and murderers'.³⁶⁷ The presence of such "undesirables" legitimises the state's indifference to toxic pollution in the area. *Body Toxic* is particularly attentive to the ways in which this indifference is expressed and felt through language.

³⁶⁵ Yusoff, p. 22.

³⁶⁶ Oliver Laughland and Jamiles Lartey, 'First Slavery, Then a Chemical Plant and Cancer Deaths: One Town's Brutal History', *The Guardian*, 6 May 2019, section US news <<https://www.theguardian.com/us-news/2019/may/06/cancertown-louisiana-reserve-history-slavery>> [accessed 19 April 2023].

³⁶⁷ Antonetta, p. 154. Further references to this book are given in the text.

Language in *Body Toxic*

By Antonetta's reckoning, the first industrial incursion into the Pine Barrens occurs in 1952, when the Swiss company Ciba-Geigy built a chemical plant along the river from her family summer cottages. Socio-economically devalued by its associations with criminality and foreigners, the area appealed to Ciba-Geigy because of the availability of 'cheap, eager labour' and 'lots of useless land for landfill' (p. 17). Significantly, Ciba-Geigy's notions of usefulness and uselessness in this context come to mean the same thing, as both refer to the ways in which the community and the land can be exploited as resources in a flattening corporate logic. The language Antonetta uses to describe the growing chemical and nuclear industry in the area is similarly flat and emptied out of affect. It reflects the contentless doublespeak now accepted as characteristic of a neoliberal political idiom. Nixon opens his monograph *Slow Violence and the Environmentalism of the Poor*, with an example of this use of language, highlighting the 'calm voice of global managerial reasoning' with which the president of the World Bank argued for the 'impeccable' 'economic logic' of exporting the 'garbage, toxic waste, and heavily polluting industries' of rich nations to 'inefficiently' 'underpolluted' countries in Africa.³⁶⁸ These words – 'calm voice of managerial reasoning' – can be taken up as a refrain that symbolises the discursive power of institutional structures. In this way both Antonetta and Nixon's interventions demonstrate the ways in which the language of power is never innocent, but rather seeks to obscure policies of racialised environmental violence in its banality.

Body Toxic's prose style constitutes a marked departure from environmental writing in the 'eco-didactic' tradition of Rachel Carson's seminal *Silent Spring* (1962).³⁶⁹ In a reaction to the 'calm managerial' language of environmental violence, Carson infuses her language with the enormity of her moral outrage: *Silent Spring* is thick with words such as 'blight', 'evil' and 'maladies'.³⁷⁰ In contrast, the imagery Antonetta uses to describe the growing scope of pollution in the Pine Barrens, the nearby Toms River Town, and surrounding Ocean County area is full of dry juxtaposition. In 1960 the nearby Boeing and Michigan Aerospace Research Center (BOMARC) nuclear facility

³⁶⁸ Nixon, p. 1.

³⁶⁹ Carmela Cucuzzella, Jean-Pierre Chupin, and Cynthia Hammond, 'Eco-Didacticism in Art and Architecture: Design as Means for Raising Awareness', *Cities*, 102 (2020), 102728 <<https://doi.org/10.1016/j.cities.2020.102728>>.

³⁷⁰ Rachel Carson, *Silent Spring* (London: Penguin, 2020), pp. 2, 93, 253.

catches fire, spreading radioactive plutonium into the soil and groundwater; Eventually, in 1972, 'the government...answering cries for protection, installed a chainlink fence' (p. 15). The matter-of-fact dryness and strategic bathos of Antonetta's prose, here and throughout *Body Toxic* overall, sets the reader up to appreciate more deeply the "punchline" of environmental negligence than a more heightened and emotive style would.

The combination of lead, mercury, dioxins, DDT, PCBs and radioactive chemical poisons have a devastating impact on the health of the local community. In their work, Chen has explored the embodied and cultural valences of toxicity, noting similarly that 'toxins are everywhere', 'mov[ing] well beyond their specific range of biological attribution, leaking out of nominal and literal bounds'.³⁷¹ Chen engages toxicity 'as a *condition* [emphasis in the text], one that is too complex to imagine as a property of one or another individual or group or something that could itself be easily bounded'.³⁷² Moving from the abstract to the personal, they foreground the extent to which 'it has profoundly impacted' their own health and 'ability to forge bonds'.³⁷³ Consonant with Chen's insights, Antonetta later learns radiation and chemical poisoning have a potentiating effect upon one another, each increasing the cellular damage inflicted by the other in ways that exceed easy categorisation (p. 139). Some of these effects lead to chronic illnesses. Antonetta and her female cousins contend with various forms of reproductive dysfunction; four out of the six of them, including Antonetta, are 'sterile', afflicted with 'endometriosis [and] misformed organs' (pp. 88, 112). Antonetta herself has a 'bicornuate' (double-chambered) uterus (p. 124). Many chemicals attack the nervous system and the brain causing 'seizures, sometimes lasting epilepsy, wild emotional changes' (p. 200). The same chemicals also result in terminal illnesses. Ocean County's disease clusters contain leukaemias, breast cancers, as well as whole cohorts of children diagnosed with cancer and autism (pp. 18, 27, 61). Antonetta muses on the deadly potency of the amount of plutonium released by the 1960 BOMARC fire: 'if evenly distributed [it] would induce lung cancer in every human being on the planet' (p. 231).

³⁷¹ Mel Y. Chen, *Animacies: Biopolitics, Racial Mattering, and Queer Affect* (Duke University Press, 2012), pp. 189, 190.

³⁷² Chen, p. 196.

³⁷³ Chen, p. 197.

The effect on animals is equally dire. Antonetta notes that ‘poisoned bees fight and frantically clean themselves, like humans with obsessive compulsive disorder...before they die’, making a suggestive connection between the drivers behind both the extinction of pollinating insects and OCD, in an example of *Body Toxic*’s wider argument about the causal relationship between toxicity and mental illness (p. 200). In the water by the summer houses ‘thousands of dead [moss] bunkers float, squat and silver’, the bridge above packed with fishermen obliviously ‘reeling’ in the live amongst them ‘warm’ and ‘stupid’ from the water heated by the nuclear plant (pp. 24–25).

The rhetorical force of this cumulative list captures only part of the wide-ranging harms Antonetta meticulously catalogues in *Body Toxic*. The totality of harm is what Nixon describes in his theory of ‘slow violence’.³⁷⁴ It is a term that seems paradoxical, as prevalent understandings of violence describe it as ‘event[s] or action[s] that [are] immediate in time, explosive and spectacular in space’.³⁷⁵ Slow violence is instead ‘a violence that occurs gradually and out of sight, a violence of delayed destruction that is dispersed across time and space, an attritional violence’.³⁷⁶ Nixon’s concept describes the ‘long dyings’ produced by ‘climate change, the thawing cryosphere, toxic drift, biomagnification, deforestation, the radioactive aftermaths of wars [and] acidifying oceans’.³⁷⁷

The deadly grammar of slow violence is further demonstrated in chapter one of *Body Toxic* in the story of Nicholas Agricola, which is another example of how Antonetta’s prose derives its impact from the rhetorically dry, matter-of-fact way in which she highlights painful ironies. Antonetta recounts how Agricola made his ‘fortune’ dumping drums of hazardous waste for Union Carbide on land leased from Reich Farm in Toms River. While the meaning of Agricola translates literally to ‘farmer’, Agricola amasses his personal wealth through environmental negligence rather than agricultural husbandry, leaving the land ‘blooming’ with 5000 leaking drums that feed into the local aquifer and municipal wells, releasing into the drinking water a ‘list of toxins that goes on for pages’ (p. 20). In an insult to the Toms River organisation for parents of children with cancer, Agricola is fined only ‘\$100’. Evoking the conventions

³⁷⁴ Nixon, p. 2.

³⁷⁵ Ibid.

³⁷⁶ Ibid.

³⁷⁷ Ibid.

of the picaresque genre to demonstrate the ways in which such agents of environmental pollution are treated indulgently as roguish adventurers, the *Agricola* vignette functions as a powerful fable of the human cost of large-scale industrial processes (including the use of pesticides in farming) that value short-term profit over long-term health. Like the chainlink fence at the BOMARC nuclear plant, *Agricola*'s fine makes a mockery of the harm caused.

Through numerous examples of such institutional indifference, *Body Toxic* establishes that Ocean County's towns have been in fact designated as sacrifice communities, not only invisible or ignored, but deliberately and systemically abandoned as necessary casualties of industry. Citing environmentalists, Antonetta defines 'sacrifice communities' as 'generally poor and rural' areas therefore 'chosen to house...toxic waste and nuclear power' (p. 26). In his book *Sacrifice Zones: The Front Lines of Toxic Chemical Exposure in the United States* (2010), Steven Lerner echoes this definition, identifying 'sacrifice zones' as 'low-income' 'semi-industrial areas largely populated by African Americans, Latinos, Native Americans, and low-income whites', where 'hundreds of thousands of residents are exposed to disproportionately elevated levels of hazardous chemicals'.³⁷⁸ Lerner's most important contribution to the discourse is to trace the origin of the term to Cold War 'National Sacrifice Zones': 'an Orwellian term coined by government officials to designate areas dangerously contaminated as a result of the mining and processing of uranium' for military activity.³⁷⁹

Highlighting the extent to which sacrifice communities are historically a by-product of western imperialism, Lerner aligns with Nixon's account of war as one of the driving forces behind forms of slow violence. Unfolding during the Cold War years, *Body Toxic* reflects on the unsuccessful attempt to transform and redirect the energies and technologies of that imperialism, demonstrating the cost to marginalised communities "at home" as much as the racialised 'Other' abroad. Antonetta notes how many of the chemicals responsible for the slow death of the Ocean County community began their existence as weapons. In addition to the BOMARC nuclear military facility nearby in New Egypt to the north-west, the Cassill summer cottages

³⁷⁸ Steve Lerner, *Sacrifice Zones: The Front Lines of Toxic Chemical Exposure in the United States* (Cambridge, Mass: MIT Press, 2010), p. 2.

³⁷⁹ *Ibid.*

also lie in close proximity to a nuclear power plant in Oyster Creek, to the south. As a child, Antonetta confuses fission power with fission weapons, imagining a 'mushroom cloud' hidden under the Oyster Creek plant roof ready at any time to erupt (p. 142). She compares her childlike equation of the two with the 'litter of utopian writing' about the potential of nuclear power that emerges from the 1940s onwards, highlighting the equally childlike naivete in the expression of 'optimism in refashioned weapons' in the context of the horrors of the twentieth century's proliferating wars (pp.143, 135). Similarly, the 'organophosphates' used industrially as 'solvents, catalysts, coolants...and as pesticides' are 'little changed from their original form as World War II's nerve gases' (p.199). Military aircraft are reappropriated in order to dust crops and bogland with pesticides and DDT, killing mosquitoes, gypsy moths and fire ants (pp.134, 200).

The environmental violence wrought by profit seeking industries is enabled again by the manipulation of language. The use of military technologies is justified by a series of metaphorical wars ostensibly intended to bring about a better future: wars on 'communism, poverty, insects... germs' and even 'stains on clothes' (p. 82). In this way, *Body Toxic* shows how a temporality of constant crisis and urgency is maintained through martial language, evoking a context in which the ends justify the indiscriminate destructiveness of the means. Like the toxic pollution in the Pine Barrens, war leaks into everything as the dominant metaphor organising daily life. Antonetta frequently describes how the notion of war infiltrates her childhood: at the Cassill summer cottage, they 'played with GI Joe dolls' and 'Risk, the board game of world conquest' (p. 82). The ubiquity of war metaphors speaks to a consolidation rather than transformation of destructive and dominating impulses. *Body Toxic* is emphatic in its message that the technologies of war cannot be separated from their inherent destructiveness. The text presents a picture of military imperialism turned in on itself, making war against its own people.

The war-like language and machinery of environmental destruction produces a sense of fatalism amongst the inhabitants of the Pine Barrens. Environmental writing often frames the resistance efforts of such communities in martial terms, as a 'fight' against institutional violence. However, such a framing might overemphasise the agency available to environmentalists of sacrifice communities, failing to recognise the asymmetries of power by which they are overwhelmingly outmatched, and the

health problems by which they are further de-energised and disadvantaged. As Nixon argues, slow violence in its inexorable progress is nearly impossible to “fight”: it represents a systemic destruction in which the effects compound each other. Against the fluent power of the ‘calm voice’ of institutional reasoning, *Body Toxic* presents sacrifice communities who have been effectively silenced.

In opening with an epigraph from an obscure, unnamed text, attributed only to the ‘testimony of a ranter’, *Body Toxic* sets up a tension between language and silence that runs through text as a whole: ‘I now am made to Speak, because I am almost weary of Speaking, and to informe the world that Silence hath taken hold of my spirit’. With religious overtones that speak to the notion of endurance, the epigraph demonstrates an exhausted fatalism expressed in relation to language. Antonetta contextualises her words and her vocation as a writer against the ‘elaborate silences’ and ‘mantras of unspeech’ that characterise ‘both sides’ of her family (p. 8) establishing silence, paradoxically, as their lingua franca and primary mode of engaging with the world. The text traces the family’s dogmatic reserve back to her Bajan grandfather Louis Cassill, who rarely appears in the text without the modifying adjective ‘silent’ (p. 1). His silence seems to her ‘unshakeable’, and she frequently returns to the image of him watching and unspeaking ‘in a deep...bulky armchair’, treating his ‘nighttime hours as time irrevocably sworn to some dark god’, sitting alone in the parlour ‘with no lights on, staring...for hours’ (pp. 33, 43, 183). Within the family his way of being is normalised and even respected rather than pathologized. Yet, looking back, Antonetta suggests – perhaps problematically reductive – that ‘the soul of [her] grandfather, untouchable and still’ resembles something of the subjectivities of the autistic children affected by the environmental toxicity in Toms River, if not also something of the manic depression with which she and her cousin Mark are eventually diagnosed (p. 61). As Chen, Kafer, Kim and Minich observe in the introduction to *Crip Genealogies*, there has been too little cross-pollination between white disability studies and discourses of environmentalism,³⁸⁰ leaving open the danger of reductive equivocation between environmental devastation, illness and dysfunction that risks reproducing structural ableism. Antonetta’s narrative at times

³⁸⁰ Chen and others, p. 48.

retreats from articulating a key issue within environmental writing – how to account for harm without pathologizing disability and neurodivergence.

Taking strategic silence as a key theme, *Body Toxic* explores how each member of the Cassill family takes up their grandfather's refusal of speech in a different way. Antonetta's mother is a 'timid woman', whose response to loaded words such as 'pregnant, stupid, sick, crazy, little, big, dead, alive' is always "don't say that" (p. 81). While these taboos seem partly to do with maintaining a particular kind of gendered social respectability, to Antonetta they also suggest something about an apprehension of the violent potential of language to make and unmake the material world: 'with my mother trying to prevent me from changing anyone with my words' (p. 81). Antonetta suggests this attunement to the negative power of language is shared by her kin. At the summer cottages the family play Scrabble 'endlessly', but always in a quasi-superstitious silence 'with just the rain sounds and the clacking of the Scrabble tiles'. In the game a '*pear* may *rape* and *reap* itself...someone puts down a *mist* and it becomes a *pessimist* soon. An *ill* becomes a *will*' (p. 70). There is a keen sense of risk in the impulse to speak and be heard, and this shared fear shapes a family wary of words and language.

Through the figure of her grandmother, Antonetta represents a different kind of relation to from language. Her grandmother uses an idiosyncratic 'Oxbridge' accent and vocabulary that Antonetta doubts 'exists or ever did in any real place' (p. 56). Her prevailing trait is her 'inscrutability', expressed in her Christian science beliefs, idiosyncratic even in the context of the religious norms of the time: "Jesus was a metaphysician, you know" (p. 60). Through the articulation of this faith, in which immortal souls are more real than illusory flesh, she distances herself from her family and her gendered body, retreating from social expectations of her as a woman and a mother. Domineering where her husband is withdrawn, her grandmother is the matriarch and de facto head of the family, who 'ruled...until her death, not just what [the family] did but how [they] thought about things' (pp. 64, 67). She travels ceaselessly, abandoning Antonetta's mother, aunts and uncles for long periods of time during their childhood to visit places where the language and cultures are alien to her: 'Barbados, Europe, all over the world', 'safari to Africa' with the Masai (p. 70). Antonetta remembers family visits as 'submitting to the physical rules of another order', suggesting the extent to which her grandmother deliberately cultivated a

similar sense of alienation and distance – of being in a foreign country – even at home, through language. Her grandmother emerges as a figure who then uses language to construct her own reality and impose it on those around her while obstructing any attempt to be known by others.

From this perspective, Antonetta's compulsion to write, and particularly her confessional style, which too also has religious overtones, is positioned as a 'weakness', a failure of stoicism and even a violation of the family 'privacy' (p. 5). She reflects on how her private girlhood diary reads also as somehow 'public' and 'infected by audience'. This word 'infected' conveys the way in which her desire to find a voice becomes a pathological act in the context of the family silence (pp. 5, 7). During teenage years of substance abuse, Antonetta uses 'marijuana, Carbona cleaning fluid...ludes, hash, acid [and] heroin' to withdraw in her own way, creating her own form of this silence. It is striking that it is during this time of arguably more pathological substance abuse that she feels the most part of her family, 'accepted, even recognised finally...doors left open...coffee handed' (pp. 44, 183).

The Cassill silences make way for forms of denial and forgetting, enabling them to engage 'insistently in rewriting [them]selves' (p. 53). Most significant perhaps is the unwillingness of the older generations to acknowledge the toxic histories of the Pine Barrens and its potential effect on Antonetta, her brother and their cousins. Eventually Antonetta 'quit[s] talking about the groundwater and radiation and DDT...censor[s] herself' (p. 65). However, *Body Toxic* also demonstrates how the denial of histories of contamination is entangled with other things Antonetta's family have tacitly agreed to 'forget': their 'multiracial' heritage, Antonetta's years of drug use and 'psychotic breakdowns (p. 54). Whole branches of the family vanish from memory, from her grandfather's brother, Frederick killed by his 'manic-depressive' mother in a fit of mania, by pulling him out of his 'pneumoniac sickbed and forcing him to scrub the kitchen floor', to her aunt Helen, never spoken of again after her divorce (pp. 41, 45).

In this way *Body Toxic* pursues the mutability of truth and communal memory as core themes; the text is interested in how such mutability is created or sustained by a turn away from language into the silence of a managed forgetting. Antonetta explores this theme most acutely through a recollection of the time her grandfather attempts to

sexually assault her when the two are alone in the Pine Barrens summer cottages. She remembers him in the bottom bunk 'on his side in a kind of crouch', calling to her and throwing the covers back to reveal 'nude skin', then her head 'blurred', 'time became space and swam past me physically' (p. 170). Through language she conveys the tangible malleability of the experience, how in blurring, swimming and transforming it is vulnerable to recontouring by her own act of memory: 'in some ways that few minutes form the clearest memory I have, I've read so much about this kind of memory I fear to taint the image' (p. 170). When she finally discloses the experience to her brother a year later, he tells her to 'forget it, no one would believe us', a response Antonetta represents as a 'compassionate' act of care (p. 170).

The incident points to how, in *Body Toxic*, family practices of silence and denial are not just acts of cruelty, they serve an important purpose, functioning often as the only available survival strategy. Silence, denial and forgetting are ways of living with traumatic histories that would otherwise be too much to bear. In admitting to the cross generational impact of madness, imperialism, poisoning and disease, Antonetta's parents would have to recognise an intolerable vulnerability, while acknowledging their misplaced hope in the American dream, and ultimately the failure and injustices of this project. Antonetta describes how their unexpressed grief comes to her 'through the blood and cells', running 'for the DNA as the only form of language' (pp. 87, 88).

Antonetta's drug addiction, her withdrawal from the world and from language, clearly also works to some extent in this way, allowing her to retreat from her own increasingly dysfunctional body. Reflecting on those years, she muses of her body, 'was it ever mine? My world had made a new air for me to breathe and a new water for me to drink. I had growths in me that did not belong...to possess my own body, I had to replace it with whatever matter I could choose' (p. 184). To compensate for 'generations of poisoning' – chemical and emotional – she poisons herself (p. 187). Substance abuse can be understood as a means of challenging and denying the power of these competing forces upon her person, a tangible statement of her own agency that reaches beyond language.

Accordingly, *Body Toxic* is an excavation of the two entangled histories of intergenerational family trauma and 'slow violence' enacted on the land. Antonetta

shows how corporations and the institutions of the state obscure their role in perpetuating environmental violence by using the language and processes of bureaucracy. State organisations such as the Environmental Protection Agency (EPA) meticulously categorise the various substances and chemicals effecting the Ocean County area. Antonetta describes her brother's job with the state Department of Environmental Protection, which involved sorting through 'four or five years' worth of water samples' contaminated with lead and mercury' (p. 32). This "activity" of documentation and categorisation displaces the requirement for real action in the form of clean-up programs, compensation or healthcare support for sacrifice communities in the area. In the process of collecting data, they generate pages and pages of documents without translating information into meaningful action. However, even when compared to this wordy institutional bureaucracy, the silences passed down along the generations of Antonetta's family appear equally "loud", and perhaps harder to parse. The text shows how the process of uncovering one history is inseparable from the act of uncovering the other, that in fact the only way the 'managerial', endlessly prevaricating language of 'slow violence'³⁸¹ can be translated and meaningfully understood is through the 'elaborate silences' of the sacrifice communities subjugated by its action.

Through this contrast between proliferating discourse on the one hand, and silence on the other, *Body Toxic* demonstrates the ways in which the politics of "speaking out" become increasingly complex in illness narratives and life writing at the turn of the twenty-first century. In *Body Toxic*, the act of disclosure is always a deeply ambivalent one and, at all times, the text is conscious of a tension between speech and silence. *Body Toxic* plays out this conflict in a circuitous structure in which it goes backwards in time in order to progress forward in narrative, and for the import of Antonetta's revelations to be properly grasped by the reader. Her grandfather's silences, described in the early pages of the text only take on sense and meaning in the context of its later revelations about his historically 'depressive' nature, his mother's past 'manic fits' of hypersexuality (p. 203), impulsivity and narcissism and of course Antonetta's revelations of his own capacity for abuse. While Antonetta discloses these histories, like her family, she is silent on what Therí Alyce Pickens has theorised as the racialised dimensions of the category of madness and the ways

³⁸¹ Nixon, p. 2.

in which the discourses of both stumble when they come into contact with one another.³⁸² I suggest this is one of the ways in which Antonetta embodies the Cassill indirectness and declares her kinship claim with them. *Body Toxic* echoes a family mode of disclosure in which everything is approached slantwise or backwards, progressing via bathos, understatement, denial and contradiction. In her adulthood, Antonetta describes how her father checks in and expresses his care for her mental health by periodically asking her husband Bruce “do those pills still work?” (p. 65). He cannot ask her directly, to do so would be to acknowledge the histories of harm and dysfunction in their family.

In this way, *Body Toxic* demonstrates a prescient anticipation of how the act of “speaking out” in the 21st century is stripped of the originally radical potential it carried within early justice movements of the 1980s, such as the ‘silence = death’ slogan which united and energised HIV/AIDS activism. Speaking out of course, also informs the transformative ethos of Lorde’s *The Cancer Journals*. Yet, as Boyer observes, ‘the silence around breast cancer that Lorde once wrote into is now the din of breast cancer’s extraordinary production of language. In our time, the challenge is not to speak into the silence, but to learn to form a resistance to the often-obliterating noise’.³⁸³

Antonetta seems to anticipate this shift by situating *Body Toxic* significantly somewhere between the proliferation and absence of language, a choice that reflects the other ways in which she sees herself, her family and community as constantly situated in a kind of space-between. Her Cassill ancestors come from Barbados, a space Antonetta characterises as having ‘two wholly different sides...the eastern Atlantic side, cliffed, unswimmable...the Caribbean side warm, placid, turquoise with its famously sugary beaches’: Barbados itself is ‘dualistic’, ‘bipolar, incapable of transition’ (p. 47). The Cassills are always between contradicting states: health and illness, poverty and aspiration, madness and sanity, silence and meaning and also, increasingly significantly in the landscape of the Pine Barrens, between life and death. In ways that become important, *Body Toxic*

³⁸² Pickens, pp. 26, 30.

³⁸³ Boyer, *The Undying*, p. 8.

positions them as not quite in the realm of the living but neither fully consigned to the ranks of the dead.

Body Toxic then is an important text for the growing body of illness and end of life narratives to reflect on, as it challenges and defies the ways in which contemporary illness narratives have become inevitably shaped and undermined by the commercial imperatives which prioritise individualism alongside a vapid and depoliticised “awareness”. In *Malignant: How Cancer Becomes Us* Lochlann Jain describes the ‘corporate use’ of breast cancer, focussing on BMW’s Pink Ribbon car collection and accessories designed to raise money and awareness for disease, while noting that ‘the atmosphere of self-congratulation and celebration [did not] leave space to mention several known carcinogens that the auto industry has lobbied hard to allow in gasoline and in car manufacture’.³⁸⁴ This fetishization of “awareness” produces social attitudes and narrative texts that focus, as Jain suggests ‘on the suffering of individuals rather than on the culture that produces cancer’.³⁸⁵ Concurring, Boyer reflects that awareness has become the new ‘lucrative, pink-ribbon-wrapped alternative to “cure”’, spawning an industry of ‘pink ribbon cop cars and pink handcuffs and pink spirit-wear and pink ping pong balls and pink plastic water bottles and pink revolvers’ that perpetuate forms of slow violence through a respectability politics of philanthropy.³⁸⁶

Writing in 2001, Antonetta seems to grasp that this is the emerging context for *Body Toxic* and, increasingly, illness narratives as a whole; a context of capital-centric institutional violence in which speaking out becomes an impotent act, solely gestural, unable to enact an impact on the future or motivate a radical ethic of care. The text is both a critique of that ‘calm voice of managerial voice of reasoning’ which inflicts slow violence,³⁸⁷ but also works through Antonetta’s own ambivalent feelings towards a revolutionary language of “speaking truth to power” which is increasingly undermined and made impotent by dominant structures. There is a significant literature which demonstrates the ways in which the language of health and environmental justice movements is appropriated by corporate actors as part of “corporate social responsibility” initiatives, or what environmentalists have more

³⁸⁴ Jain, p. 68.

³⁸⁵ Jain, p. 85.

³⁸⁶ Boyer, *The Undying*, pp. 171–72.

³⁸⁷ Nixon, p. 1.

accurately called ‘greenwashing’. In 2020 for example, Shell Oil was widely derided on Twitter for posting a ‘climate poll’ on the social network site which asked users ‘what are you willing to change to help reduce emissions?’³⁸⁸ This was recognised as a stunning act of hypocrisy which attempted to discursively shift accountability to individuals away from the disproportionately greater contribution Shell Oil itself makes to global fossil fuel emissions, as well as eliding the environmental violence Shell Oil has committed in global south nations such as Nigeria.³⁸⁹

These discursive strategies clearly play out on a spectrum in relation to questions of chronic illness, disease and death. There are gradations in the violence that language sustains and inflicts: the examples here from Shell Oil and BMW, echoing the strategies employed by Ciba-Geigy and other corporations in *Body Toxic*, seem to represent the more extreme end of such a spectrum. However, they are part of a wider “crisis management” (or perhaps, more accurately, crisis deferral) style of language increasingly reaching into every aspect of social life, which functions to anticipate and suppress dissent while foreclosing the future for profit in the present. In *Crip Theory: Cultural Signs of Queerness and Disability* McRuer critiques the all too often empty rhetoric of accessibility in the contemporary university, a site seeking to ‘manage difference’ in the service of ‘a corporate model of efficiency and flexibility’.³⁹⁰ Here, McRuer’s pathbreaking work in the field of crip theory demonstrates the ways in which institutions appropriate and water down the radical potential of decades of queer theory and disability studies in pursuit of a sleek, well-composed final product, ‘whether it is the final paper, the final grade... the student body with measurable skill’, or a stable heterosexual able-bodied identity.³⁹¹ McRuer’s arguments frame the neurotypical expectations around articulation that haunt *Body Toxic*, which Antonetta, through experimental form and elliptical structure ultimately refuses.

³⁸⁸ “What Are You Willing to Change to Help Reduce Emissions? #EnergyDebate’, *Twitter* <<https://twitter.com/Shell/status/1323184318735360001?lang=en>> [accessed 31 May 2023]; Damian Carrington, ‘Shell’s Climate Poll on Twitter Backfires Spectacularly’, *The Guardian*, 3 November 2020 <<https://www.theguardian.com/business/2020/nov/03/shells-climate-poll-on-twitter-backfires-spectacularly>> [accessed 31 May 2023].

³⁸⁹ Kara Keeling, *Queer Times, Black Futures, Sexual Cultures* (New York: New York University Press, 2019), p. 6.

³⁹⁰ McRuer, *Crip Theory*, pp. 118–19.

³⁹¹ McRuer, *Crip Theory*, p. 121.

Tracking how language is used as a tool of slow violence to silence and to dominate offers a picture of sacrifice communities in impoverished areas of the west and in the global, not left behind in time as Dipesh Chakrabarty argues, ‘consigned to an imaginary waiting room of history’ and outside of the time of modernity.³⁹² Rather, sacrifice communities are at the vanguard of the increasingly apocalyptic conditions that both give rise to illness and end-of-life narratives that unwittingly promote a neo-liberal individualism, and at the same time set the scene for the end of all life. The lived experiences of sacrifice communities and the discourses around them provide the clearest picture of how history and time might be brought to a devastating end. This is perhaps the most significant argument for reappraising *Body Toxic* as an important text for both environmental and end-of-life narratives. It is a nuanced meditation on the way in which planetary destruction approaches in silence, ‘out of sight’, as Nixon suggests in his theory of slow violence,³⁹³ masked by a particular set of languages and discourses. In this way *Body Toxic*, and to an extent *Salvage the Bones* too, capture the same temporality that Boyer represents in *The Undying* – a suspended temporality between that-which-comes-after a devastating event but yet ahead of that-which-is-still-to-come.

Relationality in *Salvage the Bones*

Reflecting on the concept ‘sense of place’, literary scholar Neal Alexander has observed that ‘the idea... occupies an important position at the intersection between literary studies and human geography, figuring prominently in the conceptual vocabularies of both disciplines’.³⁹⁴ If the exploration of a sense of place is where literary and environmental studies meet, it should be unsurprising that Ward’s environmental southern gothic novel *Salvage the Bones*, like *Body Toxic*, is primarily shaped by a powerful sense of place. This distinct sense of place – evoked in the fictional setting of Bois Sauvage, Mississippi – is central to the text’s deep

³⁹² Dipesh Chakrabarty, *Provincializing Europe: Postcolonial Thought and Historical Difference* (Princeton (N.J.): Princeton university press, 2007), p. 8.

³⁹³ Nixon, p. 2.

³⁹⁴ Neal Alexander, ‘Senses of Place’, in *The Routledge Handbook of Literature and Space*, ed. by Robert T. Tally, 1st edn (Abingdon, Oxon ; New York, NY : Routledge, 2017.: Routledge, 2017), pp. 39–49 (p. 39) <<https://doi.org/10.4324/9781315745978-4>>.

engagement with the concept of relationality and its concurrent critique of the logics of extraction.

The place at the centre of *Salvage the Bones* is a 15-acre 'gap in the woods' Esch and her family call the Pit, 'cleared and built on' by Papa Joseph, Esch's maternal grandfather (p. 1). Ward's descriptions of the Pit in the novel's early chapters capture a wild, beautiful and blighted landscape. Chickens roam freely, laying and hiding eggs which Esch and her brothers gather as supplies ahead of Hurricane Katrina. The surrounding woods are their playground, stretching for 'a mile through pine and oaks', the 'oaks stand[ing] apart from the piney clusters... solemn, immovable... Spanish moss hangs from their arms, grey as an old king's beard' (pp. 64, 66). In *Belonging: A Culture of Place* cultural theorist bell hooks describes how her early sense of identity was shaped by a similarly idyllic southern rural landscape in the 'anarchic life of the [Kentucky] hills'.³⁹⁵ These hills, hooks writes, were a place of 'magic and possibility, a lush green frontier, where nothing manmade could run us down, where we could freely seek adventure'.³⁹⁶ There hooks and her family 'learned ...to care for [themselves] by growing crops, raising animals, living deep in the earth', living a life in which 'nature was the foundation of [a] counterhegemonic black sub-culture'.³⁹⁷ One of the key preoccupations of *Belonging: A Culture of Place* is to reassert the 'agrarian roots' of southern Black folks, while initiating an attentive dialogue with the histories and cultural practices of indigenous Native Americans.³⁹⁸ In so doing, hooks discursively remakes a place for Black people within the rural landscapes on which they have been historically enslaved, while challenging an overidentification of blackness with urban spaces motivated by the appetites of white supremacist capitalism. Through the evocation of its specific sense of place, *Salvage the Bones* similarly challenges what hooks theorizes as the erasure of Black Americans from narratives of rurality. Where Antonetta's *Body Toxic* subverts the expectations of didactic sentimentality that have formed around the canon of environmental writing, *Salvage the Bones* addresses the genre's tendency to exclude Black and indigenous people in the construction of a conservative white, working-class rural identity. J.D Vance's *Hillbilly Elegy: A Memoir of a Family and*

³⁹⁵ bell hooks, *Belonging: A Culture of Place* (New York: Routledge, 2009), p. 7.

³⁹⁶ hooks, p. 7.

³⁹⁷ hooks, p. 8.

³⁹⁸ hooks, pp. 44, 35.

Culture in Crisis constitutes a notable contemporary example of this particular context, in its revanchist argument that the rural white working class has been 'decimated by a liberal government whose trade, immigration and environmental policies' have 'killed' local industry and shipped it 'overseas'.³⁹⁹

Yet, in *Salvage the Bones*, Ward also represents the stark realities of living on the land in rural poverty. There are two houses on the Pit, both in various states of disrepair. Esch, Daddy and her brothers Randall, Skeetah and Junior live in one, where 'the walls, thin and uninsulated, [are] peeling from each other at the seams' (p. 7). The other belongs to their grandparents Papa Joseph and Mother Lizbeth, who are now long dead, leaving their house 'rotting' and empty (p. 10). Esch describes this house as 'a drying animal skeleton', which over time the family has stripped and 'salvaged' for parts 'couch by chair by picture by dish until there was nothing left' (p. 58). Still, they continue to 'pick at the house like mostly eaten leftovers': Skeetah pulling up linoleum for the shed he builds for China's puppies, Daddy prying away plywood to cover windows for the hurricane. The yard around the houses is 'ruin[ed] and refuse-laden', full of 'rubbish', 'empty cars with their hoods open, the engines stripped, and the bodies sitting there like picked-over animal bones' (p. 22). The family disposes of the rest of the household rubbish in a nearby pit by burning it (p. 15). Through this imagery Ward expresses that in the Pit, as in nature, life and death are accepted as inextricably bound together. The empty and crumbling houses, skeletal junk, and pyres of rubbish create a forceful impression of Esch and her family living in and on the remains of a sprawling corpse, even as these surroundings set the stage for the rhythms of daily life. This atmosphere of deathliness hangs over the characters themselves, who – narratively confined by the claustrophobic 12-day timeline of the novel and haunted by the prospect of the coming storm – are trapped within the purgatorial, limbo-esque spatiotemporality of The Pit, seemingly circumscribed from progress or futurity.

Esch and her family live, in effect, in the temporality of the fugitive: hand-to-mouth and day-to-day. In the past, they kept 'a pig when Daddy [could] afford one' but now 'the fields Papa Joseph used to plant around the Pit are overgrown with shrubs, with

³⁹⁹ Jeffrey Fleishman, 'Review: J.D. Vance's "Hillbilly Elegy" Provides a Window into the Pain and Anger of Trump's America', *Los Angeles Times*, 7 October 2016 <<https://www.latimes.com/books/jacketcopy/la-ca-jc-hillbilly-elegy-20161007-snap-story.html>> [accessed 31 May 2023].

saw palmetto, [and] with pine trees' (p. 14). The dilapidation, refuse, fallow fields and unmanaged or absent livestock convey the ways in which Esch and her brothers are already living in the wake of the quasi-apocalyptic devastation of sickness and death, after Papa Joseph's death from mouth cancer, their mother's death in childbirth and their father's withdrawal into alcoholism and mental illness. As a novel about Hurricane Katrina the reader is privileged in a way the characters cannot be with the terrible foreknowledge of the further devastation to come. The accretive, seemingly endless nature of their hardship speaks also to hooks' account of Black rural life as 'one of hard work often without the accumulation of substantial material reward', one without any guarantee of economic success and stability.⁴⁰⁰ Even so, there is the suggestion that the symbiotic culture of foraging and subsistence represented in *Salvage the Bones* offers a different kind of reward. In this, Ward seems to align with hooks' argument that living in deep relation with land claimed as home constitutes a source of positive Black identity through the cultivation of independence and self-reliance (pp. 7, 45). As Skeetah declares proudly of the fugitive rural existence lived by himself and his siblings, 'we savages up here on the Pit' (p. 95), making a statement about how being rooted in this place has shaped and fortified their sense of self and capacity for survival. Meditating on the valence of this word – 'savage' – Ward observes,

'the word salvage is phonetically close to savage. At home, among the young, there is honor in that term. It says that come hell or high water, Katrina or oil spill, hunger or heat, you are strong, you are fierce, and you possess hope'.⁴⁰¹

Through the forms of identification between characters and place discussed, the Pit emerges as a metaphor for the racialised body. Located in a majority Black town in the Southern state of Mississippi, it signifies the lowest part, geographically and economically, of the American nation. As a scene of gothic-inflected trauma, The Pit bears a striking conceptual similarity to the sunken place, a metaphor for the racialized psyche that appears in Jordan Peele's 2017 horror film *Get Out*. The sunken place is made terrible by its isolation and its negation of the possibility of freedom. Conversely, The Pit-as-body, configured as both living and dead, retains

⁴⁰⁰ hooks, p. 62.

⁴⁰¹ Elizabeth Hoover and Jesmyn Ward, 'Jesmyn Ward on *Salvage the Bones*', *The Paris Review*, 30 August 2011 <<https://www.theparisreview.org/blog/2011/08/30/jesmyn-ward-on-salvage-the-bones/>> [accessed 31 May 2023].

great capacity for vitality even as it is also chronically ailing and disintegrating under the pressure of its abandonment and neglect. Through the relation of its living and dead constituent parts – humans, animals, organic and inorganic matter – the Pit generates resources for its continued existence even in the face of its exhaustion.

As a Hurricane Katrina narrative, *Salvage the Bones* also draws from a broad context of real-world instances of resource exhaustion and extraction. As Wai Chee Dimock has previously argued, framing Katrina's devastating impact as the primary result of a tragic but ultimately isolated engineering failure – of the New Orleans levees built by the United States Army Corps of Engineers (USACE) – is an analytical mistake which minimises the ecological context in which it takes place, 'making Katrina an event internal to the United States...something that can be fixed without changing our basic sense of what the sovereign nation amounts to, what it is equipped (or not equipped) to do, and the extent of protection it is able to offer its citizens'.⁴⁰² I would also suggest that, considering the sovereign immunity granted to the USACE, the 'engineering catastrophe' narrative vindicates both corporate interests and political administrations, past and present, of their role in contributing to the scale of disaster. Interviewed in Spike Lee's documentary epic *When the Levees Broke: A Requiem in Four Acts* (2006), Douglas Brinkley introduces a crucial further context, observing that 'Louisiana has always been treated as a colony from which natural resources could be extracted'.⁴⁰³ In his book *The Great Deluge*, Brinkley states that 'starting in the 1950s millions of barrels of oil and trillions of cubic feet of natural gas were tapped from the Gulf of Mexico'.⁴⁰⁴ New technologies allowed drilling in the Wetlands, eroding 'a vital natural filter which prevents pollution in the gulf from toxic oil and gas' and protects against storm surges.⁴⁰⁵

In *Salvage the Bones*, The Pit reads as a microcosm of such gulf coast state extractive ecologies. The Pit itself is nicknamed for a large area of excavated land on the property, where Papa Joseph's white employers dug and extracted clay 'used to lay the foundations for houses' (p. 14). Papa Joseph 'let them take all the dirt they

⁴⁰² Wai Chee Dimock, 'World History According to Katrina', *Differences*, 19.2 (2008), 35–53 (pp. 36, 37) <<https://doi.org/10.1215/10407391-2008-007>>.

⁴⁰³ Stephen Holden, 'When the Levees Broke—Review—Television', *The New York Times*, 21 August 2006 <<https://www.nytimes.com/2006/08/21/arts/television/21leve.html>> [accessed 31 May 2023].

⁴⁰⁴ Douglas Brinkley, *The Great Deluge: Hurricane Katrina, New Orleans, and the Mississippi Gulf Coast* (New York, NY: Harper Perennial, 2007), p. 11.

⁴⁰⁵ Brinkley, pp. 9, 11, 32.

wanted' until over time 'their digging ...created a cliff over a dry lake in the backyard' diverting a stream nearby and filling the Pit with water which rises and ebbs with the rain (p. 14). Papa Joseph is finally forced to put a stop to the excavations when the land becomes unstable and 'the earth' threatens to 'give under the water', to 'spread and gobble up the property and make it a swamp' (p. 14). Ward hints at the power imbalance which compels Papa Joseph to allow his employers to mine clay from his property. The clay obtained is used in the building and fortification of other houses, even as it undermines the conditions for living for Papa Joseph and his descendants. At the climax of the novel, the body of water created by this extractive activity bursts its banks and floods the main house up to the attic, nearly drowning Esch and her family.

As a source of both life and death and a site of extractive activity, The Pit as a symbol is key to understanding how *Salvage the Bones* is – at its core – both an argument for symbiotic relationality and a critique of what environmental sociologist Macarena Gómez-Barris has called the 'extractive view', a logic of the state and corporations which 'map[s] territories as commodities rather than perceiv[ing] the proliferation of life and activities that make up the human and nonhuman planetary'.⁴⁰⁶ Ward's representations of legacies of harm and the complex relations between humans, animals and environments in the act of living and dying in *Salvage the Bones* offer a powerful challenge to decolonial and post-colonial accounts of what Gómez-Barris in *The Extractive Zone* describes as the 'ruinous effects of extractive capital'.⁴⁰⁷ Gómez-Barris focuses her research across five regions within South America, with an emphasis on how 'we perceive its social ecologies'. However her definition of 'Extractivismo [as extractive capitalism is known in the Américas]' also describes 'thefts, borrowings...forced removals violently reorganizing social life...[and] thieving resources' occurring on a broader purview of 'Indigenous and Afro-descendent territories', making an implicit connection with the wider Global South.⁴⁰⁸ Gómez-Barris' extractive zones overlap with Steve Lerner's sacrifice zones in that extractive industrial activity often produces and consolidates sacrifice communities subject to the kind of racial zoning which sees them abandoned by the

⁴⁰⁶ Macarena Gómez-Barris, *The Extractive Zone: Social Ecologies and Decolonial Perspectives*, Dissident Acts (Durham ; London: Duke University Press, 2017), p. 133.

⁴⁰⁷ Gómez-Barris. Taken from the blurb of the book.

⁴⁰⁸ Gómez-Barris, p. xvii.

state without care. Lerner describes how an area of oil waste dumps later used as municipal garbage landfill in Texas was designated by city officials in the 1940s as ‘reserved for Mexicans’:⁴⁰⁹ in this example, US soil devalued by the byproducts of the petrochemicals industry is reconfigured as an outpost of Central America and excluded from the laws ostensibly protecting US citizens. In his analysis of Indra Sinha’s *Animal’s People*, a novel about the 1984 Union Carbide chemical leak in Bhopal, India, Nixon makes a similar suggestion about the shared experiences of toxicity and institutional neglect across sacrifice communities worldwide. Citing Dimock, Nixon argues that the novel’s fictional town of Khaufpur is ‘both specific and nonspecific, a fictional stand-in for Bhopal, but also a synecdoche for a web of poisoned communities spread out across the global South’ and indeed further afield: ‘the book could have been set anywhere the chemical industry has destroyed people’s lives’.⁴¹⁰ Before the Union Carbide leak of 1984 in Bhopal, India, Antonetta’s account of environmental pollution in *Body Toxic* details how the US petrochemicals giant was poisoning the Toms River community of Ocean County in the 1970s (p. 20). It is significant also that Union Carbide is among the companies, like Denka in Cancer Town, with a base in the former slave state of Louisiana, not two hours away from Ward’s hometown in Mississippi. Collectively, these circumstances evidence the ways in which, enabled by the state, the same companies pursue the same transnational profit-seeking policies of violence, devaluing the lives of the non-white Other both abroad in the Global South and “at home” in the sacrifice zones of the Global North.

Embracing a character and plot driven structure, *Salvage the Bones* might not explicitly address such concerns. However, it is significant that Ward’s hometown DeLisle – the model for the novel’s Bois Sauvage – has a well-documented history of toxic pollution. Since 1979, DeLisle has been the site of a Chemours (formerly DuPont) industrial plant producing titanium oxide, a chemical used to whiten food, toothpaste, plastics and paints.⁴¹¹ The Mississippi Center for Investigative Reporting notes the painful irony with which a company representative can praise titanium

⁴⁰⁹ Lerner, p. 99.

⁴¹⁰ Nixon, p. 65.

⁴¹¹ Ann Marie Cunningham, ‘Mississippi: Magic, Mystery and Environmental Racism’, *Mississippi Centre for Investigative Reporting*, 2020 <<https://www.mississippicir.org/perspective/mississippi-magic-mystery-and-environmental-racism>> [accessed 24 May 2023].

dioxide for 'lift[ing] the world because of its ability to brighten', while releasing more than 3 billion pounds of toxic pollutants into the air, water and soil around DeLisle, and plunging the majority Black local community into endemic illness and premature death.⁴¹² The telescopic focus of *Salvage the Bones* compresses these past and present realities of environmental racism, seemingly registering them only on the bodies of characters. The novel's epigraph, a quotation from Spanish poet Gloria Fuertes' poem *Now*, is a statement of this strategy: 'For though I'm small, I know many things, / and my body is an endless eye / through which, unfortunately, I see everything'. Ward's suggestion then is that the Black body continues to be one of the most devastating records of the vicissitudes of capitalism in America, yet it is simultaneously not a record that matters to the state or gets to count politically or even culturally, given the relative absence of the Black experience from the canon of late twentieth century illness narratives.

The novel also critiques the logic of extraction in the more abstract and expansive sense in which this term is employed by literary scholar Christine Okoth. Okoth identifies extraction as an important rubric for approaching questions of race in twenty-first century literature, arguing that extraction 'refers not just to the actual site of resource extraction, but to how that site produces an expansionary and portable extractive logic that acts as the literary formal condition of contemporary Black writing'.⁴¹³ Rather than playing a 'merely diagnostic function, pointing to the sites of extraction across the globe and lamenting the state of ecological damage', literature has the capacity to 'identify the forms that extraction produces and appropriate those same forms in pursuit of both political and literary formal invention'.⁴¹⁴ This perspective has important implications for understanding how Ward's aesthetic and allegorical formulations function as meaning-making political strategies in *Salvage the Bones*.

In her epic lyric poem *Citizen*, Rankine exposes the conditions Ward is writing against, conditions I explored in the previous chapter, where the Black body counts more readily as abject spectacle than political or cultural witness. In that chapter, I focused on carceral sites such as the border and other scenes of police brutality.

⁴¹² Cunningham.

⁴¹³ Christine Okoth, 'The Extractive Form of Contemporary Black Writing: Dionne Brand and Yaa Gyasi', *Textual Practice*, 35.3 (2021), 379–94 (p. 380) <<https://doi.org/10.1080/0950236X.2021.1886705>>.

⁴¹⁴ Okoth, p. 391.

Here, I place the tendency to frame Black death and suffering in the context of a history and tradition of reporting energized by unethical, exploitative images of the non-white Other in sites of military, environmental and humanitarian devastation, a tradition postcolonial literary scholar Upamanyu Pablo Mukherjee evokes in his piercing analysis of the 'allure' of the 'spectre of a tropical "disaster zone"' persisting from the time of the Victorian British Empire.⁴¹⁵ A specific focus on the section of *Citizen* addressing the devastation wrought by Hurricane Katrina, which riffs formally on a selection of 'quotes collected from CNN', suggests Rankine reappropriates found language shaped by this tradition of writing to draw attention to the dehumanizing thread running through much of the media coverage of Katrina (p. 82). In this coverage, the media demonstrates a racialized regime of visualization, seeing criminality while simultaneously refusing to see suffering. In the cacophony of competing voices, emerges a speaker, perhaps a reporter: 'and so many of the people in the arena here, you know / she said, were underprivileged anyway, so this is working / very well for them' (p. 85). The speaker appears to refer to those unable to evacuate who sheltered in the Louisiana Superdome, where the situation deteriorated in the wake of Katrina due to unhygienic conditions caused by illness, overcrowding, lack of supplies, organization and the untimely provision of aid. At the time, media outlets perpetuated reports of a descent into general lawlessness – murder, sexual assault, drug abuse – which were unsubstantiated, decontextualized and later found to be distorted and amplified by hearsay.⁴¹⁶ Rankine places this speculation alongside a chorus of voices seeking validation for their suffering through cumulative testimony: 'standing where the deep waters of everything backed up, / one said, climbing over bodies, one said, stranded on a / roof, one said, trapped in the building', 'the missing limbs, he said, the bodies lodged in piles of / rubble' (pp. 83, 84). Mukherjee's analysis of the construction of Katrina as a tropical disaster zone shows how 'the obsessive production and circulation of stories about rampant criminality and urban warfare in New Orleans immediately after the storm' compounded the suffering of these individuals (strategically depersonalized here by Rankine in an appropriation and critique of an extractive logic) and had a 'direct

⁴¹⁵ Upamanyu Pablo Mukherjee, *Natural Disasters and Victorian Empire: Famines, Fevers and the Literary Cultures of South Asia* (Houndmills, Basingstoke, Hampshire ; New York, NY: Palgrave Macmillan, 2013), p. 22.

⁴¹⁶ Mukherjee, pp. 2–5.

effect on decisions about relief delivery and recovery operation'.⁴¹⁷ In the discriminatory visual regime I have identified, Rankine repeatedly shows how blackness dominates the visual field to the exclusion of all else: 'He gave me the flashlight, she said, I didn't want to turn it / on. It was all black. I didn't want to shine a light on that', 'You simply get chills every time you see these poor indi- / viduals, so many of these people almost all of them that we / see, are so poor, someone else said, and they are so black' (pp. 84–85). Here the literal blackness of the water and disintegrating matter is overlaid and extended into the blackness of the people trapped by the fallout of the storm, inviting the reader to think about the political conditions which establish and maintain the racial dimensions of disaster.

Citizen echoes some of the ways in which Ward too appropriates a racialized regime of visibility in the construction of character and plot in *Salvage the Bones*. Ward reinforces the insularity and remoteness of Esch and her family's social world by framing their blackness as coterminous with invisibility during their few encounters with other white people in the novel. Their insularity acts as an ever-present reminder of the ways in which the infrastructure of racial segregation in this and other Mississippi towns remains largely unreconstructed. In one incident Esch, Skeetah and Big Henry, returning from the store for storm supplies, come across a white couple who have crashed their car. Esch suggests that the speed at which they have taken the road shows 'they not from here' (sic), that the man 'could not have known the road would curl like his streaming blood in this, the trickiest part of the bayou to drive... that the road clung to whatever dry land it could find' (p. 31). The circumstances of the crash seem to suggest his ignorance and disregard for the local landscape while speeding through to his destination elsewhere, which heightens by contrast the intimate knowledge of the area and respect for its dangers demonstrated by Esch, Skeetah and Big Henry. While the stranger is passing through, using the road as a route to his own ends, they are bound there by a confluence of poverty and kinship ties which demand that they live in tune with their environment for survival. When they stop to help, the man pushes his bloody phone into the passenger side window for them to speak to the emergency services, without regard for Skeetah who is seated there. The man's voice is 'loud, as if he is shouting at an old person who is hard of hearing' and when they pull over to wait for

⁴¹⁷ Mukherjee, p. 5.

the ambulance, he 'stares off as if he cannot see Big Henry's car sliding past him, inches away' (pp. 31–32). The man's disregard for the landscape seems to extend to them, as he fails to directly acknowledge their presence, even as they go out of their way to help him. In another encounter, Esch accompanies Skeetah on a scouting mission when he plans to steal de-wormer from some wealthy 'white people who lived in [a] house on the edge of the black heart of Bois Sauvage', on the other side of the woods by The Pit (p. 65). In preparation for the excursion, Skeetah tells Esch 'you got to change...wear something green or brown or black. Don't wear nothing white or tan...you got to blend in' (p. 65). The house is described as 'a blind house with closed eyes', 'all the windows shut and white curtains drawn over them' (p. 71), further emphasizing the sense in which it is separate from the earthy poverty of the rural landscape that, in their camouflage, includes Esch and Skeetah. By the eve of Hurricane Katrina, the house is completely boarded up, as its inhabitants have the means to evacuate. Later, while waiting for Daddy at the hospital after he is injured preparing for the storm, Esch and her brothers share the waiting room with an elderly white couple, 'their clothes...clean and faded along the ironed edges' (p. 132). Esch notes how 'they studied the receptionist station the whole time we were there and never looked over to Big Henry and his hands, Junior's feet that kicked in his sleep as if he were dreaming of falling, and me' (p. 132). The couple seem to refuse to see the things in which Esch sees Junior and Big Henry's own humanity and vulnerability. Each encounter, while small and seemingly incidental to plot, in actuality suggests something about the ways in which whiteness as a structure sits uneasily alongside Bois Sauvage's class of Black rural poor, refusing to see, hear or communicate directly with them, poised to leave them in the wake of Hurricane Katrina. As Esch says, 'before a hurricane, the animals that can, leave' (p. 45). These incidents seem to index a pattern of white flight and withdrawal from scenes of environmental danger, privation and injury, once these occupied landscapes can no longer offer benefits.

In *Salvage the Bones*, Esch's own body is also configured as a site on which extractive logics are symbolically played out. Esch is sexually available to the boys who visit the Pit, a resource they can use for their own gratification. Esch describes how this dynamic begins when she is twelve years old, first with Skeetah's friend Marquise, then with Randall's friend Manny, or 'Franco or Bone or any of the other

boys when they hint' (p. 57). Early on in the novel, it is revealed both that she is love with Manny and that she is pregnant by him. Manny himself treats her without commitment, care or tenderness, ignoring her or avoiding speaking to her in front of others, not even looking at her during their rushed and clandestine sexual encounters (pp. 9, 11, 16, 54, 56, 93, 94, 144). When Esch reveals the pregnancy to him, he reacts with characteristic cruelty. He throws her to the ground, asking "How you come to me saying something's mines (sic) when you fuck everybody who come to the Pit...You think they [your brothers] don't know you a slut?" (p. 203).

Ward's representations of the sexual exploitation of Esch's body mirrors the same logic which directs the excavation of clay on the Pit, resonating too with the wider context of the historical exploitation of the Black female body from the time of the transatlantic slave trade, in ways that echo the medical exploitation I discuss earlier in this thesis. Through Esch's character, the novel considers the consequences of indifferent and violent appetites, asking what it means for Esch to both give and endure in such circumstances. When Marquise first sexually solicits her, for Esch 'it was easier to let him keep on touching me than ask him to stop, easier to let him inside than push him away, easier than hearing him ask me, *Why not?* It was easier to keep quiet and take it than to give him an answer' (p. 22). Eventually though, as with the Pit, there is a reckoning in which rapacious incursions must be quelled and resisted, with Esch physically fighting back against Manny's rejection and disrespect (p. 144).

Big Henry is the only character whose interactions with Esch are shaped by an ethic of care and respect. Esch notes that he has not tried to touch her since he 'used to let me ride on his back in the deep part of the pit, the part that was lined with oyster shells. He used to carry me so my feet wouldn't get cut' (p. 27). At the close of the novel this relation of care opens up the possibility of a future for Esch. As they come together in the wreckage of Hurricane Katrina, Big Henry helps Esch stand, a gesture which symbolizes his role in the novel as steadfast source of support, stating "you wrong...This baby got a daddy, Esch...This baby got plenty daddies...Don't forget you always got me" (p. 255). Care retracts the telescopic focus of the novel to open out onto a wider view of a speculative future, reflecting Levine's arguments about a third kind of ending beyond either indeterminacy and 'uncompromising

finality', one interested in the question of 'ongoing material survival'.⁴¹⁸ Ward's transition between contraction and expansion contrasts with the fixed focus on the scale of the single human lifetime I observed in the kind of illness narratives I explore through the introduction and chapter one of this thesis.

In this way, relations of care emerge as a countervailing force to the dehumanizing, resource and profit-oriented logic of extraction. Representing what Nixon has theorized as an 'environmentalism of the poor',⁴¹⁹ *Salvage the Bones* is willing to work through the complex and often messy relationality between humans, animals and environments to find relations of mutual compromise rather than asymmetry, most obviously perhaps in its treatment of Skeetah and China the Pitbull. Skeetah notably states of his unique relationship to China that 'some people understand that between man and dog is a relationship...equal' (p. 29). In this he echoes the ethos that informs Donna Haraway's *Companion Species Manifesto* (2003). In this manifesto celebrating 'the beauty of dogs', Haraway concedes importantly that at times 'the relationship is not especially nice...full of waste, cruelty, indifference, ignorance, and loss, as well as of joy, invention, labor intelligence and play'.⁴²⁰ This complex, almost contradictory mix of violence and care is perhaps best demonstrated when Skeetah is preparing China to fight another dog in the woods beside the Pit. He croons a litany that weaves a remarkable thread of affects: care, aggression, violence, yearning, love, desire and destruction, moving in all directions:

China white...my China. Like bleach, China, hitting and turning them red and white, China. Like coca, China, so hard they breathe you up and they nose bleed, China. Make them runny, China, make them insides outsides, China, make them think they snorted the razor, China. Leave them shaking, China, make them love you, China, make them need you China, make them know even though they want to they can't live without you, China. My China, make them know, make them know, make them know (p. 175).

However at times, Skeetah's relationship with China seems to be complicated by what Haraway has described as a form of anthropocentric narcissism. Haraway writes that 'the idea that man makes himself by realising his intentions in his tools, such as domestic animals (dogs) and computers (cyborgs), is evidence of a neurosis

⁴¹⁸ Levine, p. 391.

⁴¹⁹ Nixon, p. 145.

⁴²⁰ Donna Jeanne Haraway, *The Companion Species Manifesto: Dogs, People, and Significant Otherness*, Paradigm, 8 (Chicago: Prickly Paradigm Press, 2003), p. 11.

that I call humanist technophilic narcissism'.⁴²¹ After all, Skeetah trains and uses China as a fighting dog; her survival is important because her and her puppies constitute a potential source of income for himself and his family. At key points in the novel China also becomes a proxy for Skeetah's suppressed aggression towards his father: 'China hates him [Daddy]' (p. 3). Here Ward seems to collapse their subjectivities into one, in a way that seems to contravene Haraway's insistence on the reciprocity and difference that must characterize the relation between companion species. In that sense, their relationship at times reflects the logics of extraction always circulating and permeating the atmosphere of the novel. However, at the end of the novel, when China has been washed away by the storm, Skeetah tells his siblings that he cannot stop searching for his dog because 'China's waiting on me', repeating a phrase he utters at the novel's beginning (pp. 35, 240). Her capacity to wait for him is configured as an expression of the strength of their relation and their love, differentiating their relationship from the extractive logics that define encounters between institutions and ecologies in the novel.

China is also the key to another kind of relationality that shapes the text. *Salvage the Bones* is in the most essential sense, a novel about four mothers, the mythical Medea, the mother storm Hurricane Katrina, China and Esch herself. A figure of Greek mythology, Medea is at first what scholars have identified as the archetypal 'helper-maiden' or helpmate, enabling the mythical hero Jason to steal the Golden Fleece in this role.⁴²² Ward's integration of Medea into the novel's imaginary is significant, aligning with critiques of how classics in the Greek and Roman tradition have been weaponized in the service of white supremacy.⁴²³ As Sarah Derbew suggests in *Untangling Blackness in Greek Antiquity* (2022) the study of antiquities, and even the museum architecture in the spaces where they are displayed, has been long animated by the racialized distinction between the primitive and classical.⁴²⁴ Following Medea's radical transformation from helpmeet to enacting infanticidal vengeance, the mothers in *Salvage the Bones* ultimately fight back against their continued devaluation and exploitation, resisting the role of what Joy

⁴²¹ Haraway, p. 32.

⁴²² *Medea: Essays on Medea in Myth, Literature, Philosophy, and Art*, ed. by James J. Clauss and Sarah Iles Johnston (Princeton University Press, 1997), p. 5 <<https://doi.org/10.1515/9780691215082>>.

⁴²³ Sarah F. Derbew, *Untangling Blackness in Greek Antiquity* (Cambridge: Cambridge University Press, 2022), p. 3.

⁴²⁴ Derbew, pp. 52, 56.

James has theorized as the captive maternal. James coins the term to describe 'either biological females or those feminized into caretaking and consumption', unfolding ways in which the US state has historically exploited the 'generative properties of the maternals it held captive', contributing to a Western democracy sustained on 'black frames'.⁴²⁵ In the end China kills several of the puppies Skeetah hopes to sell; although the novel implies Esch will keep her baby, she does finally react to Manny's disrespect with violence of her own after he refuses to acknowledge the child; and as I noted in the early part of this essay, scientists have long connected the increasing intensity of gulf coast storms to the exploitation of the natural environment. In this way the mothers of the novel, like Medea, resist being positioned as merely a resource and instead stake a radical demand for their own place within social life.

Seeking a way to relate to his siblings and make a place for himself within the family, Junior also identifies with dogs, exhibiting the same 'flexibility and opportunism' Haraway argues has been key to the evolution and survival of the species throughout their planetary history. In the novel, Junior is characterised by the same ferality and wildness narratively associated with China. In his book *Wild Things: The Disorder of Desire*, Halberstam highlights importantly how wildness has been 'weaponized' against the Black and Indigenous racialized Other, 'associated with racialized forms of precivilized disorder', providing 'some of the language for what Sylvia Wynter has called the "coloniality of being"'.⁴²⁶ Halberstam demonstrates how, in the white literary canon, 'fantasies of becoming feral fall under the sway of primitivist notions of unspoiled nature or fetishistic desires for a pure otherness', representing problematically charged notions of 'unrestrained temperament'.⁴²⁷ Conceptions of wildness have emerged in relation to colonial, and inherently extractive, orders of being that 'come to tame'.⁴²⁸ It is 'for this reason, to work with the wild is also to risk reengaging these meanings'.⁴²⁹ However, unlike the racist rhetoric that relies negatively on depictions of Black people as animals, Ward's

⁴²⁵ Joy James, 'The Womb of Western Theory: Trauma, Time Theft and the Captive Maternal,' *Carceral Notebooks*, Vol. 12, 2016, pp. 253 – 296, pp. 255 - 256.

⁴²⁶ Jack Halberstam, *Wild Things: The Disorder of Desire*, Perverse Modernities (Durham: Duke University Press, 2020), pp. 7, 9.

⁴²⁷ Halberstam, *Wild Things*, pp. 5, 9.

⁴²⁸ Halberstam, *Wild Things*, p. 4.

⁴²⁹ Ibid.

portrait of what Christopher Lloyd, following Eric Santner, has thought through as the ‘creaturely life’ of the American South,⁴³⁰ is itself animated and transformed by a sense of compassion and love that seeks to bring out what is beautiful about both human and non-human animals even as she troubles these hierarchies through his character. In this way, I suggest Ward vivifies Halberstam’s argument that ‘wildness can escape its function as a negative condition and can name a form of being that flees from possessive strictures of governance and remains opposed to so-called normal humanity’, functioning instead as ‘a form of disorder that will not submit to rule, a mode of unknowing, a resistant ontology, and a fantasy of life beyond the human’, lived as productively fugitive.⁴³¹

Parented by his siblings, of all the characters in *Salvage the Bones* Junior most clearly represents the Pit, bringing together its human and non-human modes of relationality in an alignment with the wild expressed through his physicality. Esch observes him ‘sweating and twitching in his sleep’ as she holds him to her (p. 245). In the novel, he often occupies liminal spaces, ‘squatt[ing] and slither[ing] under the house’, a space that does not scare him the way it ‘always scared [Esch] when [she] was little’ (p. 5). Rather than fear, Junior’s reigning affect is curiosity, particularly towards China’s puppies, and his curiosity extends to a desire to be fully involved in what he sees as the mysterious and dynamic action of his much older siblings (pp. 3, 113, 92). Yet Junior also has his own inscrutable private preferences, games and modes of self-soothing: he goes off into the woods to hunt armadillos, is startled from digging a cluster of holes in the dirt by Daddy’s shouting, or sobs while dropping nails he finds for storm-proofing into the back of Daddy’s truck to hear the ping of metal-on-metal (pp. 13, 88, 186). Junior evokes Halberstam’s reading of Max, the protagonist of Maurice Sendak’s dark children’s picture book *Where the Wild Things Are* (1963). Max is ‘a young and untamed traveler’ positioned in limbo between ‘the domestic world of the family and the wild world of lost and lonely creatures’, whose narrative arc maps both the ‘potential and the dangers of wildness’.⁴³² Ward’s depiction of Junior differs in its demonstration of the ways in which poverty and race complicate readings of agency in the contraposition and movement between

⁴³⁰ Christopher Lloyd, ‘Creaturely, Throwaway Life after Katrina: Salvage the Bones and Beasts of the Southern Wild’, *South: A Scholarly Journal*, 48.2 (2016), 246–64 (p. 248).

⁴³¹ Halberstam, *Wild Things*, p. 8.

⁴³² Halberstam, *Wild Things*, p. 4.

domesticity and wildness. Unlike Max, Junior does not seek out the wild in a rejection of parental authority but adapts to it out of loss, trauma and parental absence.

In the novel, Junior's affinity with dogs presents differently to Skeetah's. In Skeetah this form of relation manifests exclusively through China, who takes precedence seemingly at times over his own family. In the opening chapter, Esch notes that Skeetah ignores Junior's pleas to see the puppies, 'because he is focused on China like a man focuses on a woman when he feels that she is his, which China is' (p. 3). Their relationship is often configured in terms of the intimacy and possessiveness associated with heterosexual partnership: after giving birth China 'walks past Skeetah, licks his pinkie' and 'it is a kiss, a peck' (p. 17), then she looks past Skeetah to where the family is gathered at the door and 'bristles' at their presence, as they leave Skeetah 'refastens the curtain' of the shed behind them, excluding them from the privacy of the post-natal scene. Like Haraway, Halberstam has written about the libidinal dimensions of the bonds between humans and their domesticated pets. Junior, in contrast, does not form an equivalently gendered or hierarchical dyad with any one dog, and is rather represented in the text as part of the pack of stray dogs which adopt the Pit as a temporary home. These dogs seem to emerge from the very ground itself, are 'mottled the color of dried sticks, of leaves sinking into earth and darkening', and so their connection with a natal or parental point of origin feels as tenuous as Junior's (p. 88). Esch describes how 'they followed Junior around the Pit, licked his face when he had it out with Randall over not wanting to take a bath, or because he'd failed another test (p. 88). They seem to console, even attempt to reconcile him to what might be understood as the limitations and indignities of being a young human boy. In an extension of earthy symbolism, 'they [boil] around him like a rain-swollen creek when he'd run out into the bare yard...and cry', 'nested with him under the house' (p. 88). They are his 'mutts', 'his mangy family member[s]' and by opening up the concept of family in this way, the novel enacts what Halberstam articulates as 'a refusal to observe the proper distinctions between humans and animals and between different kinds of animality'.⁴³³ Like Sendak's Max, Junior's developmental 'immaturity' seems key to the confusion of these boundaries between the wild and the domestic. Elsewhere he is poetically rendered as 'forever the puppy

⁴³³ Halberstam, *Wild Things*, p. 4.

weaned too soon' (p. 89). His improvised family is interrupted by the arrival of the territorial China, who runs the stray dogs off in the consolidation of her position, a situation which also reflects the dominance and sway of certain modes of organised relation over others which are more dispersed, harder to define - perhaps wilder.

This idea of Junior as 'forever the puppy' also suggests something about how wildness disrupts the normative flow of temporality. For Halberstam, feral subjectivity occupies an indeterminate third space between 'attachment and detachment' characterised by 'indifference to the human',⁴³⁴ which I suggest might include an attention to time. Junior operates in a space of curious timelessness, evoked through language as simultaneously both very old and very young: 'there are bruises under his eyes, so he looks like a little brown nervous man' and his back when he sleeps reminds Esch of 'a young turtle's shell, so thin it would snap if stepped on' (pp. 184, 197). These images bring together ideas of longevity with fragility and vulnerability, connecting with the sense that Junior exists in a temporality that somehow confounds both age and youth. He has little memory of the past and it is implied that he also thinks little of the future. Esch wonders if he even remembers Mudda Ma'am, an elderly neighbour who watched him and other children for extra money while their parents were at work: 'He never talks about her, never says her name even when we walk down to the park and see her wandering among her azaleas like a child losing at hide-and-seek', affected by symptoms of increasing dementia (p. 91). In fact, there is a question about whether,

'Junior remembers anything, or if his head is like a colander, and the memories of who bottle-fed him, who licked his tears, who mothered him, squeeze through the metal like water to run down the drain, and only leave the present day, his sand holes, his shirtless bird chest' (p. 92).

Junior's evacuated sense of memory mirrors aspects of Mudda Ma'am's experiences of dementia; they are curiously inversely aligned, she configured as increasingly childlike, he as somehow aged. 'Wandering' among her azaleas, she echoes Junior's outdoor rambling in a way that orients her, in her advancing illness, away from normative subjectivity towards the disinhibition of wildness. Wildness, through forms of temporal suspension and incommensurability, also conceptually connects subjectivities beyond the norm with a queer relation to time which echoes the

⁴³⁴ Halberstam, *Wild Things*, p. 148.

temporalities I explore in chapter one. Subject to racialization and poverty, Junior and Mudda Ma'am already, as Freeman and Bradley have argued, queer normative conceptions of the family through their extended and diffuse networks of improvised and fugitive caring.⁴³⁵ There is significant literature that demonstrates that racialization and poverty act on the body in particular ways, producing experiences analogous to those Ward represents in Junior and Mudda Ma'am's characters. The climate of poverty and racialization thereby also works to disrupt time, opening them up to the same kinds of unexpected accelerations and regressions through time that both Sedgwick and Samuels have identified as queer, or crip, time travel. Citing Pete Coviello, Halberstam too notes the queer untimeliness nestled in the concept of wildness, as a term which has historically eluded some of the regulatory force of classification and categorization attending nineteenth and early twentieth medical and sexological discourses.⁴³⁶

If wildness is untimely, and queerly so, it also provides the ground to explore the 'complex pattern of dead and living things'.⁴³⁷ For Junior the distinctions between dead and living things, already unstable in the space of the Pit, are further blurred in ways that are possibly threatening and profane. After Daddy loses three fingers in the tractor accident preparing for the storm, Junior returns to the scene to retrieve the wedding ring from the severed and decaying fingers, carrying the ring 'small and maroon, the size of a quarter', and 'covered in blood' in his pocket (p. 185). Junior takes the ring because 'she [his mother] gave it to him [his father]', he 'wanted it...her' (p. 185). The ring's connection with deathliness and abjection is precisely what draws Junior to it, to him the bloody object is resonant with aura of his lost mother. The reader may also recognize the ways in which its bloodiness is suggestively consonant with the description of the last time his mother was physically present at the Pit, 'dragged...from the bed to [Daddy's] truck' to the hospital, 'trailing her blood' (p. 2). Where Junior is indifferent, his siblings are mostly disgusted: Randall tells him 'that's so. Nasty. You. Could've. Got. A disease', emphasizing his message with physical discipline, and Esch throws up after cleaning the ring (p. 186). However, Skeetah laughs when he hears, pronouncing Junior 'dead

⁴³⁵ Bradway and Freeman, pp. 15–16.

⁴³⁶ Halberstam, *Wild Things*, p. 11.

⁴³⁷ Halberstam, *Wild Things*, p. 13.

wild' with something like approval or pride. After all it is Skeetah who identifies Junior among the 'savage' things on the Pit, who know death intimately.

The Figure of the Undying

Arguing for a grassroots environmentalism of the poor, Nixon warns that there is more at stake in the question of ecological devastation than simply material wealth. Extractive capitalism attempts to 'discount spiritualized vernacular landscapes as if [they] were uninhabited by the living, the unborn, and the animate deceased'.⁴³⁸ He invokes John Berger, who strikingly formulates the idea thus:

'the living reduce the dead to those who have lived...until the dehumanization of society by capitalism, all the living awaited the experience of the dead...by themselves the living were incomplete. Thus living and dead were interdependent. Always. Only a uniquely modern form of egoism has broken this interdependence. With disastrous results for the living, who now think of the dead as the eliminated'.⁴³⁹

Investigating environmental racism in Death Alley, Louisiana, the Goldsmiths-based human-rights violation research agency Forensic Architecture (FA) present a reversal of this logic. The research agency have documented how, in a cluster of majority Black communities where the heavily industrialised 'Petrochemical Corridor' overlays a territory formerly known as 'Plantation Country', the presence of the dead is being mobilized to protect the health and wellbeing of both the living and those yet to be born.⁴⁴⁰ The former plantation sites, now repurposed as industrial, or industrial-adjacent monoracial communities, are also the sites of cemeteries that constitute the final resting places of enslaved people. In their short film and accompanying dossier, FA asks the viewer 'how might we recover the memory of the hundreds, if not thousands, of missing cemeteries at risk of desecration?'⁴⁴¹ FA shows how the efforts of fenceline community activist group RISE St. James to protect these

⁴³⁸ Nixon, p. 17.

⁴³⁹ Nixon, p. 18.

⁴⁴⁰ Forensic Architecture, 'Environmental Racism in Death Alley, Louisiana', *Forensic Architecture*, 2021 <<https://forensic-architecture.org/investigation/environmental-racism-in-death-alley-louisiana>> [accessed 8 February 2023].

⁴⁴¹ Forensic Architecture.

ancestral sites is also an action that protects the living from the injurious effects of the further expansion of the petrochemical corridor.

This is deeply significant for the readings of the texts I have offered in this chapter. Building on Boyer's synthesis of life and death to formulate the condition of survivors of cancer treatment as that of 'the Undying', and on artist Martin O'Brien's conceptualization of the chronic or terminally ill living beyond their prognosis in an extended temporality he calls 'zombie time', I argue that far from treating the dead as 'the eliminated', the protagonists of both *Salvage the Bones* and *Body Toxic* integrate the dead and death into their lives as the ground for their own survival in much the same way demonstrated in the FA dossier.⁴⁴² Living in the transitive, future-less temporality of the fugitive in sacrifice communities consigned by the state to 'slow death' – marked for wearing out –⁴⁴³ those Ward and Antonetta narratively represent find ways to mobilise this relation to death in the care of their collective identities and continued existence.

Salvage the Bones offers the most arresting example of this practice in its third act climax. Hurricane Katrina rages, bursting the banks of the man-made clay quarry lake on the Pit, flooding the main house where Esch and her family have intended to wait out the storm. The rising water forces them into the attic and continues to rise, evoking among them the memory of another family: 'fourteen of them drowned in [Hurricane] Camille. In their attic' (p. 229). It is first the spectre of this dead family, then the 'hollow carcass' of their deceased grandparents' house that saves them (p. 231): the former by compelling them with the urgency with which it is vital to move, the latter by offering a means of escape and shelter from the devastation of the weather. Although long dead, Mother Lizabeth and Papa Joseph have continued in various ways to care for their wellbeing, their empty house providing for the family both before and during the storm. Poignantly, Esch reflects 'the house [of their grandparents] must have been built on a small hill, and we never noticed it' (p. 233), suggesting how easily the role of the dead in the lives and care of the living can be dismissed and overlooked in the way that Nixon and Berger have argued.

⁴⁴² Nixon, p. 17; *Forensic Architecture*.

⁴⁴³ Berlant, 'Slow Death', p. 761.

In ways I already endeavoured to illustrate in the previous section, *Salvage the Bones* is constantly showing how cherishing death is synonymous with cherishing life. In the novel, Skeetah treats Esch with incredible care and attention. He notices without being told the things about her that others fail to see: her sexual encounters with the boys who come to the Pit, the painful dynamics of her unspoken love for Manny, and most importantly perhaps, her pregnancy, advocating for the future of her child by telling her cryptically as the storm strikes that “everything need a chance...Everything” (p. 214). His sustaining care for her is underpinned by the memory of their dead mother, who he sees resurrected and rematerialized in Esch’s features: “you look like her. You know that?...You not as big as her, but in the face. Something about your lips and eyes. The older you get the more you do” (p. 222).

Boyer further demonstrates the ways in which death haunts the survivor in *The Undying*. Somewhere towards the end of the book after enduring her chemotherapy, Boyer recognises herself ‘as one of the undying’.⁴⁴⁴ As her hair falls out, her fingernail and toenails peel away and fall off and the nerves begin to die in her extremities, Boyer feels as if she is ‘probably dead, haunting the earth’s slightly familiar territory’.⁴⁴⁵ This word – undying – seems initially to be celebratory, connoting a victory over death and mortality, but, as Boyer demonstrates, it is an empty, pyrrhic sort of victory. Boyer describes a woman who ‘has never really returned from the cancer she had thirty years ago...she goes to work and comes home each day in disassociated blankness, and because she has to work for a living, must go there once more in the morning and pretend that she exists again’.⁴⁴⁶ Boyer learns ‘that feeling like you are dead can have its mechanical cause in certain kinds of brain damage, such as the kind...endured from chemotherapy’.⁴⁴⁷ The dissociative state of feeling not quite alive emerges as the cost of surviving cancer, meaning that to exceed the horizon of your own death in this way is to be transformed into something other than you were. Citing the Roman poet Lucretius’s argument ‘that we can die inch by inch’, Boyer theorises that the experience of the undying is a creeping, insidious death which slowly overcomes the body.⁴⁴⁸ I was

⁴⁴⁴ Boyer, p. 202.

⁴⁴⁵ Boyer, p. 142.

⁴⁴⁶ Boyer, p. 141.

⁴⁴⁷ Boyer, *The Undying*, p. 144.

⁴⁴⁸ Boyer, p. 142.

struck again by how this speculation links with O'Brien's metaphor of the zombie, evoking the imagery of an invading agent slowly overcoming the "host" body. However, unlike O'Brien, Boyer is emphatically more ambivalent about the potential of this new state of being. She writes, 'the rational explanation of why I feel dead half the time does little to mediate the irrational horror of existing in a way that I feel I don't exist'.⁴⁴⁹ Her passage ends in the form of a litany or chant, which in its evocation of ritual materialises the undying as a collective rather than singular state: 'here we are, here I am, alone and myself, half of me fallen off, half of us gone, and all of us ghosts or the undying ones, half of us dead and half of myself nowhere to be remembered or to be found'.⁴⁵⁰

I connect Boyer's meditation on the life-in-death that constitutes living out one's prognosis to O'Brien's striking articulation of the conditions of zombie time. As an artist living with cystic fibrosis, O'Brien's recent work has also thought through what it means to exceed the time of your prognosis. He writes,

The life expectancy for someone born in 1987 with CF is 30 years old; this information was plastered all over charity appeals for the CF Trust. I was sure I would die at 30. The temporal movement towards this age was the defining condition of growing up for me. Death was an obsession. I reached and surpassed 30. Death did not come for me. In attempting to understand what it means to live longer than expected, I formulated the notion of zombie time. This is the temporal experience of living on when death was supposed to happen.⁴⁵¹

Zombie time insists on a 'different temporal proximity to death'.⁴⁵² O'Brien compares this state to that of the Hollywood zombie 'both dead and alive'. Halberstam aligns with this reading, suggesting 'the popularity of the metaphor of the zombie...evidences deep anxiety in contemporary Euro-American culture over things that refuse to die, on the one hand, and things that occupy a realm between life and death, on the other'.⁴⁵³ He links the figure of the zombie to questions of ecology by way of reference to 'the daily news of disappearing species, of new viruses and threats to complex ecosystems, [which] puts the larger category of life into question and raises the possibility that earth is already in a zombified condition of living

⁴⁴⁹ Boyer, p. 144.

⁴⁵⁰ Boyer, p. 144.

⁴⁵¹ O'Brien, p. 3.

⁴⁵² O'Brien, p. 3.

⁴⁵³ Jack Halberstam, *Wild Things*, p. 148.

death'.⁴⁵⁴ While I am invested and compelled by O'Brien's mobilisation of the zombie as metaphor, I mediate this usage with reference to Luckhurst's cultural history of the zombie which insists on tracking the figure's culturally specific origins. He notes, 'the word originates from a belief system that is a product of the slave trade plied between Africa, Europe and the Americas from the sixteenth century onwards'.⁴⁵⁵ 'The zombie is rarely stable', and maybe, I suggest productively so 'because it is a syncretic object'.⁴⁵⁶

O'Brien's thinking on zombie time expressed itself in a new iteration in 2021 as the 'semi-fictional' group 'The Last Breath Society' around which he bases a series of performance artworks.⁴⁵⁷ The Last Breath Society is a community of those newly proximate to death in the wake of the COVID-19 pandemic, which expands the ranks of the sick to include the previously able-bodied, the economically insulated, the young the old, the queer and even members of the establishment. Taken together, Boyer and O'Brien's thinking articulates importantly what it is to 'exist in a liminal temporal space'⁴⁵⁸ of devalued and embattled embodiment. This space has the potential to be deeply lonely and isolating: O'Brien highlights the fact that those with CF 'are unable to be in a room with any others who share the condition. We must remain six feet apart from one another when outdoors'.⁴⁵⁹ Through Boyer's manifesto of the undying, I also note the continuous threat of depersonalised isolation. In the face of such threat, it is important for both to construct a community, even in the most abstract and speculative sense and as fugitively and elusively as they do, in an act of care for themselves and others.

I was struck by how aptly Boyer and O'Brien's formulations of a state of surreal living-death align with how Antonetta characterises the 'pineys' in *Body Toxic*. Like the uncanny 'dwarf forests' growing impossibly on 'sandy soil' after which they are named, the 'piney' people are positioned somewhere between the real and the surreal (p. 154). Antonetta relates the folk accounts which construct the pineys as mythologically monstrous anachronism, 'inbred...troglodytes...pale hairless but

⁴⁵⁴ Jack Halberstam, *Wild Things*, p. 148.

⁴⁵⁵ Luckhurst, *Zombies: A Cultural History* (London: Reaktion Books, 2015), p. 14.

⁴⁵⁶ Luckhurst, *Zombies*, p. 14.

⁴⁵⁷ O'Brien, p. 4.

⁴⁵⁸ O'Brien, p. 4.

⁴⁵⁹ O'Brien, p. 4.

recognizably Neanderthal children...[who] practiced cannibalism' (p. 154). In more grounded terms, the 'Pine Barrens spirit' is further defined as an attitude of 'embracing... the unworkable...[in] a region of putting up and shutting up, where nothing is guaranteed' (p. 165). The pineys are the descendants of those 'who came by choice to the dragon's place, [a] region of boglands and difficult if not impossible soil', but nevertheless 'made their homes' (p. 165). Migrating to the area under similar circumstances, Antonetta's grandfather also 'had a bit of the piney about him', taking on, and then passing on the characteristics of the people of this 'hard landscape he'd chosen' (pp. 10, 41, 156). She describes how he loved to eat eels, normally thrown back into the water when caught by others. These eels evoke something possessed 'writh[ing] like full gospel people' before her grandfather 'hung them, skinned in [the] kitchen, like soft bloody ropes', in demonstrable relish of the gory and uncanny (p. 156). In this way, the text makes a connection between a sensibility aligned with images and tropes of horror, and the piney capacity to survive which 'built [their] houses and sank [their] well[s]' (p. 156). Antonetta's descriptions of cultures of salvaging – 'our local dwellings were known for their scavenged materials' (p. 165) – resonates strongly with *Salvage the Bones*, suggesting a parallel between the self-proclaimed 'savages' on 'the Pit' and Antonetta's family of piney outcasts, living on detritus at the limits of the tolerable. Collectively, the images employed contribute to a sense of a community situated between the space of the Human and the animal that Halberstam defines in his thinking on wildness. This impression is heightened by the parallel unfolding of another kind of myth in the form of the Jersey Devil, 'a fabulous killing creature...with batwings and claws and horselike head' in one account, or the head of 'a ram or a collie dog, crane's legs, hooves and a short tail' in another (pp. 128, 156). Born supposedly in 1735, the myth of the Jersey Devil shares in the same impossible continuity and longevity attributed to the pineys. Comparisons arise here between Antonetta's grandfather and the Devil: like the mythical beast, Louis Cassill is a thirteenth child of uncertain provenance cast out by his mother. The affinity between the Cassill pineys and their Devil totem is affirmed by the fact that they 'never organize posses or mobilise dogs and militias to hunt their Devil as outsiders did', instead tolerating 'incursions into [their] space' (p. 167). This complicity has a darker aspect, as it absorbs Grandfather Cassill's attempted sexual assault of Antonetta into the family silence.

In the text, the pineys are as equally durable as the immortal chemicals which permeate the soil and water of their home. As Antonetta observes, the extended half-lives of plutonium-239 (50,000 years), cesium-135 (6 million years) and uranium-238 (10 billion years) span temporalities that even the most speculative cryonics can only dream of, decaying in radioactivity and immortality (p. 209). However, the pineys have as yet endured in this place longer. Through their mythological idiom of living death, the pineys emerge as impossible, wild, mutated things, neither human nor animal, and thus able to survive in this barren space. Living in O'Brien's zombie time, they appear to 'keep moving but not towards anything, just for the sake of moving. No goals, only desires. No plans only reactions...know[ing] death and breath[ing] in death' in from their tainted environment.⁴⁶⁰ Attentive to the racialized histories of the cultural figure of the zombie which both Luckhurst and Halberstam mindfully draw out, I note the traces of stigma in Antonetta's representation of the pineys and their hybridity. However, she also conveys the sense in which this stigma is reclaimed, following the traditions of embracing queer and crip identities, with the pineys embodying and celebrating the radical 'impropriety, performativity, and criminality' Moten explores as features of fugitivity.⁴⁶¹

Conclusion

The death narratives contained within *Salvage the Bones* and *Body Toxic* exhort the reader not to consign the sacrifice communities that they represent to the status of 'the eliminated',⁴⁶² but to recognize them, in John Berger's words, as the living world's 'ultimate future'. In her monograph *Narrative in the Age of the Genome*, literary scholar Lara Choksey asks 'in a toxic present, where the periphery is a site of dumping and extraction, attending to the ways that narratives produced within it disturb and resist these processes returns us once more to the question of time. In what forms of temporality can these sites find purchase outside the perpetual present that is imposed by these practices? What futures are possible...?'⁴⁶³

⁴⁶⁰ Martin O'Brien and Gianna Bouchard, 'Zombie Sickness', in *Routledge Handbook of the Medical Humanities*, ed. by Alan Bleakley (Routledge, 2019), p. 263.

⁴⁶¹ Harney and Moten, p. 50; Shulman, p. 283.

⁴⁶² Nixon, p. 17.

⁴⁶³ Lara Choksey, *Narrative in the Age of the Genome: Genetic Worlds*, Explorations in Science and Literature (London: Bloomsbury Academic, 2021), pp. 154–55.

Reading texts by Svetlana Alexievich and Jeff VanderMeer against an 'eschatological sense of an approaching end' Choksey counters 'the idea that new forms of time are no longer possible – and that time in some way has already come to an end' by offering the 'weird and toxic animacies between humans, nonhumans and the substances that move through them and transform them' as a form of life that persists fugitively beyond the conceptualization of the end time and thus the end of the Human and the subject.⁴⁶⁴ Initiated through toxicity into a space between life and social/bodily death, these ecologies Choksey describes, being in Moten's words 'more and less than one',⁴⁶⁵ move from the periphery of the world system into its center as its ultimate future. Through their narratives, Antonetta and Ward explore how the politics of toxicity and extraction work similarly through porous, sensing bodies to unmake the Human. Discarded in the function of capital, the life that remains finds fugitive ways of being by reclaiming and mobilising conceptions of "savagery", wildness and un/death. Proximate to both life and death but belonging fully to neither, they create new modes of *going-on* in the care for their own survival. The characters in these texts embrace complex racial histories, on their way to an "outlawed social life of nothing" they resonate with Halberstam's assertion, which I refer to earlier in this thesis: 'there are spaces and modalities that exist separate from the logical, logistical, the housed and the positioned'.⁴⁶⁶

⁴⁶⁴ Choksey, p. 155.

⁴⁶⁵ Harney and Moten, p. 95.

⁴⁶⁶ Halberstam, 'The Wild Beyond', p. 11.

Thesis Conclusion

Bringing the interrelated threads of this thesis together, I find myself turning to Dodie Bellamy's *When the Sick Rule the World* (2015), a text which disrupts genre in interesting ways by blending essay, memoir and story in its fragmented constituent parts. While Bellamy's text addresses the themes of illness, death, environmental toxicity and transgressive relationality that have preoccupied this project, it does so in very different ways to the texts considered thus far. The titular essay 'When the Sick Rule the World' for example, offers a representation of the politics of environmental toxicity strikingly different in tone and focus to Antonetta's *Body Toxic* and Ward's *Salvage the Bones*, while elsewhere in the book 'Phone Home' – which I will not consider at length in this conclusion – returns to themes of terminal cancer and end-of-life care with which this thesis started. It does so slantwise, queerly, mediating the experience of Bellamy's mother's decline and death from lung cancer through the childhood memory of watching ET, and thus evincing the kinds of regression, temporal incommensurability I draw out as a feature of queer time travel in illness in chapter one.

In 'When the Sick Rule the World', Bellamy describes the accretive impact of chemical sensitivity and how it changes the relationship between herself and body in ways that echo interventions by Antonetta, but also Chen in their chapter 'Lead's Racial Matters'. It opens with Bellamy's consultation with a naturopath, who assaults her with a 'wall of questions':

Have you often had to lower the regular dose of prescription or over-the-counter medication or herbal supplements because you were too sensitive to normal doses do you avoid caffeine in the afternoon or altogether because it can keep you up at night have you experienced adverse reactions to medications if so what happened do you smell odors when others can't what kinds of odors do you have a sudden onset of symptoms headaches skin rashes nausea shortness of breath etc on exposure to chemicals mold dust pollens or other environmental allergens what symptoms please list all the chemicals you get a reaction to when do you last remember feeling really great describe your residence when your illness began...describe your work environment when your illness began...⁴⁶⁷

⁴⁶⁷ Dodie Bellamy, *When the Sick Rule the World* (South Pasadena, California: Semiotext(e), 2015), p. 25. Further references to this book are given in the text.

Bellamy reproduces these questions, which continue over two pages of unbroken, unpunctuated text, evoking in the reader the same overwhelming feelings of 'devastat[ion] and hopeless[ness]' they create in her: it is likely the reader too will 'have lived in and worked in and gone to so many bad places' (p. 27). Her encounter with the naturopath is an initiation into the parallel world of those she calls 'the sick'. She joins a 'listserv' – an electronical mailing list – for 'the sick' and attends one of their monthly meetings, becoming a somewhat ambivalent member of this underground community (p. 28). Bellamy's essay is a series of matter of fact, yet ironically inflected observations about this community which highlight the surreal aspects of its cultures and practices, placing her between the position of participant and outsider. Those attending the meetings of 'the sick' must use 'fragrance-free soap, lotion, shampoo, hair conditioner, gel, deodorant...', and 'no fabric cleaner or clothes that have been dry cleaned' (p. 28). 'The sick rinse their bodies with vinegar and dry off with a blowdryer to prevent mold growth...travel in used cars which they sell to one another...that have never been detailed [professionally cleaned using industrial products], that have been aired out and cleared with activated carbon felt blankets and zeolite' (p. 30). They use 'organic cotton bedding' and hang curtains made of soft mesh metal from their windows and canopy beds to protect them from electromagnetic fields (EMFs) (pp. 32, 34). They live itinerant lifestyles, moving from house to house, sleeping in cars, steel utility trailers with 'non-fragrant wood', in homemade tents and even outdoors, unable to work or 'tolerate' being indoors as 'indoor air is a chemical soup' which provokes adverse reactions (pp 30, 33–34). Despite her implicit mockery of this strange cult of sickness, Bellamy is herself experiencing something similar and cannot therefore deny the veracity of the suffering which drives 'the sick' to such lengths. Like them, she is desperate for relief from an endless series of debilitating yet indeterminate chronic symptoms, which places her, like the sick, outside of the temporal and diagnostic sphere of conventional medical care.

If this thesis has focused on literatures emerging from an extended contemporary period coterminous with a neoliberal periodicity, spanning the last thirty years, 'When the Sick Rule the World' calls attention to the contemporary contexts and dynamics of illness in a more historically immediate sense. It proleptically represents cultures of health, illness and death that have become familiar in the wake of the 2020

COVID-19 pandemic in which sickness became a feature of everyday life and discourse for the otherwise able-bodied majority in western industrial society, rather than a state of exception for the impoverished and racialised few. Bellamy's account of 'the sick' describes a range of diffuse symptoms, which in Rose's words apply to both 'everyone and no-one' (*Love's Work*, p. 78): 'headaches, burning eyes, asthma symptoms, stomach distress/nausea, dizziness, loss of mental concentration, muscle pain...fever, loss of consciousness, motor skills and memory...impaired' (p. 29). While Rose is describing the indeterminacy of the 'cancer personality' as defined by the field of alternative medicine, both her words and this sense of vague, non-specific debility resonate with experiencing bodies navigating the boundaries between health and debility in the wake of the pandemic. During the pandemic, alternative medicine and wellness cultures bridged the gap between individual uncertainty and established clinical protocols in the ways that both Bellamy, Rose and others in this thesis describe; significantly, these alternative wellness cultures have demonstrably continued to operate into the present with the same evacuated politics these texts highlight and critique, reinforcing the neoliberal logic of care and an occlusion of structural inequality which I have argued tended to dominate archetypal narratives of cancer and other illnesses.

I was struck by the ways in which Bellamy's representations of 'the sick' resonate with Boyer's imagined community of sick and 'undying' stretching over time discussed in chapter three of this thesis. While her focus is not the abstract threat of EMFs, Boyer describes a changing landscape of health, wellness, illness and death similarly mediated by technology: 'once we were sick in our bodies...now we are sick in a body of light'.⁴⁶⁸ She acknowledges that 'in a world where so many people feel so bad, there's a common unmarked and indefinite state of feeling ill that provides, at least, membership in a community of the unspecified' and 'those who endure that suffering must come together to invent it...[that] the sick but undiagnosed have developed a literature of unnamed illness, a poetry of it, too, and a narrative'.⁴⁶⁹ Boyer's underclass of sick and 'undying' encompasses both the very specific sickness of cancer and an unspecified malaise that seems to reflect the condition of the 'sickening' world itself.⁴⁷⁰ Bellamy's surreally rendered 'sick' are also something

⁴⁶⁸ Boyer, p. 15.

⁴⁶⁹ Boyer, p. 18.

⁴⁷⁰ Boyer, p. 35.

like O'Brien's 'semi-fictional' 'Last Breath Society', initiated into a new relationship with death and their own physicality 'because of their proximity to it'.⁴⁷¹ As discussed in the previous chapter, O'Brien, an artist living with Cystic Fibrosis (CF), suggests COVID-19 opens up a space of fluidity and confluence, both psychological and physiological, between those living with CF and those living with and in the time of the virus, creating the conditions for the expansion of the 'Last Breath Society' which elides easy distinctions between the sick and the well. In this new landscape, it is sensitivity to the destructive potential of the cough, rather than sensitivity to smells as in Bellamy's essay, that unites the sick: 'the cough speaks directly to the flesh of others, like a warning siren, triggering bodily memories of illness'.⁴⁷² However the cough for O'Brien is also a call of shared experience: he 'can recognise a CF cough anywhere, the raspy, moist, phlegm filled sound which vibrates through the floor'.⁴⁷³ Both Boyer and O'Brien develop the vision of sickness and dying experienced in collectivity which I have explored over the course of this thesis, constructed through identification rather than exception, thinking ways to 'be together when we clearly cannot be together', creating a space in which those subject to conditions outside of their control 'can decay together'.⁴⁷⁴ One of the interventions of this thesis has been to read across these and other texts that offer critiques and alternatives to narratives of illness aligning with individualistic, neoliberal conceptions of health and care, troubling the assumed distinction between life and death nestled within the concept "end-of-life", in order to draw attention to representations of the *space-between* of deathly life. Bellamy's is an important text through which to mediate these concluding thoughts as it takes questions I have been considering with reference to an extended contemporary period and resituates them within conditions recognisable in the immediate present.

However, unlike Boyer and O'Brien and the other writers I have engaged over the course of this thesis, Bellamy offers a representation of the experience of 'the sick' as overwhelmingly isolating, taking the idea of individual self-management to its extreme, in so doing exposing the emptiness of this rhetoric for critique. While Boyer and O'Brien's societies of the sick and un/dying are given shape through a textual

⁴⁷¹ O'Brien, p. 4.

⁴⁷² O'Brien, p. 5.

⁴⁷³ O'Brien, p. 5.

⁴⁷⁴ O'Brien, p. 6.

imaginary, 'the sick' in Bellamy's essay are less a community than a group briefly brought into alignment. One of the essay's key themes is a preoccupation with boundaries and (the fear of) contamination, which often gets expressed through rituals that symbolically, rather than actually, maintain ontological hygiene. This is very different, for example, from the boundary crossing identification I discuss in chapter one, which Sedgwick articulates in her experiences of breast cancer and in forging a sense of queer kinship with male friends dying from AIDS. In Bellamy's essay, sickness does not involve attempting to stay in contact with potentially transgressive entanglements or shared experiences of bodily excess. Rather, it necessitates a withdrawal and a retrenchment of the boundaries between self and other.

After joining the listserv for 'the sick' and attending her first meeting, Bellamy is subject to such scrutiny. When she arrives, she learns she has "to be sniffed first", 'deep noisy sniffs': the two women at the threshold smell something in her hair – the extra virgin olive oil she has used on her scalp – which gives one a headache, so she is required to cover her hair with two bandanas (p. 28). During the presentation, Bellamy changes seats to get a better view, and 'the woman [she] sit[s] next to looks stunned and immediately gets up and moves across the room', to maintain distance (p. 31). Bellamy learns that maintaining distance is an important part of being sick and imitates this behaviour: 'when someone wearing perfume lies down next to me in yoga I get up and move. When someone sits beside me in a theatre wearing perfume I get up and move' (p. 29). Yet 'when a student comes to class wearing perfume' and her 'nose runs', 'there's nowhere to move to' and nothing to do, which demonstrates the limits of this avoidant behaviour and how it involves a rejection of the realities of social and public life, as well as social connection (p. 29). During her earlier consultation, the naturopath demands a radical extension of this practice, telling her "you are very sick, your apartment is making you sick. You have to move" (p. 27). When Bellamy mildly raises the realistic question of what to look for in a new apartment, the naturopath 'stares back...confused and suspicious', repeating "you can move, I know you can move. Many patients have moved and they felt so much better" (pp. 27–28). The whole surreal exchange reinforces the sense that moving itself is the object, that the practical or indeed financial realities should be irrelevant for 'the sick'. It is clear to Bellamy, once she becomes acquainted with the group,

that many of 'the sick' have taken up this practice, living isolated, itinerant lives: 'sick Bonnie...has moved from house to house but cannot find one she can tolerate...she used to sleep in the kitchen or outside ...until the neighbours in the cul-de-sac began to spray pesticides'; 'sick Rhonda and her husband...[sleep] in their van, which is parked on five acres belonging to a sick friend'; 'a former psychologist, sick Nina has been living in her van for three years...there is no place to cook and no place to rest, which has made Nina even sicker'; 'sick Patrice ...spent a couple of winters freezing on friends' screened-in porches', but now rents an apartment 'so she could have a bathroom to use though she still sleeps outside' (p. 33). Sick Rhonda does not even see her three sons, presumably as Bellamy speculates because 'the well are too rich, too funky, neurotoxic deodorant off-gassing from pores' (pp. 32–33). Bellamy ends the essay imagining 'sick Elizabeth...cradled in the impermeable membrane of her galvanised steel shed', isolated and contemplating suicide as an ultimate act of "taking care" of the problematic: 'with an organic rope hanging is totally non-toxic' (p. 36).

What Bellamy's essay also brings importantly to light is something that I have endeavoured to explore over the course of this thesis: the ways in which the sick role, ostensibly neutral and universal, is often classed and racialised. The beginning of 'When the Sick Rule the World' takes as its epigraph the final line from Sylvia Plath's poem 'Tulips', decontextualised: 'and comes from a country as far away as health'. In this well-known poem, the tulips – 'opening like the mouth of some great African cat' – are racialised in their rude vigour: representing life as a state of intolerable wildness, excitation, complexity and relationality, they are contrasted unfavourably by the poem's speaker with the sterility and safety of a whitewashed hospital ward.⁴⁷⁵ Bellamy's well-chosen epigraph sets up the ways in which, throughout her essay, the other is consistently configured as outside of the space of sensitivity and care, which is also necessarily a space of whiteness. The reader's initiation into the world of 'the sick' is mediated by the naturopath, who is 'young, small, blond' and with her 'little girl's voice' appears as an asexual figure (p. 27). The kinds of transgressive, embodied encounters with the other which I explored in chapter one as a condition of queer relationality and kinship have no place here: the

⁴⁷⁵ Sylvia Plath, 'Tulips', *Poetry Foundation* <<https://www.poetryfoundation.org/poems/49013/tulips-56d22ab68fdd0>> [accessed 31 May 2023].

sick turn away from sexual congress, contaminated and ‘sickened with remorse’ (p. 33). The racialised other too has no place in this world, as is demonstrated by the women who ‘sniff’ Bellamy and police the terms of entry to the meeting of the sick: when Bellamy dons the requisite bandanas to cover her hair, they make a racist joke comparing her to ‘Aunt Jemima’ (p. 29), a food brand mascot modelled after the racist “mammy” stereotype. In this space, where sensitivity has taken on a new kind of morality, the racialised other cannot be conceived as one of ‘the sick’ and sensate.

As I touched on in chapter three of this thesis, in their chapter ‘Lead’s Racial Matters’, Chen theorises along the same lines, analysing the role of the 2007 United States “lead panic” and other ‘spectacles’ of toxic contagion in playing out fears around ‘domestic security and sovereign fantasy ...defined here as the national or imperial project of absolute rule and authority’.⁴⁷⁶ In the official materials published to warn the public about the contaminated lead toys, Chen notes how ‘black children...disappeared from the lead representations’, in favour of images of ‘overwhelmingly white and generally middle- class children playing with the suspect toys’, constructing the white subject as solely or exceptionally vulnerable to toxicity and contamination, as in Bellamy’s essay.⁴⁷⁷ However, as Chen relates in *Animacies*, chemical sensitivities are also, even perhaps disproportionately, experienced by non-white people, in contrast to racialised perceptions. Chen notes how they must move in the world due to this sensitivity: making the quick assessment as to whether it is ‘likely [strangers] might be the “kind of people”... to wear perfumes or colognes or to be wearing sunscreen’, scanning heads for heads for the ‘smoke puffs or pursed lips pre- release’ of a cigarette.⁴⁷⁸ However, ‘suited up in both racial skin and chemical mask’, Chen is most often themselves ‘perceived as a walking symbol of a contagious disease like SARS, a vector of contamination, rather than a person sensitive and vulnerable to their environment.

As Chen draws out how anxieties about China as a vector in contamination echoes previous discourses about the ‘Yellow Peril’,⁴⁷⁹ I note that such discourses have only been revived in the wake of the COVID-19 pandemic, demonstrating the ways in which race is strategically mobilised and/or occluded to support narratives of

⁴⁷⁶ Chen, pp. 159–60.

⁴⁷⁷ Chen, pp. 168, 163.

⁴⁷⁸ Chen, pp. 198–99.

⁴⁷⁹ Chen, p. 169.

nationalism and white supremacy in concepts of illness, disability and death as moments of crisis, threat and rupture. Such discourses erase the temporally extended co-presence of death in marginalised communities this thesis has endeavoured to make at least partially visible. I have suggested that this co-presence is what Nixon has conceptualised as the ‘long dyings’ evinced by a slow violence which disproportionately affects impoverished and racialised communities.⁴⁸⁰ Racially insulated by whiteness, Bellamy’s sick outsource their further depletion to the unacknowledged makers of the products they use – the crystals often mined in the developing world, the anti-EMF meshes and carbon felt which is itself ‘wasteful to produce and difficult to recycle’ –⁴⁸¹ contributing through their own lifestyles to conditions of pollution, with some driving ‘2,000 to 3,000 miles per month trying to find a safe spot’ in which to isolate themselves (p. 35). As Chen observes, ‘blithely overlooked—or steadfastly ignored—are the toxic conditions of labor and of manufacture, such as inattention to harmful transnational labor and industrial practices that poison, in many cases, badly protected or unprotected workers’.⁴⁸²

Also relevant for this thesis are the ways in which Bellamy illustrates that the sick take for granted certain forms of class privilege. Sickened by their places of work, they are able to remove themselves from these toxic labour environments: Bellamy describes them in terms of their former occupations – ‘former psychologist’, the telling past tense of ‘worked as a counsellor’ or ‘used to be a bodybuilder’ – explaining that ‘wary of money, the sick use credit cards whenever possible’ (pp. 33, 35). Bellamy fantasises about institutionalised structures of indolence whereby ‘when the sick rule the world the well will be servants’ (p. 35), but this fantasy is obviously emphatically just that: as this thesis has endeavoured to show, this distinction between who is sick and who is well might more properly be thought as a distinction between those whose vulnerability, sensitivity and debility register as legible, and those whose does not. In chapter one for example, I highlighted the contrast between the cancer treatment experiences of Conway, economically stable in a

⁴⁸⁰ Nixon, p. 2.

⁴⁸¹ Mark Harris, ‘Carbon Fibre: The Wonder Material with a Dirty Secret’, *The Guardian*, 22 March 2017, section Guardian Sustainable Business <<https://www.theguardian.com/sustainable-business/2017/mar/22/carbon-fibre-wonder-material-dirty-secret>> [accessed 2 June 2023].

⁴⁸² Chen, p. 174.

heterosexual partnership, and Boyer, a precariously employed single mother: Conway is allowed the time to recover, the luxury of an anti-social anger within her stable relational network of care, Boyer must work through her cancer treatment and depends upon not alienating a care network comprised of friends. In chapter two, I draw out the ways that Rankine's sabbatical schedule is policed by colleagues during her own experience of cancer, likening this to the ways in which other Black scholars such as Lorde and Jordan 'were...denied a reduced teaching load and medical leave from their institutions (Hunter College and UC Berkeley, respectively), despite their documented battles with breast cancer'.⁴⁸³

In this thesis, I have thought with the concept of fugitivity as a way of foregrounding the collective and structural realities of illness and dying. As Halberstam argues in *The Undercommons*, being fugitive is an orientation to life that encompasses a 'coalition' of 'black people, indigenous peoples, queers and poor people'.⁴⁸⁴ These are the experiences I have attempted to attend to in the previous three chapters. As Moten and Harney posit, to be a member of such 'dispossessed' groups is to share in the condition of 'the shipped', to recognise the state of being 'both more and less than one'.⁴⁸⁵ Collectivity becomes key to those historically excluded from the Human given that 'the hold's terrible gift was to gather dispossessed feelings in common', to create a new way of 'feeling through others, a feel for feeling others feeling you'.⁴⁸⁶ In the absence of, or threat to 'all the things that were supposed to produce sentiment, family, nation, language, religion, place, home', the dispossessed are 'thrown together', brought into a haptical relation precisely opposite to the individuated isolation Bellamy's 'sick' attempt to rigidly maintain. In so doing they are called to 'feel (for) each other' in the manner of something I have called fugitive care.⁴⁸⁷ This stands in stark contrast to the preoccupation with individual agency and sovereignty that I have highlighted as evident in archetypal illness narratives and affirmed in early medical humanities scholarship. In chapter one, for example, I draw out the ways in which Conway and Picardie orient themselves away from the manifestation of sickness in others, focusing on the distinctness and tragedy of their

⁴⁸³ Kim, 'Toward a Crip-of-Color Critique', p. 3.

⁴⁸⁴ Halberstam, 'The Wild Beyond', p. 6.

⁴⁸⁵ Harney and Moten, p. 95.

⁴⁸⁶ Harney and Moten, p. 97.

⁴⁸⁷ Harney and Moten, p. 98.

own experience. I argued that in this, they reproduce the subject position constructed through a post-Enlightenment, liberal Humanism, from which ‘the shipped’ – and those marginalised who share in their conditions of being – are necessarily excluded, even, or especially in the state of illness and death. I suggest that the form and subject positions of illness narratives, and cancer narratives in particular, are shaped by external, structural distinctions between which lives are designated ‘grievable’ and which are not, which bodies and experiences register as legible and which do not, and which communities are ultimately discarded as a ‘sacrifice’ to the workings of racialised capitalism. Kim observes, ‘for Lorde, cancer is not an individual property limited to and contained by her body’s boundaries, but an extension of the state-sanctioned and extralegal systems that seek to delimit, contain, and exploit black life’.⁴⁸⁸ This is also true of the writers I have examined in this thesis, who share Lorde’s attention to the politics of illness. In each chapter, I attempted to draw out how forms of collectivity arise to counter a politics of occlusion and neoliberal self-management.

In chapter one, I read Rose’s *Love’s Work* and Sedgwick’s *A Dialogue on Love* against Conway’s *Ordinary Life* and Picardie’s *Before I Say Goodbye*, dwelling on the ways in which the former enfold other subjectivities into their own narratives, through a sense of queer kinship and identification between their male friends affected by the HIV/AIDs crisis and their own positions as queer women negotiating the gendered experience of cancer. In their narratives, Rose and Sedgwick remain in contact, even productively entangled with, the forms of bodily and social abjection which attend both illness and queer life, refusing to retract their view to the individual subject or family unit. Although Rose and Sedgwick, like Conway and Picardie, are still situated within what Luckhurst has called the ‘liberal intelligentsia’,⁴⁸⁹ a demographic benefitting from certain class privileges and cultural capital, through investments in relational constellations which exceed or confound the normative, they recognise their illness as imbricated in the wider fabric of the social. In chapter two, I explored how two memoirs, Danticat’s *Brother, I’m Dying* and Ward’s *Men We Reap*, further expand the scope of the illness narrative form beyond the individual to illustrate how experiences of illness and death for those racialised as Black

⁴⁸⁸ Kim, ‘Toward a Crip-of-Color Critique’, p. 1.

⁴⁸⁹ Luckhurst, *The Trauma Question*, p. 130.

compound generationally and cannot be thought exclusively through the terms of the nuclear family. As Freeman points out, Black and indigenous people have long been queering the shape of the family as normatively understood: she cites Spillers to note the ways in which captive persons were “forced into” patterns of “dispersal,” into “horizontal” relatedness, which engender[ed] new forms of affinity and solidarity.⁴⁹⁰ Freeman acknowledges that Black kinship can be characterised by its ‘expansiveness and creativity’: that ‘brothers, othermothers, honorary aunties: even ostensibly heterocentric Black communities have always had a vocabulary that exceeds the state’s imaginary, and in this they have much to teach queer theory’.⁴⁹¹ However, just as these expanded notions of relationality struggle for legibility within structures of white supremacy, Danticat and Ward struggle to gain legibility for their loved ones within the same logocentric system, through their engagement with narrative form. In reproducing in their accounts the failures of care endured by their relatives, they are also bound to emphasise the enduring duration of systemic anti-blackness which offers no space for reprieve in its continuity. I contrasted their texts with Mullen’s poem ‘All She Wrote’ and Rankine’s *Citizen* in order to suggest that the forms of breaking off, breaking down and breaking-up native to poetry create a medium of shelter from, in Sharpe’s words, the orthography or grammar of the wake in which anti-blackness resonates into the present. The poetic form differs from narrative in allowing for the kinds of opacity that Glissant demands for forms of irreducible difference which include the experience of living and dying while racialised as Black.⁴⁹² In chapter three, I read Antonetta’s memoir *Body Toxic* alongside Ward’s novel *Salvage the Bones*, thinking about how sensing, ailing and dying bodies form an account of the vicissitudes of extractive capitalism. In the sacrifice communities which both represent, consigned to death by ‘necropolitics’,⁴⁹³ the body is often the only account of such extractive regimes, in a dynamic in which the exploited and dispossessed are forced into silence. I note how Ward’s novel presents the complex webs of fugitive relationality between the living and dead, the human and the animal, as a counterbalancing force to the logics of extraction. In this space, the communities living in a state of social devaluation and physical debility,

⁴⁹⁰ Bradway and Freeman, p. 15.

⁴⁹¹ Bradway and Freeman, p. 16.

⁴⁹² Glissant and Wing, p. 49.

⁴⁹³ Mbembe and Corcoran, p. 66.

which Boyer has imagined as the condition of ‘the undying’, construct their own strategies and practices of care for one another which exceed and transgress normative structures.

Central to my arguments has been the question of temporality, specifically temporal scale. In chapter three, I allude to the ways in which *Salvage the Bones* can be situated within a tradition of the novel which seeks to expand or go beyond the scale of an individual life course. It has this in common with *Body Toxic*, *Brother, I’m Dying*, *Men We Reaped*, *Citizen*, *Love’s Work* and *A Dialogue on Love*. In each of the successive chapters of this thesis, I found myself expanding further and further beyond the temporalities of the individual lifetime, which dominate narratives of cancer and illness that follow the conventional linear temporal progression through diagnosis, treatment and relapse/recovery. In chapter one, Rose and Sedgwick reach out from the nuclear family unit over time to integrate the histories of HIV/AIDS into their narratives. I note how Rose is also interested in histories of ‘transgenerational haunting’ following the Holocaust that animate her position as a woman of Jewish heritage. This orientation presages the intergenerational outlook evident in Danticat and Ward’s memoirs, which as I have suggested with reference to Freeman, represent the expanded structures of Black kinship as central to the understanding of racialised death and dying. Their memoirs demonstrate the ways in which experiences of illness and death for the Black subject have a temporal scale which proceeds the moment of diagnosis and continues after the moment of death. Mullen and Rankine’s poetic interventions experiment with how such oppressive temporalities of racial subjugation might be short-circuited through the opacity of form, in many ways offering a queering of time commensurate with that represented in Rose and Sedgwick’s narratives. In chapter three, I expand my view further, placing experiences of illness and dying in the context of deep, environmental and planetary time, arguing that the sacrifice communities that Ward and Antonetta represent are not ‘consigned to the waiting room of history’ as Chakrabarty suggests,⁴⁹⁴ but at the vanguard of an apocalyptic time that white supremacy cannot yet understand as applicable also to itself. In this way, I found myself, through the progression of this thesis, questioning the definition of “end-of-life”, as a temporal and medico-legal category and by extension as a literary category used to describe

⁴⁹⁴ Chakrabarty, p. 8.

certain narratives and not others. If end-of-life care describes the treatment received when death is imminent, or in more specific definitions, when one is within a year of death in a state of active decline, what does this mean for those living in a real and constant proximity to death, and how do lives suddenly and violently curtailed factor into this linear perception of time as a progression through medically identifiable stages? And if you live with the likelihood of early death, how does that transform how you perceive time in the present? Following Kafer, I contend that living with a poor prognosis, whether the cause is medical or socio-structural, is ‘an extended, if not indefinite, period of negotiation and identification. During that period, past/present/future become jumbled, inchoate’: time is liable to strange regressions or contraction.⁴⁹⁵ If you are to die aged twenty, as Ward’s brother does in *Men We Reaped*, how might that freshly reconfigure adolescence as a premature mid-life? As I discuss in chapter three, I see some of this disrupted time-sense in Ward’s portrayal of Junior in *Salvage the Bones*, who appears as both a child and yet impossibly aged by the accretion of hardship in his life, barely escaping death with his family in the devastation of Hurricane Katrina.

My preoccupation with time in this thesis has also extended to a consideration of disciplinary orientation. From the outset of the introduction, I have questioned the intellectual history of the medical humanities, highlighted the ways in which it has focused on certain kinds of subjects and intellectual traditions to the exclusion of others. I found myself going beyond the limits of the medical humanities, incorporating queer theory, crip theory, Black studies, disability studies and environmental studies into a literary studies methodology of criticism and close reading to think, as Murray puts it, in ‘in/disciplined ways’.⁴⁹⁶ As such my intervention might also be thought through as a question or a troubling of time, in the sense that it exceeds how the medical humanities has defined itself in the past, and even the present, looking instead to post- or in- disciplinary spaces of future study. I became interested in what it might mean to work in ways and across modalities that remain separate, or as yet incompletely integrated, expanding disciplinary scope to think towards a way of animating archives of past experience in the present and future. This is what I think Moten might mean when he offers a fugitive orientation to thought

⁴⁹⁵ Kafer, p. 37.

⁴⁹⁶ Murray, p. 12.

in *The Undercommons*. Suspended between the meanwhile of flight and arrival, a fugitive orientation to thought might be 'understood as wary of critique, weary of it, and at the same time dedicated to the collectivity of its future, the collectivity that may come to be its future'.⁴⁹⁷ This future might revolve, I suggest, around finding different disciplinary forms through which to encounter different rhythms of living and dying.

Over the course of this thesis, I have approached form as a vehicle and function of temporality: the writers I have discussed negotiate the limits of narrative form in their attempt to capture something of the occluded untimeliness and collectivity of dying. I conclude that Rose, Sedgwick, Danticat, Ward, Mullen, Rankine and Antonetta speak to the temporal incommensurability in the ending of life in ways that have profound and continued relevance for the understanding of death and care in a landscape of heteronormativity, racism, economic inequality and environmental negligence. In undertaking this research, I have been provoked, inspired and enlivened by the ways in which they each use language and form as a means of escape, shelter and hope in the pursuit of something other than what has gone before.

⁴⁹⁷ Harney and Moten, p. 38.

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