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Medicine and Metaphor:

The Poetics of Disability and Environment

& The Poetry Collection ‘Gut Feeling’

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Abstract

The creative portion of this thesis is an experimental collection of poetry titled *Gut Feeling*. In this collection, I explore my own disability, its complexities, and its intra-activity with environment as a form of creative writing as research. Thematically, I discuss my own lived experiences with disability, medical consent and autonomy, contagion, the impact of covid-19 on extremely clinically vulnerable people, and the boundaries of the body. I do this through experimental forms and found materials.

In the critical portion, I expand on the work of disability and pain theorists, Scarry and Sontag, and explore ways that figurative language can enable discussion of disability and intra-activity in environment—complex topics which often evade symbolic and medical language. Within disability studies, disability is regarded as being influenced by biological, social, and environmental factors. Yet, environmental factors are often overlooked and overshadowed, leading to a distorted understanding of the condition in question.

I compare two texts: the contemporary experimental poetry collection, *Love Minus Love* by Wayne Holloway-Smith, and the popular medical textbook, the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed*, *text revision* (*DSM-5-TR*). I analyse what is implied to the reader regarding the environmental factors which are attributed to causing and exacerbating obsessive-compulsive disorder, and the uncomfortable relationships that are often created with the nonhuman (i.e., fear of bacteria). I will be analysing the two texts in the same way, considering their language choices and modes, their formatting, and performing an ecocritical reading, whilst acknowledging their different contexts and purposes. In an innovative and interdisciplinary literary reading of the *DSM-5-TR*, I consider how different modes of language enable or hinder discussion on the environmental factors of OCD.

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Overview

This thesis is divided into a critical portion and a creative portion.

The creative portion is an experimental poetry collection titled *Gut Feeling*. This is an exploration into my own lived experiences of disability, investigating the ways my health has been impacted by environmental factors, such as by covid-19 and air quality. *Gut Feeling* discusses topics such as medical consent, trauma, and shame, in experimental forms. It consists of 50 pages, including found materials of GP and covid-19 related letters. Through this collection, I sought to challenge the reader, and myself as a writer, in exploring intimate and emotional experiences of disability with a stark vulnerability.

In the critical portion, I consider how the poetic mode enables exploration into the environmental factors of disability. I propose that poetic language and metaphor can help readers to understand the intricates and nuances of disability and environment, without reducing their complexity. With metaphor being a useful tool for understanding the world through its relatedness. This, I argue, is particularly useful for writers and readers regarding topics such as pain and disability, as they evade symbolic language due to their phenomenological and complex nature. In expanding upon the work of the theorists Sontag, Scarry, and Kristeva, I challenge the limitations of putting phenomena into language.

My methodology is to use close textual analysis and to consider poetry as its own form of practice-based research. This research will advance the ways disability is considered within language, by providing a different viewpoint on the benefits of figurative language, and to highlight the significance of fully considering environmental factors in discussions on disability. Figurative language is often analysed for its detrimental effects when describing disability, but as I will demonstrate, it can be equally as powerful for aiding understanding.

To demonstrate this, I compare the contemporary experimental poetry collection, *Love Minus Love* (2020), by Wayne Holloway-Smith, and the popular medical handbook, the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision* (*DSM-5-TR*) (2022). I will be analysing how, through different lenses and modes of language, experiences of disability are explored, and how environmental factors can either be appreciated or diminished. *Love Minus Love*, using poetic, semiotic language, and the *DSM-5-TR*, using medical symbolic language. These texts both consider obsessive-compulsive disorder (OCD); I have chosen to investigate the depictions of OCD in these two texts as environmental factors attributed to its causality and exacerbation, and it can create uncomfortable relationships with the nonhuman (i.e., fears of bacteria).

Through performing ecocritical readings of disability poetry and medical literature, I highlight how, through different modes and lenses, different perceptions of OCD and its environmental factors are created. An ecocritical reading being an investigation into the relationship between the speaker and their environment, one which fully considers the impact of nonhuman on the speaker. I draw upon ecocritical thought in order have an appropriately expansive definition of environment, and to analyse these factors on a more detailed level—going beyond considering disability and the built environment and considering the body as transcorporeal.

In performing an ecocritical reading of both texts, and indeed a literary reading of the *DSM-5-TR*, I am using a radical interdisciplinary approach which will expand both disability studies and the medical humanities. Reading these texts this way provides an excellent basis for comparison of lens and language, and how these lenses and modes distort our perception of both the illness and how the illness inter-acts with the environment. This analysis also highlights how the *DSM-5-TR* is received to those outside of the medical field—as it is often used outside of this context—with the results of this study illustrating that this limited medical perception of OCD is not one which fully encompasses the embodied and emotional impacts of this illness.

Gut Feeling

Lucy Hurst

[THE CREATIVE SECTION OF THIS THESIS HAS BEEN REDACTED
FOR PUBLICATION PURPOSES]

Chapter 1

Reflective Creative Commentary

For the creative segment of this project, I have written an experimental poetry collection titled *Gut Feeling*. Within the text, I reflect upon my personal experiences with chronic illness and disability, and subtly consider the ways that health is impacted and formed by environments. These factors span from contagion and its politics to trauma as an environmental factor.

The aim of this text is to use poetry as a creative research method to explore my own disability and its engagement with environment. This has resulted in a collection which experimental, dark, and jarring, yet is also emotive and intimate. It was crucial to me as a writer that the formal elements of this text would reflect and complement its content, creating a closeness with the reader. I sought to make this collection immersive and interactive using found materials and including dark humour.

In this reflective commentary I will introduce the poetry as practice-based research and the “lyric ‘I’” (a term which I will be unpacking in the first section); the literary contexts of my practice, including experimentation and influential poets; the themes of the text; the use of found materials; and the methodology and writing process.

Poetry as Research

I have chosen to use poetry as a form of practice-based research as I have found this method to be particularly useful as a writer exploring my own experiences, and as it can help readers engage emotionally with this subject, providing them with ‘multiple, new, and diverse ways of understanding and living in the world’.[1]

As semiotician Wendy Wheeler writes in *Expecting the Earth: Life / Culture / Biosemiotics*, ‘art, and especially art in language, remains the best place of our hopes of self-understanding’[2]. Through the act of writing, we may discover things we might not have otherwise—particularly when exploring the self. In 1984, in an interview with *The Paris Review*, James Baldwin stated that:

> When you’re writing, you’re trying to find out something which you don’t know. The whole language of writing for me is finding out what you don’t want to know, what you don’t want to find out. But something forces you to anyway.[3]

When we write, we are forced to confront ourselves as we place all our thoughts and ideas on to paper. One thing I was confronted with whilst writing this thesis was the extent of my own internalised ableism. It is only in putting the words on to the page that I noticed this sense of shame—I asked myself, *am I ‘allowed’ to write this experience up? Would anyone want to listen? How should I make myself more palatable?* In many of my editing sessions with tutors, I struggled with hitting a mental block in my poetry—there were so many things I wanted to write about but the prospect of having it written down for others to see felt terrifying. When I was writing ‘Astral Projection’, I deliberated for a long time on the line: ‘when I lose a quarter pint of blood in diarrhoea’[4]. The experience that this poem is based on was stressful, so part of the hesitation I felt was a fear of reliving these experiences through writing them, and the rest of my hesitation was shame surrounding my symptoms. At first, this line was shrouded in

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[1] Susan Finley, *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*, ed. by J. Gary Knowles, Ardra L. Cole (California: SAGE Publications, Inc., 2008) p. 72.

[2] Wendy Wheeler, *Expecting the Earth: Life, Culture, Biosemiotics* (London: Lawrence & Wishart Ltd, 2016) p. 276.

[3] James Baldwin, interviewed by Jordan Elgrably, *James Baldwin, The Art of Fiction No. 78* (1984), *The Paris Review* <https://www.theparisreview.org/interviews/2994/the-art-of-fiction-no-78-james-baldwin> [accessed 27th April 2023].

[4] Lucy Hurst, ‘Astral Projection’ (p. 14 of this document) ll.19.

comedy—an attempt at a joke about a never-ending red ribbon as if I were a circus trick. This shame was written in then edited out.

We as poets are given a creative freedom of expression in creating narratives and in choosing which aspects get to be explored. Within poetry, a strict devotion to the 'truth' of an experience is not required—it is not categorised as creative non-fiction. This leniency means that certain aspects can examined, creating impressions of specific experiences rather than whole timelines and experiences. Poets are able delve into certain aspects of a topic without needing to provide readers will full context, complete logic, or a complete plot line (as required in other formats such as novels). The form of poetry helped me to think about moments and ideas, as opposed to these experiences as plot points. These poems became an eclectic array of experiences, ways my view on my health has changed, notes on fear and forgiveness, and on our interconnectedness and dependency on one another. Poetry differs from other research methods (such as quantitative) because of this element of creative freedom and not necessitating a 'full story' or 'full truth'.

Poetry as a research method can be considered as a subset of qualitative enquiry, as argued by Debbie McCulliss in 'Poetic inquiry and multidisciplinary qualitative research'. McCulliss writes:

> Poetry, perhaps more than any other approach or discipline, gets to the essence of qualitative methodology. It presents, and is a catalyst for, a window into the heart of human experience. […] Poems employed as catalysts provoke insightful responses, allowing for a more in-depth and holistic understanding of the ethnography and perceptions of a particular group or population.[5]

In using poetry as a research method there is a different initial intention behind the artistic endeavour, and consequentially, there is a different impact on the reader. Through using poetry, as a poet I am intending to delve into the 'the heart of human experience', and in doing so, the reader is asked to engage emotionally with the research in a way which goes beyond what is asked of the reader in other research forms. As McCulliss continues:

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[5] Debbie McCulliss, 'Poetic inquiry and multidisciplinary qualitative research', *The Interdisciplinary Journal of Practice, Theory, Research and Education*, issue 2 (2013), 83-114 (83).

> The use of poetic devices such as metaphor, symbols, imagery, and cadence allows the audience to develop their own relationship to a work. Poetry seeks metaphoric generalizability, that is, while a poem usually starts out with one person's experience, it attempts to move beyond the study of one person to the study of many. Poetry is not generalizable in the statistical sense of the world, but generalizable in that it helps stimulate an empathetic understanding in the reader. [6]

Through poetic form, readers are asked to attempt to understand others though emotion and imagination. Within the case of 'Gut Feeling', readers are asked to engage emotionally with the subject (the speaker), through different features of the text—particularly the use of the lyric 'I'. As Francesca Beretta, former columnist for *The Oxford Culture Review*, states in a review of 'The Lyric I as Other Mind', 'the first-person narrator [of lyric poetry] prompts the reader to imagine the speaker, to try to go beyond the page in order to understand who [speaker] is.'[7] The reader employs an emotional imagination to attempt to construct the speaker for themselves, rather than having a strict view of who the speaker is. This involvement on behalf of the reader creates a closeness to the text, and thus also to the subject (speaker).

In 'Gut Feeling', the use of the lyric 'I' is largely autobiographical, yet the speaker is not bound to 'the whole truth', for the sake of my own privacy. In writing this text, I was not consciously aware of how I was using the 'I' throughout the poems—I did not want to impose certain ideas onto the text, and instead wanted to see where this research led me. The outcome of this was an intimate reading experience, with the heightened emotional experience juxtaposed with the flat affect tone of medicine. For example, in 'Gag Reflex', the speaker considers the imposition of the 'hands on and in [her] body'[8]. The reader is brought unnervingly close to the clinical world and is asked to consider how this testing impacts the speaker in an intimate way, and what it is really like to be subject to medicalisation. Equally, in the poem 'The Guts I Have Left', there is a shift in the use of the lyric 'I', moving from more intimate subjective moments with the speaker, to broader and more seemingly universal feelings. For example, the first stanza reads:

'I have become tired of being a good patient

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[6] Debbie McCulliss, 'Poetic inquiry and multidisciplinary qualitative research', *The Interdisciplinary Journal of Practice, Theory, Research and Education*, issue 2 (2013), 83-114 (89).

[7] Francesca Beretta, 'Review: The Lyric I as Other Mind' (2016), *The Oxford Culture Review* < https://theoxfordculturereview.com/2016/02/22/review-the-lyric-i-as-other-mind/> [accessed 15th February 2024].

[8] Lucy Hurst, 'Gag Reflex' (p. 13 of this document) ll. 1.

fitting into bedsheets & procedural settings
trying to commit feeling into the state of exile
& pretending that all of life is curable'[9]

Here, the use of the lyric 'I' changes at the beginning of the third line, as the speaker moves away from the specific medical setting and rules, into an overarching, even existential, type of feeling. Through this shift, the reader is reminded that in the sterile world of medicine there are forms of lived experience which are tender and vulnerable. This type of knowledge can often go underappreciated or acknowledged, due to the nature of medicine and its influence.

Through the form and the use of the lyric 'I', the experiences themselves are shown for their emotional complexity. For me, these experiences were never simplistic or easy, they came with anxiety, existential questions, and thoughts on the disruption to my body-mind. In using this technique, the juxtaposition that I felt—that of emotional experiences clashing with dispassionate environments—is reflected for the reader.

Another example of the lyrical 'I' being juxtaposed with medicine can be found in Betty Doyle's debut pamphlet, *Girl Parts* (2022). Doyle's pamphlet shifts in and out of using the lyrical 'I', and intermittently uses found medical materials, settings of '[phlebotomy waiting room[s]]'[10], and medical terminology. Here, Doyle demonstrates how the sterile world of medicine continues to inform the experiences of disabled people, and through this juxtaposition it is highlighted how medicine remains dispassionate, despite the emotions that come from being subject to it.

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[9] Lucy Hurst, 'The Guts I Have Left' (p. 50 of this document) ll. 1-4.

[10] Betty Doyle, *Girl Parts* (Birmingham; Verve Poetry Press, 2022), p. 14, ll. 5.

Influential Poets

Throughout writing and forming this collection, I have been influenced by a variety of poets, some of whom are disabled writers, and others who discuss different topics but have a specific writing style which has influenced to my own. In this section, I will be highlighting disabled poets who have been particularly influential on my own practice, and how their works have inspired creativity and experimentation. Firstly, however, I want to acknowledge the broader poetic contexts that my work is situated in, and why I consider my work to sit within the category of ‘experimental poetry’.

Whilst most of the texts I took inspiration from have been published in the past ten years[11], like many contemporary writers, my practice has been informed by poets who have gone before me. Particularly, I am interested in poets who have pushed against traditional ideas of what constitutes as a poem and how poems should be structured. Many contemporary UK poets share a similar approach to form[12], which has been influenced by the shift away from traditional styles in the British Poetry Revival (1960s-1970s)[13].

Ken Edwards, a poet associated with the movement, argued that the British Poetry Revival was ‘an exciting growth and flowering that encompasses immense variety of forms and procedures and that has largely unheeded […] by the British literary establishment’[14] This ‘explosion of poetic activity’ as poet and critic, Gavin Selerie, discusses in *North Dakota Quarterly*, ‘was in itself a reaction against the full common-sense politeness of the ‘Movement’ poets of the 1950s’—the dominant poetic style and agenda at the time. He writes:

> After a period dominated by such figures as Philip Larkin, qualities of inventiveness, passion, intelligence entered once again into British verse. Poets as diverse as Lee Harwood, Tom Raworth, Roy Fisher, and Tom Pickard exhibited a toughness and also a splendour that were entirely absent from the writing collected in the Movement anthology New Lines (1956) [15]

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[11] As of 2024.

[12] Such as Racheal Allen, Daljit Nagra, and Jack Underwood, who have moved away from rhyme schemes and stricter forms.

[13] Robert Sheppard, 'The British Poetry Revival 1960–1978', *The Poetry of Saying: British Poetry and its Discontents, 1950-2000* (Liverpool, Liverpool Scholarship; 2013) p. 36.

[14] Ken Edwards, ‘Reviews’ (1979), *Reality Studios*, vol 2. No. 1. Found online <https://jacket2.org/reissues/reality-studios> [accessed 15th February 2024] p. 9.

[15] Gavin Selerie, ‘Introduction’, *North Dakota Quarterly*, vol. 51, no. 4 (1983), 5–18 (6).

In taking influence from experimental North American poets, such as L=A=N=G=U=A=G=E poets[16], The Black Mountain Poets[17], and The New York School of Poets[18][19], the British Poetry Revival diverted away from the more rigid approach to form that Movement poets upheld[20] and its 'perception of an insular, antimodern, and empirical British orthodoxy'[21]. This radically re-shaped British poetry publishing, and thus has had lasting impact on writing since.

Whilst the legacy of the British Poetry Revival has been influential in shaping my own work through shaping the literary landscape of contemporary writers, I want to acknowledge the influence that these experimental North American writers have had on my practice. Particularly Frank O'Hara, one of the most prominent New York School Poets.

Frank O'Hara's influence on my practice is shown in various ways, from the occasional use of found materials (i.e., 'LANA TURNER HAS COLLAPSED'[22]), to the interest in the mundane, and the lyric 'I'. One aspect about O'Hara's poetry that I similarly aim to capture, is how the speaker's voice does not shy away from feeling and is indeed bold in its emotion. For example, in 'Having a Coke with You', the speaker does not use grand and flowery language to describe his love interest, he instead says:

'I look
at you and I would rather look at you than all the portraits in the world

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[16] 'Language poetry is an avant garde poetry movement that emerged in the late 1960's and early 1970's as a response to mainstream American poetry. It developed from diverse communities of poets in San Francisco and New York who published in journals such as *This*, *Hills*, *Tottels*, *L=A=N=G=U=A=G=E*, and Tuumba Press.' Taken from: 'Language poetry' ([n.a.]), *Poetry Foundation* <https://www.poetryfoundation.org/learn/glossary-terms/language-poetry> [accessed 15th February 2024].

[17] 'A group of progressive poets who, in the 1940s and 1950s, were associated with the experimental Black Mountain College in North Carolina.' Taken from: 'Black Mountain poets' ([n.a.]), *Poetry Foundation* <https://www.poetryfoundation.org/collections/151709/an-introduction-to-the-black-mountain-school> [accessed 15th February 2024].

[18] https://www.poetryfoundation.org/collections/147565/an-introduction-to-the-new-york-school-of-poets

[19] 'A group of poets aligned with the New York School of painting in the 1950s and '60s.' Taken from 'New York School', *Poetry Foundation* < https://www.poetryfoundation.org/learn/glossary-terms/new-york-school> [accessed 14th February 2024].

[20] Robert Conquest, 'Review: *New Lines. An Anthology*', *Studies: An Irish Quarterly Review*, Vol. 45, No. 180 (1956), 475-479 (475).

[21] Linda A. Kinnahan, 'Experimental Poetics and the Lyric in British Women's Poetry: Geraldine Monk, Wendy Mulford, and Denise Riley', Vol. 37, No. 4 (1996), 620-670 (626).

[22] Frank O'Hara, 'Poem [Lana Turner has collapsed!]', Lunch Poems (San Fransisco: City Light Books, 1964) ([p. n.a]) found on Poets.org <https://poets.org/poem/poem-lana-turner-has-collapsed> [accessed 16th February 2024].

except possibly for the *Polish Rider* occasionally and anyway it's in the Frick
which thank heavens you haven't gone to yet so we can go together for the first time'[23]

O'Hara makes a profound statement—of wanting to see someone's face more than any portrait—then immediately grounds it in the mundane, of going to a gallery. For the reader, this use of the mundane grounds the reader, creating an immediacy, and an intimate reading experience.

Like O'Hara, I also consider myself to be an experimental poet, and 'Gut Feeling' to be experimental collection due to the inclusion of found materials[24] and my play with form and grammar (such as a lack of punctuation). This experimentation stems from both the contemporary UK poetry scene and the legacy of the British Poetry Revival, and as influenced by experimental writers such as O'Hara, and many contemporary disabled poets.

In contemporary writing, one of the most prominent influences on my practice throughout this writing process has been Daniel Sluman's collection, *Single Window* (2021). Within this collection, Sluman explores how he and his wife, Emily, were 'unable to safely navigate the stairs to bed, […] spent 24 hours a day together on their sofa, isolated from society except for a single window, where they watched the world moving around them'[25]. Thematically, *Single Window* explores inaccessibility, chronic pain, and the intimate lives of disabled people through experimental forms, such as the inclusion of images of Emily and himself.

I consider my writing to be stylistically similar to Sluman's, especially regarding his approach to punctuation. In *Single Window,* Sluman uses minimal punctuation—splitting his lines with forward slashes and only using ampersands, for example. Sluman's lack of punctuation creates a long flow of text, creating poetic voice similar to a 'stream-of-consciousness' and a closeness with the reader. Whilst some of my poems do use full punctuation, I experimented with a scarcity of punctuation, with some poems only using an em-dash for example. Through this technique, I found that the poems had a better flow, and complemented the voice of the speaker—as intimate and often conversational.

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[23] Frank O'Hara, 'Having a Coke with You', *The Collected Poems of Frank O'Hara* (New York: Penguin Random House LLC, 1971) ([p. n.a]) found on *Poets.org* < https://poets.org/poem/having-coke-you> [accessed 16th February 2024].

[24] Which I discuss further on in this chapter.

[25] As taken from the blurb.

One of the most prominent experimental formal elements of this collection is the use of images, and how they interact with the poetry. For the reader, these images provide a sense of closeness to the speaker, which has a powerful effect when paired with thematically similar poems. An example of this can be found on pages 86-87, where an image of Sluman looking visibly in pain, holding his head down, unable to look up at his laptop (shown below), is paired with a corresponding passage of poetry. He writes:

two paracetamol / a glass of ice-
water / headache clouded / with nausea
unfurling / through the afternoon /
like the resurrection / flower
sucking every drop / of moisture
from my skull[26]

Figure 1 – Image of Sluman, slouched down on his sofa unable with his head to his laptop p 87.

Images such as this are used throughout the entire collection to remind the reader of the reality that these poems are grounded in. This interactive quality has a lasting effect on the reader, as

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[26] Daniel Sluman, *Single Window* (Warwickshire; Nine Arches Press, 2021) p. 86.

they are immersed into the world of the speaker. Including images within my work was something that I considered, but ultimately decided against as I felt they retracted too much attention away from the poetry itself. Yet, in immersing myself in Sluman's sense of playfulness in approaching difficult topics, I felt encouraged to experiment with form and ways of grounding the text. This resulted in incorporating found materials, such as a letter from a GP, which I will discuss in more detail further on in this chapter.

Similarly, I was influenced by Jamie Hale's, *Shield* (2021), a pamphlet released amidst government-advised lockdowns, which considered how disabled people were being treated during shielding, as written from their personal experience. During this time, ventilators were being rationed and D.N.R. orders were being placed on more vulnerable individuals, much of which Hale explores in this pamphlet.

The voice within these poems is compelling; whilst being appropriately angry at the political and social decisions being made, the voice is also deeply heartfelt and full of compassion. Hale starts their collection with a powerful stanza:

> i write an email to my GP telling him please
> i love my life telling him please i want to be
> the opposite of a Do Not Resuscitate order
> the opposite of a patient you'd give a quiet death[27]

In an intimate and emotional voice, Hale highlights how these governmental decisions have a profound impact on daily life, as the lives of disabled people become a topic of public debate. What I appreciate about how Hale has written these poems, is how they are filled with an overwhelming desire to live and experience joy, contrasting the situation the speaker finds themself in[28]. Within my collection, I also consider the contrast between harsh realities of being disabled to the moments of affection and joy. For example, in the poem 'Extremely Clinically Vulnerable', I broach the topic of the 'utilitarian approach to ventilators / & which of us would be safe'[29], whereas in others, I consider friendship and solidarity. I took inspiration from Hale, and how they weave the topics of governmental decisions with personal insight and feelings. I

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[27] Jamie Hale, *Shield* (Birmingham; Verve Press, 2021), p. 6, ll.1-4.
[28] Regarding governmental decisions and being centred in debate.
[29] Lucy Hurst, 'Extremely Clinically Vulnerable' (page 29 of this document) ll. 27-28

wanted to create the same sense of intimacy and closeness that I had experienced as a reader of their work, and to do so, I assessed how Hale's formal elements helped to achieve this.

In this pamphlet, Hale avoids the use of capitalisation, and refers to the speaker by using a lowercase 'i'. This stylistic choice creates a sense of closeness with the reader, as it constructs an intimate voice. As a reader, I felt that my experience of reading this text was similar to reading text messages from a friend, with the use of all lowercase reflecting the thoughts that are not yet filtered by auto-correct, or indeed edited for the comfort of nondisabled readers. Though I choose to capitalise my 'I's, I do, for the most part of my collection, also write in lowercase, with the intention of creating a more intimate reading experience.

I found comfort in reading *Shield*, as at the time it was published as I felt my anxieties were not necessarily reflected elsewhere. Despite much of society being worried about the impact of the pandemic, voices of disabled people seemed to be overpowered by discussions about the economy, hospitals, and supply issues. I do hope that through my creative practice, other disabled people can also find their experiences reflected back to them, as I did with Hale's work. Much of my process, and especially in the initial stages, involves writing the poems I wish I could have read when I became ill.

Another significant influence on my work has been The Cyborg Jillian Weise's poem 'Biohack Manifesto'. This is a poem that I had read long before my writing process had begun, and it remains a poem that I return to when I need writing inspiration. Much of Weise's poetry, such as her collection *The Amputee's Guide to Sex* (2017)[30], is provocative and bold, pushing the reader to view disability for its complexities and intimate insights. In 'Biohack Manifesto', Weise writes:

'No! says my mentor
Not this. This is too angry

This is too much about
Not that. Not that

I like to hack, sometimes,
the Hebrew Bible

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[30] Jillian Weise, *The Amputee's Guide to Sex*, (New York: Soft Skull Press, 2017).

I don’t think my mentor hacks
the Bible b/c it has too much
lame deaf blind circumcised in it

Not that. Not that in poetry
Didn’t we already have
Judd Woe? He was so good to us
so good and sad and sorry

The great thing about Judd Woe
is that now we don’t have to
keep looking for a disabled poet
We got him

Everybody together now: We got him
Thank YHWH he’s a man’[31]

In this poem, Weise highlights how disabled writers are confined to limitations, such as only exploring disability without its intersectionality, as enforced by publishers and mentors. What I enjoy most about this poem is how the speaker creates her own definition of what poetry is, and who gets to write it. In the repetition of the negative comments made by ‘the mentor’, Weise directly highlights how prevalent ableism is within the publishing industry, and retaliates at the idea that ‘enough’ disabled writing has already been written. The constant impeding voice of ableism is inescapable for the speaker (‘Not that. Not that’, ‘THIS IS NOT POETRY, they said’[32], and ‘CUT ALL OF IT my mentor says / This is not poetry’[33]). Reading this as a writer, the use of this repetition reminds me to remain aware of how ableism and the circumstances that I am writing

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[31] The Cyborg Jillian Weise, ‘Biohack Manifesto’, POETRY (March 2015) <https://www.poetryfoundation.org/poetrymagazine/poems/58002/biohack-manifesto> [accessed 11th October 2023]. ll. 8- 26.

[32] The Cyborg Jillian Weise, ‘Biohack Manifesto’, POETRY (March 2015) <https://www.poetryfoundation.org/poetrymagazine/poems/58002/biohack-manifesto> [accessed 11th October 2023] ll. 38.

[33] The Cyborg Jillian Weise, ‘Biohack Manifesto’, POETRY (March 2015) <https://www.poetryfoundation.org/poetrymagazine/poems/58002/biohack-manifesto> [accessed 11th October 2023] ll. 95-96.

under can influence and shape my practice, and that I can, and should, also retaliate. Weise's poem ends in the lines:

> I am sorry if you offended me
> Role of disabled artist:
> Always be sorry[34]

'Biohack Manifesto', to me as a disabled writer, is doing more than giving permission for disabled poets to explore different aspects of disability, it is encouraging being unapologetic in the face of ableism. What I take from Weise's work is that I can always choose to be bolder. Through my writing, I want to challenge my reader, but to do so I must challenge myself by overcoming internalised feelings (or ones forced upon me) of shame and social expectations.

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[34] The Cyborg Jillian Weise, 'Biohack Manifesto', POETRY (March 2015) <https://www.poetryfoundation.org/poetrymagazine/poems/58002/biohack-manifesto> [accessed 11th October 2023]. ll. 104-106.

Themes

My collection, *Gut Feeling*, starts with poems that consider how self-exploration comes with physical and emotional difficulty, and the amount of intrusion and discomfort that is required in this process. The speaker is initially confronted by, and must come to terms with, how her health is impacted by her environments. She is then forced into the inevitable discomfort that stems from her individual lack of control.

For the speaker to understand more about herself and the ways in which her health is shaped through her environment, she must become aware of the way that the human boundary is continually broken. This is both in more personal feeling ways (such as in through medical testing) and ways that she is not consciously participating in (i.e., autonomic systems). For the speaker, self-exploration and the boundaries of the body are profoundly complex and overwhelming topics. This is demonstrated in the first few poems, with examples taken from ‘Gag Reflex’ and ‘Gut Feeling’, respectively, below:

> it takes a camera being piped down my throat
> for me to hit a limit of what I want to know[35]

> How unbearable it must be to know everything. I refuse to see it; I can’t bear to look.[36]

The speaker is forced into self-exploration and investigation into how she is continually impacted by her environments because, as she notes in the title poem, it is required ‘if [she] want[s] to stop being as sick’[37].

In exploring the ways that the speaker has been impacted, she is forced to look inside of herself in various ways. This can be painful, as much of the body-mind activity goes on in the subconscious, she must find ways to access this material. Some of the ways the speaker can see what is happening within herself is through medical testing—whilst this is informative, it

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[35] Lucy Hurst, ‘Gag Reflex’ (p. 13 of this document) ll.12-13.
[36] Lucy Hurst, ‘Gut Feeling’ (p. 17 of this document) ll. 25.
[37] Lucy Hurst, ‘Gut Feeling’ (p. 17 of this document) ll. 25.

also requires losing a sense of autonomy, and this creates an uncomfortable line of consent. Whilst done out of necessity, these methods can become uncomfortable or distressing.

I decided to add in dark humour when writing these distressing or somewhat traumatic topics. As much of this collection is based in my own experiences, I wanted to make sure that the voice in the poems did not feel too claustrophobic, for both the sake of the reader and myself as a writer. I wanted to avoid creating too much claustrophobia as it would not give the experiences themselves justice. Whilst many of the experiences described do have a slight sense of claustrophobia to them, I am not intending to write horror or anything for shock value, and instead I am writing experiences which are full of mixed emotions—with the speaker feeling fear, confusion, and attempting to calm herself down. The dark humour is equally in part how I perceive and understand my own experiences as it is a way of coping with difficult experiences. This dark humour comes to the fore in ‘An Erotic Poem for Vampires’[38]. In this poem, I wanted to make the comparison between medical consent and a relationship with a vampire. Human bodies can feel durable, yet through blood being taken or lost, we can be left feeling weaker and our fragility can become apparent quickly. There is a level of trust required when blood is taken, as there is in all forms of medical procedures. This poem serves as a playful exploration of that trust and vulnerability. To make light of these scenarios, in many ways, is to take the negative emotions away from them.

Following ‘An Erotic Poem for Vampires’, the speaker’s relationship with medical testing starts to shift away from using medicine for self-discovery and moves towards more everyday discoveries. The speaker has, so far in the collection, explored why she finds medical testing exhausting, but now she is starting to think about other aspects of health. As shown in the poem ‘Know Thyself’:

> I’ll let my blood become the sum of my experience
> […]
> ‘I feel most alive when the disqualified realm
> of what we do not know becomes insurmountable
> when I look into the world   & it looks back
> & when the comedic timing collapses’[39]

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[38] Lucy Hurst, ‘An Erotic Poem for Vampires’ (p. 18-19 of this document).
[39] Lucy Hurst, ‘Know Thyself’ (p. 24 of this document) ll. 3, ll. 13-18.

The speaker becomes disinterested in what can be found through the invasive medical testing, and instead focuses her attention to the 'insurmountable' and unknowable world that impacts her. She begins to investigate how health and trauma are intrinsically environmental, and how the boundaries of the human are pushed open through traumas and contagions. This is highlighted in the poem, 'Animal Instinct':

> the removal of weight to
> flee faster from predators—
> I wish I had known what it meant
>
> a reaction called *abnormal*
> it took me too long to realise
> that I should have listened
>
> my emotional extremities go cold
> at the thought & as they warm & thaw
> they grow a newfound sensitivity[40]

The speaker is a recognising that illness and health are heavily impacted by external factors such as trauma. In the speaker stating that her 'emotional extremities go cold' and 'grow a newfound sensitivity', she is acknowledging that she needs to be conscious of the situations she finds herself in, and that as she is impacted by these things profoundly, she must appreciate safety as a factor of health.

In what is roughly the middle third of the text, the speaker explores how the boundaries of the body are broken through contagion and environmental factors. Specifically, she considers the impact of covid-19 on extremely clinically vulnerable people, and how the pandemic was handled regarding disabled people.

Initially, when writing this collection, I did not want to discuss the pandemic, despite the impact it was having on my life, and more generally throughout the world[41]. Many people had already spoken on this topic, and I feared that I would not be producing innovative or original work. Yet, as I wrote about my own health, whilst reflecting on my day-to-day

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[40] Lucy Hurst, 'Animal Instinct' (p. 25 of this document) ll. 10-18.
[41] The thesis was written in 2020-23. I had to shield within this time, officially and unofficially.

experiences, it became inevitable that my practice would be informed by the monumental changes and threats that we all found ourselves in. In allowing myself to write from this perspective and letting myself have time to process, I found that I was writing about the more nuanced experiences of the fears I had (or still have) and the adjustments I've had to make, rather than the initial feeling of discontent towards how the government was handling the situation[42].

Throughout the pandemic, I have been forced to reconsider my own environments and how my body as a part of it, as I imagine many readers will have too. In seeing and living through such tragedy, we are reminded of the absolute fragility of human life, and it truly emphasised how we are all dependant on healthy environments to survive. This has been reflected into my poetry, with the speaker asking:

> what am I supposed to do if I
> can't stop thinking about bacteria?
>
> I'm full of the thought
> in my lungs   in my veins[43]

The pandemic also raised questions about where the boundaries of the human body are, and just how easily these boundaries can be broken (especially by bacteria). In discussing covid-19 in my creative work, I was able to look at how disabled and chronically ill people have been treated by the government, what the threat still is for immunosuppressed people, and highlight the types of isolation (both physical and social) disabled people can face from a lack of accessibility. Whilst also being able to make the reader consider their environments in greater detail, by considering themselves as part of the environment. In drawing upon a shared experience for the readers—though all experiences of the pandemic will have been different—the reader is put in an empathetic position as they also relate to the experience.

In the final section, I explore ideas of internalised shame, translation of pain to language, living with the aftereffects of trauma and with illness more generally, and friendship and solidarity. In exploring these topics, I feel that the collection is given a sense of balance. In shifting away from heavier topics of illness, medicine and consent, the speaker considers

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[42] Although, this does also bleed into the text.

[43] Lucy Hurst, 'Extremely Clinically Vulnerable' (p. 33 of this document) ll. 53-56.

how, even if language fails, she can explore herself through the care that other people have for her. This section has a hopefulness, not of overcoming disability, but of solidarity and care. These poems have themes of self-understanding with the support of others, the limitations of language, and rejecting ableism. In this section, the reader is given moments of relief, and the collection is grounded in a reality of experience, as demonstrated in a passage taken from ‘Everything is Blue’:

> when I can’t grasp at words   I know
> I can grasp onto you—
> you know me enough that the answer
> no longer matters   how lovely
> it is to be seen through the eyes of
> someone who loves you this much[44]

The speaker moves from the more claustrophobic experiences into discussing the more liberating ones. She starts to embrace a certain beauty in experiences evading symbolic language and categorisation. In the poem ‘The Guts I Have Left’, the speaker is shown to be embracing illnesses evasion of language, and how the boundaries of her body, which were impeded in a distressing way through medical testing, have always been impeded on by her environments. The speaker remarks:

> when irony is undone from its cruelty
> & all the things we’ve separated
> show themselves as not separate at all
>
> & nuance becomes human
> & human becomes human
>
> […]
>
> these symptoms are my living proof
> of a person distilled by a brutal world
> to make a pain as primal & real[45]

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[44] Lucy Hurst, ‘Everything is Blue’ (p. 42 of this document) ll. 32-37.
[45] Lucy Hurst, ‘The Guts I Have Left’ (p. 52 and 55 of this document) ll. 18-22, ll. 36-38.

The collection ends with the speaker performing surgery on herself—or at least imagining that she is. There is an intentional ambiguity to what is happening, whether it is figurative or literal. I have done this to reflect the exploration which she has done throughout this collection—there are moments of physical exploration (as literal) and moments of introspection (which is done through figurative language). This figurative and literal exploration culminates in the final poem where the speaker is lost in a fantasy which 'catches up on [her]'[46]. In using this metaphor of self-surgery, the pain and precision of self-discovery is emphasised to the reader as something which is both messy and brutal, but also as liberating and exciting. The clinical world of surgery is brought into the domestic sphere of the bathroom with a household 'paring knife', representing how the speaker's understanding of bodily knowledge shifts away from pathologisation, into a more personal self-exploration away from ableism. The speaker has, in some way, dissected herself through changing her definition of bodily knowledge, taking apart ableism, and understanding more about the ways she is impacted by, and made up of, environmental factors ('recycled air & / germs I have collected like a magpie'[47]).

In 'Self-Surgery', the speaker is both thrilled and distressed at what she is learning (and at her chosen methods):

> I follow muscle to bone
> *god I feel it   I feel it now*
> the fantasy catches up on me
>
> I'll have made such a mess on the floor
> & be quickly out of my depth[48]

This surgery is a form of self-exploration, one in which she has control over her autonomy. The speaker has a newfound sense of curiosity which helps her to realise how she is made up of things she had thought were external to her body. The poem ends with the lines:

> but I'm reassured in thinking   when I go
> I return as something else entirely[49]

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[46] Lucy Hurst, 'Self-Surgery' (p. 61 of this document) ll. 30.
[47] Lucy Hurst, 'Self-Surgery' (p. 60 of this document) ll. 18.
[48] Lucy Hurst, 'Self-Surgery' (p. 61 of this document) ll. 28-32.
[49] Lucy Hurst, 'Self-Surgery' (p. 61 of this document) ll. 38-39.

In the end, the speaker is coming to terms with her health and disability being shaped through environment, and how they not strictly clinical matters, but are intimate, on a cellular level, and are informed by the mundane and the personal (‘liver teeming with alcohol / from first dates & the stuff of life / gushing to my bleeding liberal heart’[50]). Whilst she is claiming autonomy within her health and disability, she is letting go of her attempt at control over what impedes on her body (as it is a boundary that she realises she cannot fully control, or only in limited ways) and instead sees a beauty to being made up of the world and the fragility that comes with it. She is comforted in the security of this relationship, so much so that even in death, she will be at peace with the idea of becoming some other part of the world.

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[50] Lucy Hurst, ‘Self-Surgery’ (p. 61 of this document) ll. 30 ll. 25-27.

Found materials

In this collection I chose to use found materials from my own medical literature to create a sense of closeness through an engagement with the reader. In adding the found materials of the covid-19 letters from the government and local councils, the reader is immersed within the text and interacts with the same materials as the speaker. These texts detail rules which the speaker (and myself at the time) had to follow, yet when read in this different context, the isolation of the speaker is emphasised to the reader. In the original texts, these passages, for the most part, are a small sections of four-page long documents. They are easily overlooked when in their original context, but in this framing, they become stark, implying a social isolation as well as a physical one. They read:

- ‘minimise the time you spend with others in shared spaces (kitchen, bathroom and sitting areas) and keep shared spaces well ventilated
- aim to keep 2 metres (3 steps) away from others and encourage them to sleep in a different bed where possible
- use separate towels and, if possible, use a separate bathroom from the rest of the household, or clean the bathroom after every use
- avoid using the kitchen when others are present, take meals back to your room to eat where possible, and ensure all kitchenware is cleaned thoroughly.[51]

I also chose to include these texts as much of my own experiences with healthcare have come with a bombardment of paperwork, with administrative tasks being time consuming and endless. I wanted to include these letters as they highlight the extent to which these papers, and the medical system more broadly, can dictate our lives. This is particularly true in the case of the GP letter. At the time, I had faced ableist comments in an interview for a job, and needed to get a letter from my GP to confirm that my chronic illness is not contagious. It reads:

> Please note Lucy suffers from a condition called Ulcerative Colitis. This condition can cause abdominal pain, nausea, diarrhoea, vomiting, but this is not a contagious condition.[52]

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[51] Lucy Hurst, ‘Extremely Clinically Vulnerable’ (p. 28 of this document) ll. 17-24.

[52] Lucy Hurst, ‘On Being Contagious’ (p. 41 of this document) ll. 67-68.

I wanted to include this letter particularly as it grounds the text, and forces the reader to participate, further creating a closeness with the reader. This letter is an emotionally-charged text for me as it implies the ableism that I was facing at the time, and how I was not fully aware of my rights, or was desperate enough to overlook them[53].

In drawing on found materials, I took inspiration from contemporary poets such as Romalyn Ante. In her debut collection *Antiemetic for Homesickness* (2020), Ante writes on her experiences migrating from the Philippines and as a nurse in the NHS. The collection starts with a poem titled ‘Half-empty’, in which Ante uses the formal elements of side-effect leaflets to explore the benefits and difficulties of migrating as a parent within the medical field. It commences with an epigraph:

> ‘The Philippines must be half-empty; you’re all here running the NHS.’ -PRINCE PHILIP, DUKE OF EDINBURGH[54]

For the reader, this epigraph both establishes the theme of the poem and, as this remark reads as ambiguously a compliment and an insult, the reader anticipates a political undercurrent to the work. The poem then follows:

> *Drug:*
>
> Migrationazoline (available in full of half-empty bottles)
>
> *Indications*:
>
> - prophylaxis of parents who nag like surgical drills saying they did not send you to college to become a healthcare volunteer
> - episodic blindness secondary to power cuts
> - ulcers on the lips from eating *kamote* or *kangkong* every night
> - chronic ache for a house and garden of your own
> - chest tightness and/or dyspnoea as you watch your child drool over Special Siomai[55]

Ante’s use of appropriated medical language and form is an effective way of entangling the personal into the clinical and dispassionate medical, as it immerses the reader into both worlds.

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[53] Though, notably, I have informed the company since of this behaviour.

[54] Romalyn Ante, *Antiemetic for Homesickness,* (London: Random House, 2020) p. 9.

[55] Romalyn Ante, *Antiemetic for Homesickness,* (London: Random House, 2020) p. 9, ll. 1-9.

It is a creative way of providing context to the reader and establishing themes, and the intended perspective of the speaker. Whilst I have included my medical literature as explicitly found materials—as opposed to embedding it into poems—I wanted to achieve this same effect on the reader.

Play as Process

In my writing process, I experimented with the form many of these poems would take, and what the effect it would have on the reader. The poems which changed form the most throughout this process were the ‘Extremely Clinically Vulnerable’ sequence. Initially, I wanted to draw upon the formatting of the *DSM-5-TR*, using listing, capitalisation, and notes. Shown below is an example of an early version of what was originally the first poem in this sequence, which was eventually cut from the collection.

CRITERIA FOR A PAINFUL REALITY

A. The medicalisation of life is soul-destroying. I think I’m going insane thinking about it. any problem which persists longer than six months can be made psychiatric.

B. Presence of the following:

    1. Persistence
    2. Fixation
    3. Avoidance
    4. Numbness
    5. Loneliness

C. PERSISTENCE
D. mid-pandemic, the term ‘prolonged grief disorder’ clogs my twitter feed. PGD meaning grief illness.
E. every story I hear of farewells sent via text breaks my heart
F. & every offensive governmental decision feels like drinking petrol I can no longer afford
G. no amount of sertraline undoes unprecedented death. grief is harrowing and desolate and hard but not shameful, not for us.
H. it is shameful for those that danced & drank on the bodies piling high

Note: the anger I feel for all the harm done may soon be categorised into the DSM, under *living in England disorder.*

Whilst I think this form certainly has its merits—such as the subversion of expectations and the challenge for myself to conform to the structure—but I felt that these poems stood out too much in the overall book formatting. I had also experimented in turning poems into graphs.

Below is a poem called ‘Avoidance’ which would eventually make it into the sequence, but in a different form:

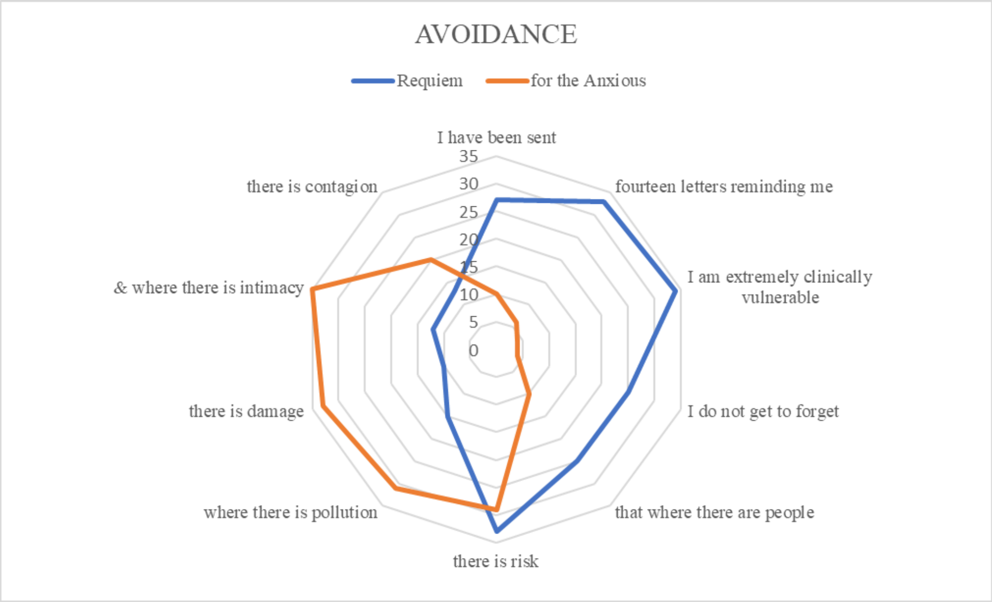

Figure 2- A section of ‘Extremely Clinically Vulnerable’ make into a graph form.

I would like to experiment with these forms more in the future in a different project as I they have an interesting playfulness and subverts how these forms are typically used. However, for this collection I felt that their prominence was jarring when compared to the other poems, and this was pulling the reader out of the text.

During the construction of this collection, I contemplated the wider book through, what I referred to as ‘the wall’. I had covered one of the walls in my bedroom with pages from my collection, as shown below:

Figure 3- 'The Wall' is a wall in my bedroom covered in poems from Gut Feeling.

In using 'the wall' to help visualise the collection, I started to observe themes and patterns that I hadn't otherwise noticed. This technique helped me to recognise that, as I discussed earlier, when ordered in a certain way, the speaker goes through a narrative arc of self-exploration and developing a sense of control and curiosity. This stage of construction also highlighted poems which did not fit with the rest of the collection, such as the graph, which were then either cut or changed forms.

Throughout writing this collection, I have found it difficult to decide what it was that I wanted to say. I find play and risk-taking key in my creative practice as it helps me to explore topics from a different perspective and within different restraints. Play with form has become necessary to my work as it makes me realise what it is I want to say, exactly, through how I respond to the form—whether it is restricting, challenging, or helping me as I explore these topics. Poetry has acted as a research method for me as writer as it is a reflexive practice, and my thinking and the message of the poem has adapted depending on form and structure.

One of the most difficult parts of writing this collection was initially putting the words on to the page—it was much harder than I thought it would be. I had underestimated quite how traumatising some of these experiences were, and how much fear I had about people knowing some of these experiences. I started to see writing about my health as a bit of a dare for myself, it was a challenge beyond my comfort zone, as I was still getting used to even talking about the topic with anyone outside of close family and medical professionals. I spent the most part of a year struggling with getting my thoughts onto paper. I was advised to start making lists of things I wanted to share, and what I felt I needed to keep for myself. I had lists of experiences and feelings I wanted to explore but writing the initial drafts of some of these poems felt incredibly jarring to me as much of the writing felt life reliving or reimaging. My supervisors said, if it helped, to imagine that I was just writing to them, and that they would be the only people to read them. This helped in many ways, as I do trust them to look at this work for its craft rather than an ableist approach. I decided to experiment and challenge myself in the content of my writing.

In my transfer meeting, I was asked about catharsis in my work, and whether I experienced it in the writing process. The answer was yes and no. For some of the poems, I felt that I could explore a rage I had bottled up about losing my autonomy through medical testing, and at governmental decisions which heavily impact my life. Such as noted in the poem ‘Used to It’:

> I’ve become docile in ways I don’t want
> to be—[56]

It felt great being able to let myself feel this anger and recognise that these things can feel traumatising. It has been more cathartic and freeing to have these poems exist beyond the thesis, such as in readings and publication.

Yet, in writing the first drafts of many of these poems, I felt a surprising amount of fear from having to reimagine some of these experiences again whilst I was finally in remission. When I started this thesis, for the first time since my diagnosis of Colitis, I was entering remission (or in a way which I felt could last for a while). Whilst I still have a few symptoms of my Colitis, and other conditions I have, I have not felt as concerned about potential hospital

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[56] Lucy Hurst, ‘Used to It’ (p. 21 of this document) ll. 9-10.

trips or having to find new ways to get work done around symptoms. So, at times, I really did not want to discuss these topics at all. It felt like I was encouraging my illness—I was no longer consumed by the thought of it, and now that I could free my mind up to think about anything else, I was still choosing to explore illness. I feel that as this topic is so substantial within my life, I owe it to myself to explore it creatively, and to work though the mixed and overwhelming feelings that come with it.

As I have discussed in this chapter, my practice has been greatly influenced by the work of contemporary disabled poets, and how their use of formal techniques creates a closeness with the reader, immersing them in depictions of disability. I felt it was necessary to use forms that best enables of disability, autonomy, intra-activity, etc., that consistently ground the poems in a personal reality. Without this grounding in the personal, a layer of meaning and significance is lost on the reader.

Chapter 2

Body-Mind Meets World

[Content warning: illness, ableism]

Poet's Note

I became chronically ill shortly after turning sixteen. I had been diagnosed with Ulcerative Colitis—a chronic inflammation of the large intestine—which has had a profound impact on my life. When my symptoms first started, I did not tell anyone for about a week. I did, eventually, because *I hope it just goes away,* very quickly became, *please take me to A&E.* I had felt such an intense shame and embarrassment about my symptoms that I delayed getting help as much as I could. However much I would have considered myself an ally to disabled people—or at least considered myself as accepting—I had no idea of the internalised ableism I was harbouring until I became ill.

Within the span of a few months, I went from a reasonably healthy teen, to profusely vomiting, losing blood in diarrhoea, and becoming underweight and deeply afraid. The feeling of shame seemed to run parallel to being ill, constantly blocking me from speaking up and sharing how I was really feeling. It is only years later that I revisit these feelings and share what it was, and still is, like.

In the few years that followed my diagnosis, I started to acknowledge that this shame was not helping me get into remission, it was hindering me. From avoiding using a cane at school when needed, to trying to ignore my pain, internalised ableism was preventing me from caring for myself properly. Over time, I became better at asking for help, though it was still something I did not want to talk about openly. I remember, briefly, referring to myself as 'not so able-bodied'—it was an awkward stepping stone, a phase I imagine a lot of us go through. Over time, I had also started to collect other diagnoses—as many chronically ill people will likely relate to—and in the process, I was forced into properly taking care of myself as a matter of survival. Coming to terms with the idea that this would be my new way of life was difficult, but slowly, 'disabled' became a term I started to engage and identify with. It has taken a long time to undo this shame—in fact, I'm still working on it, but through acknowledging that I was having these uncomfortable feelings about my health I learnt how to care for and respect myself more.

It took a while before I was willing to put these experiences into poetry. Before, I had only written semi-cryptic diary entries and complaints in text messages. When I started to hit a breaking point, I decided to start channelling my frustration and fear into writing.

My ulcerative colitis had started to flare again after finishing my undergraduate degree—it had been on and off throughout, but now the steroids were becoming far less effective. I was hospitalised and came out on a significantly higher dose. Something started to feel very wrong, and I was feeling sensations of pain that I had not felt before. It became very difficult to walk, to read, to stay awake. These symptoms are common with colitis, but not often to this extent—I was struggling profoundly, and I did not know what was happening to my body. I soon moved back in with my parents, to whom I am grateful.

I had stayed on at university to do my Masters, as I could travel in and eventually classes were put online[1]. Within the first few months, I was hospitalised again. This time, because I had been given a drug to help with the pain—which worked, to some extent, but had knocked me out of remission to do so.

When I was returning to class, the pain had eased slightly but I was still consumed by the thought of it—I had become so aware of the sensations in my body, many of which I had not experienced before. When asked to write on a topic or in a specific style, I would keep coming back to pain and disability. I wrote a pamphlet of poetry that year, which ended up becoming *Modern Medicine*[2]. I had dived into research on disability theory and disabled poets and learnt new and healthy ways to think about myself and to process what I was going through. In this research, I became aware of the need for self-care and taking rest seriously. By beginning to dismantle internalised ableism surrounding the expectations of professionalism and productivity, I realised that it was okay to pace myself, to write from my bed, and do things in different ways where I could put my health above everything else.

I chose to take a class called ‘writing the environment’, a class which transformed my thinking. By now, I was already contemplating how disability had seeped into every aspect of my life, it was (and still is) an instrumental factor in how I experience life and the world. I was able to note how my illness changed, not just over time, but how much my body-mind[3] reacted

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[1] As, at the time, covid-19 broke out in England.

[2] Lucy Hurst, *Modern Medicine* (Manchester: Fly on the Wall Press, 2021).

[3] I follow Eli Clare in using the term ‘body-mind’, meaning mind is entangled into body, and is meshed into and consequently becomes environment. I am using this term as the dichotomy of mind and body within this context is inappropriate as I am demonstrating how these boundaries are not definitive.

to my emotional state, to what food I ate, to the exercise I was or wasn't doing, to levels of pollution, to heat, to every kind of experience. Yet, through this class, I was challenged to think about the boundaries of the body and the influence of the non-human on my own life. Ecocriticism has become equally influential in changing the way I perceive myself, in that it provides a framework that goes against individualistic and ableist narratives, showing disability to be a part of human biodiversity. I realise that in being in the medical system for as long as I have, I have failed to consider so many aspects of health, and it is through using ecocriticism that I can expand the way I perceive myself and the factors that form my health. Gradually, my perception of my health has shifted from *my body is the problem*, to *my body is reacting in natural ways to its environments and circumstances*. Through the intersection of disability theory and ecocriticism, I understood the extent to which my health is formed and exacerbated by factors which I had previously considered as being beyond the parameters of my body. These 'external' forces have always been at play inside of me—from the food and drink I consume, to the bacteria I need to survive.

This investigation is personally meaningful to me as I want to find out, and demonstrate, how perceptions of ill health and disability through the medical lens can skewer our viewpoints, and through changing how we speak about disability, we can view ourselves and others in a kinder, more holistic, light.

> I've taken to correcting degrading comments
> that seep into my line of thinking.
> standing under the harsh bathroom light,
> pulling myself back, no longer as corrosive
> but to softer, softer.[4]

This is where my exploration begins.

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[4] Lucy Hurst, 'High Risk / High Reward' (p. 12 of this document) ll. 26-30.

Defining Disability

‘Our beautiful crip bodies, broken or bent, and whole.’

Laura Hershey[5].

I have introduced the idea that ‘disability’ has become part of my identity. In this section, I explain what this word means and how I am going to use it in this thesis.

Throughout much of Western history, disability has been understood in narrowly physical terms, as those with impairments and conditions who were, broadly speaking, ‘lacking an ability’[6]. John Simpson, lexicographer and former chief editor of the Oxford English Dictionary, argues in *The Word Detective: Searching for the Meaning of It All at the Oxford Dictionary*, that the word ‘disability’ was first used in the English language in the Middle Ages and was used as a more ‘neutral’ term than other words used at the time to describe those with physical or mental conditions, ill, or impaired individuals. He writes:

> Our first record of the term dates from 1545, in the general sense “lack of ability (to do something).” […] But the specific application of the word to a person’s mental or physical incapacity also comes from around the same period: it was first noted in 1561, and contrasts strongly with many of the other words used at the time (such as *imbecility*, *dumbness*, etc.) for personal-disability terms which are now no longer regarded as acceptable. […] The word *handicap* dates from the seventeenth century, over a century after *disability*. It comes from a time when the English enjoyed experimenting with new vocabulary. But at first the term had nothing to do with disability. In the beginning, *handicap* was a game. As the OED [Oxford English Dictionary] says, it was “a game in which one person claims an article belonging to another and offers something in exchange, an umpire being chosen to decide the difference of value between the two articles, to be made up in money by the owner of

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[5] Laura Hershey, *Translating the Crip, poets.org* (2010) <https://poets.org/poem/translating-crip> [accessed 24th April 2023] ll. 21.

[6] Historic England, ‘Disability from 1486-1660 ([n.d.]) <https://historicengland.org.uk/research/inclusive-heritage/disability-history/1485-1660/> [accessed 11th October 2023]. para. 4 (Laws and Social attitudes). Historic England references the Poor Law Acts, where disability was being used as an umbrella word. ‘The person naturally disabled, either in wit or member, as an idiot, lunatic, blind, lame etc., not being able to work…all these… are to be provided for by the overseers of necessary relief and are to have allowances … according to…their maladies and needs.'

> the less valuable one.” The handicap, then, is the difference between the value of two items, or the value you have to add to one to make it equivalent to the other. [..] It wasn’t until around 1888 that the handicap was first applied to physical or mental disability. The earliest records for this come from the United States. At first it was regarded as a perfectly normal expression—an acknowledgement of the difference in ability between two people. But, by the later twentieth century, *handicap* had come to be considered generally unacceptable: an unfamiliar-looking word implying too marked and dismissive a distinction between the able and the disabled. Maybe the expression also seemed to imply going “cap in hand” to beg for public assistance[7]

As term ‘disability’ has been used as a more neutral term in comparison to ‘handicapped’ for the attached connotations that Simpson discusses, many disabled people and disability rights groups chose to adopt this term[8]. I am using the term ‘disability’ throughout this thesis, as it encompasses a ‘shared human experience of embodiment’[9]. As an umbrella term, disability can encompass a range of impairments, physical difference, chronic illnesses, and neurodiversity[10]. The word itself is intentionally broad, but as argued disability rights activists, such as Disability Rights UK, using the term can be viewed as a form of collective action[11].

Here, I will also recognise that not all experiences of disability are inherently painful or distressing, they may come with their own joys, and for many the most distress comes from a lack of accessibility as opposed to the condition itself.

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[7] John Simpson, *The Word Detective: Searching for the Meaning of It All at the Oxford Dictionary*, (New York: Basic Books, 2001) p.189-190).

[8] Celebrating Disability, ‘Disability Language: How To Talk About Disability’ ([n.a]) <https://celebratingdisability.co.uk/disability-language/> [accessed 11th October 2023] para. 12.

[9] Rosemarie Garland-Thomson, ‘Integrating Disability, Transforming Feminist Theory’, NWSA Journal, Vol. 14 (2002), pp 1-32 (4).

[10] Evie Lee, *What are the Different Types of Disability* (2022) https://cpdonline.co.uk/knowledge-base/care/different-types-of-disabilities/ [accessed 26th July 2023].

[11] Disability Rights UK, *Social Model of Disability: Language* ([n.a.]) <https://www.disabilityrightsuk.org/social-model-disability-language#:~:text=A%20Disability%20is%20caused%20by,by%20barriers%20constructed%20by%20society.> [accessed 26th July 2023].

The Disability Rights Movement

In the United Kingdom, the formation of the first organisations run *by* disabled people *for* disabled people was a pivotal moment in the disability rights movement. These included the British Deaf Association and the National League of the Blind, which were both established in the 1890s[12]. Early disability rights organisations which encompassed a variety of disabilities, such as the Union of the Physically Impaired Against Segregation (UPIAS) (1972), shaped definitions of disability by developing the 'social model of disability' which emphasised the inaccessibility within society. In 1975, London, a meeting between UPIAS and The Disability Alliance was held to establish the 'fundamental principles of disability'. As taken from the meeting notes:

> Fundamental principles to which we are both in agreement: disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed.[13]

In establishing the social model of disability, in which disability is 'a situation caused by social conditions', the emphasis is shifted away from the individual's physical or mental impairment, and instead placed on how societal structures are 'disabling' on the individual. With the limitations faced by disabled people stemming from systemic ableism, creating 'social isolation, oppression and exclusion from participation in social life'[14] The Union aimed to:

> have all segregated facilities for physically impaired people replaced by arrangements for us to participate fully in society. These arrangements must include the necessary financial, medical, technical, educational and other help required from the State to enable us to gain the maximum possible independence in daily living activities, to

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[12] The British Council of Organisations of Disabled People (BCODP), *The Disabled People's Movement, Book Four* (Equal Ability,1997). This version has been accessed through the university of Leeds. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/BCODP-workbook4.pdf> [accessed 11th October 2023] p. 9, para. 1.

[13] The Union of the Physically Impaired Against Segregation, The Disability Alliance, *Fundamental Principals of Disability* (London: Union of the Physically Impaired Against Segregation, 1975). This version was accessed through the Disabled People's Archive <https://disabledpeoplesarchive.com/fundamental-principles-of-disability-union-of-the-physically-impaired-against-segregation/> [accessed 11th October 2023] p. 3, para. 5.

[14] Juan Toro; Julian Kiverstein; Erik Rietveld, 'The Ecological-Enactive Model of Disability: Why Disability Does Not Entail Pathological Embodiment', *Frontiers in Psychology*, vol. 11 (2020).

> achieve mobility, to undertake productive work, and to live where and how we choose with full control over our lives.[15]

In advocating for disability to be understood as socially constructed, these organisations aimed to address systemic ableism and discrimination within society. 'Disability' started to be perceived through its social contexts, and as much of a 'a symptom of historical and cultural contingencies as it is a physical and psychological reality'[16].

In 1981, the United Nations International Year of Disabled Persons (IYDP), the British Council of Organisations of Disabled (BCODP) was established, including notable groups such as UPIAS. BCODP became a significant national voice in advocacy for disability rights. In taking influence from American activists and the Americans with Disabilities Act (ADA), BCODP protested social security cuts in 1988[17], and advocating for anti-discrimination legislation[18] (1995[19], 2005[20], and 2010[21]).

In more recent research and activism[22], the social model, which was supported by many disabled activists in the Disability Rights Movement, has also come under scrutiny, as investigating a specific aspect can become reductive in considering disability. Critical disability theory highlights that impairment cannot be isolated from social contexts, which in turn construct the way we perceive them[23], and that disability should not be understood only

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[15] Union of the Physically Impaired Against Segregation, *Union of the Physically Impaired Against Segregation* (1976). This has been accessed through the University of Leeds <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/UPIAS-UPIAS.pdf> [accessed 11th October 2023] para. 1.

[16] David T. Mitchell; Sharon L. Snyder, *Narrative Prosthesis* (Ann Arbor: The University of Michigan Press, 1997), p. xiv.

[17] Disabled People's Archive, 'BCODP Day of Action, London – 1988' ([n.a.]) <https://disabledpeoplesarchive.com/1988-bcodp-day-of-action-london/> [accessed 11th October 2023].

[18] The British Council of Organisations of Disabled People (BCODP), *The Disabled People's Movement, Book Four* (Equal Ability,1997). This version has been accessed through the university of Leeds. <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/BCODP-workbook4.pdf> [accessed 11th October 2023] p 10.

[19] The *Disability Discrimination Act 1995*. <https://www.legislation.gov.uk/ukpga/1995/50/contents> [accessed 11th October 2023].

[20] The *Disability Discrimination Act 2005* <https://www.legislation.gov.uk/ukpga/2005/13/notes/division/2#:~:text=The%20DDA%2C%20as%20originally%20enacted,disposal%20and%20management%20of%20premises.https://www.legislation.gov.uk/ukpga/2010/15/contents> [accessed 11th October, 2023].

[21] The *Equality Act 2010*, <https://www.legislation.gov.uk/ukpga/2010/15/contents> [accessed 11th October 2023].

[22] Around the 2010s and onwards.

[23] Sarah Jaquette Ray, 'Risking Bodies in the Wild', in *Disability Studies and the Environmental Humanities: Towards an Eco-Crip Reader* (United States of America: University of Nebraska, 2017) p. 33.

as an impairment, or as a physical limitation[24], but also 'a form of [societal] disadvantage which is imposed on top of one's impairment'[25]. As Rosemarie Garland-Thomson writes in 'Integrating Disability, Transforming Feminist Theory':

> Disability—like gender—is a concept that pervades all aspects of culture: its structuring institutions, social identities, cultural practices, political positions, historical communities, and the shared human experience of embodiment.[26]

Disability theorist Tom Shakespeare adds in *Disability: The Basics*, that we cannot reduce disability down 'to either a biological problem, a psychological problem, or a social problem', we must instead appreciate the complexity of disability. He writes:

> Disability differs from the other identity politics […] Thinking of people who are from a minority ethnic community, if you remove racism and discrimination from the equation, there is no reason why they cannot flourish and compete equally with the majority ethnic community. [...] Yet for disabled people, even after discrimination and prejudice is removed, inequalities are likely to remain. The level playing field does not liberate everyone. For some people with impairments, barrier removal is not enough. [....] We cannot reduce the complexity of disability to either a biological problem, a psychological problem, or a social problem. We need to take account of all the factors and intervene at all the different levels to benefit and include disabled people. […] Disability is not simply a natural phenomenon: it is always influenced by social relations and cultural values. Whereas illness and impairment have been experienced across human existence, there have been very different reactions to it, from incarceration, to elimination, to fascination and sometimes inclusion. In different societies, disabled people have lived very different lives.[27]

What Shakespeare is describing is a model which follows a biopsychosocial approach, one which I will also be following. This approach acknowledges the socio-political contexts and biological realities of disability and its intersections. When considering the lived experiences of and barriers disabled people face, it is beneficial that disability is viewed through a myriad

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[24] *Critical Disability Theory* (2019), *The Stanford Encyclopaedia of Philosophy* <stanford.edu/entries/disability-critical/> [accessed 24th April 2023].

[25] Shelly Tremain, *Foucault and the Government of Disability* (Ann Arbor: University of Michigan Press, 2005) p. 9.

[26] Rosemarie Garland-Thomson, 'Integrating Disability, Transforming Feminist Theory', *NWSA Journal*, Vol. 14 (2002), pp 1-32 (4).

[27] Tom Shakespeare, *Disability: The Basics* (Oxfordshire: Routledge, 2017) p 20-24.

of factors as acknowledging its complexity can advance discussions on the intersections between impairments and social oppression, both on a societal and inter-personal scale. I will also be drawing upon the same approach. In acknowledging that disability is formed of a myriad of factors, when considering lived experiences and barriers that disabled people face, disability can be viewed in a way which encompasses both challenges that arise from impairment, the social oppression, and how these interact and overlap with one another

The Medical Model

> ‘tear up the diagnoses
> let them rain down
> like pride parade confetti’
>
> Eli Clare[28].

In this thesis, I will not be using the medical model of disability, but in this section, I will provide context as to what this model is, and why many disability theorists, activists, and disabled people alike choose not to use it.

Historically, disability in the West has been largely understood through the medical model[29]. This model of disability originates from within the medical profession, regarding disability as something to be ‘cured’ and treated, whilst largely overlooking the impacts of socio-economic factors on health[30]. *Physiopedia*, an online medical resource, defines the medical model as:

> focused on pathology and impairment, which describes disability as a consequence of a health condition, disease or injury/trauma that can disrupt the functioning of a person in a physiological or cognitive way. It then focuses on the prevention or treatment of the condition, which is generally lead by the physician who directs the delivery of the service, with the physician being the decision-maker in the process[31].

In focussing on ‘pathology and impairment’, isolated from its social construction, the medical model creates a reductive perspective of disability which posits physicians as the sole authority on the knowledge of the condition. This understanding of disability has been disregarded by many disability theorists due to the implications it has on disabled people, both as category of people and on an individual level.

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[28] Eli Clare, ‘The Art of Disassociation’, *Split This Rock* (2022) <https://www.splitthisrock.org/poetry-database/poem/the-art-of-disassociation> [accessed 11th October 2023] ll. 6-8.

[29] It still remains in use today, albeit less frequently.

[30] Charles E. Drum, ‘Models and Approaches to Disability’, *Disability and Public Health* (Washington D.C.: American Public Health Association, 2009) p. 28.

[31] *Conceptual Models of Disability and Functioning* ([n.d.]), *Physiopedia* <https://www.physio-pedia.com/Conceptual_Models_of_Disability_and_Functioning> [accessed 28th March 2023].

The Alaska Mental Health Consumer Web, an American mental health charity and support centre, argues that that in placing emphasis on cure, rather than a more holistic approach, the medical lens creates a perspective of disability as being an 'abnormality'. The Web writes:

> The Medical Model places the source of the problem within a single impaired person and concludes that solutions are found by focusing on the individual. […] In simplest terms, the Medical Model assumes that the first step solution is to find a cure or — to use WHO terminology – make disabled people more "normal". This invariably fails because disabled people are not necessarily sick or cannot be improved by remedial treatment. The only remaining solution is to accept the "abnormality" and provide the necessary care to support the "incurable" impaired person. […] This Functional-Limitation (Medical) model has dominated the formulation of disability policy for years. Although we should not reject out-of-hand its therapeutic aspects which may cure or alleviate the physical and mental condition of many disabled people, it does not offer a realistic perspective from the viewpoint of disabled people themselves[32].

Through the medical model, individuals who are in some way impaired are treated as an abnormality and in need of 'curing'. As disability theorist, Simi Linton, adds in *Claiming Disability: Knowledge and Identity*, this model posits disabled people as 'deviance from the norm, as [a] pathological condition, as [a] defect, and, significantly, as an individual burden and personal tragedy'[33]. Eco-crip theorist and poet, Eli Clare, highlights in his memoir and essay, *Brilliant Imperfection*, how this emphasis on cure becomes detrimental to disabled people on an individual level. He writes:

> The belief in cure tethers us not only to what we remember of our embodied selves in the past but also to what we hope for them in the future. And when those hopes are predicted on cure technology not yet invented, our body-minds easily become fantasies and projections.[34]

The idea of 'cure technology' is simply not a reality for most disabled people, and this focus on a disabled body as one to be 'cured', comes with consequential implications on how disabled people are perceived socially and by themselves. For people with painful conditions, an emphasis on cure becomes a fantasy, wishing for something which has not been created yet.

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[32] *Models of Disability: keys to perspectives* ([n.d.]), *The Alaska Mental Health Consumer Web* < https://www.theweb.ngo/history/ncarticles/models_of_disability.htm> [accessed 28th March 2023].
[33] Simi Linton, *Claiming Disability: Knowledge and Identity*, (New York: New York Press, 1998) p. 11.
[34] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (North Carolina: Duke University Press, 2017) p. 87.

These fantasies are redundant for stopping pain in the present. It is counterproductive and constructs a reductive view on pain—through this lens, pain is to be eradicated (such is usually not possible) instead of being continually cared for and attended to. In my own experience, the fantasy of 'cure' has been something I actively try to dissuade myself from thinking about. I have known from moments of diagnosis that my health concerns are not yet curable, but in wishing that they are, I am desiring for body-mind to be changed profoundly, which I feel is an unhealthy approach.

Those who consider their disabilities as differences, and may not experience painful realities, may not want to be 'cured' at all, and are instead seeking acceptance and accommodation within society. The focus on 'cure' here is something which is inflicted upon the individual by society—when politicised, this can become a vehicle for immense social violence. Clare demonstrates how this hyper-medicalisation can immediately create political implications from the moment of diagnosis:

> Diagnosis names the conditions in our body-minds, charts the connections between them. It holds knowledge. It organizes visceral realities. It draws borders and boundaries, separating fluid in the lungs from high blood pressure [....]. It legitimizes pain as real; it identifies other pain as psychosomatic or malingering. It reveals little about the power of these borders and boundaries. [....] It predicts the future and shapes all sorts of decisions. It unleashes political and cultural forces. At its best, diagnosis affirms our distress, orients us to what's happening in our body-minds, helps make meaning out of chaotic visceral experiences. But diagnosis rarely stays at its best. It can also disorient us or devalue what we know about ourselves. It can leave us with our doubts, questions, shame. It can catapult us out of our body-minds. All too often diagnosis is poorly conceived or flagrantly oppressive. It is brandished as authority, our body-minds bent to match diagnostic criteria rather than vice versa. Diagnosis can become a cover for what health care providers don't understand; become more important than our messy visceral selves; become a totality of who we are[35]

Whilst beneficial in identifying sources of pain or types of impairments, diagnosis acts as a social categorisation which means that people can be then controlled, subjugated, and excluded

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[35] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (North Carolina: Duke University Press, 2017) p. 41-2.

from society. This act of diagnosing and labelling, as Anthony J. Nocella II writes in 'Defining Eco-Ability', leads to the stigmatisation of those who are different:

> If you are not labelled normal by society, you are inherently viewed as abnormal, a threat that must be controlled, disciplined, and punished. Repressing people with disabilities has always been a complex system of stigmatization of those who are different[36]

This sentiment has been expanded upon postcolonial disability theorists, such as Shaun Grech in *Colonialism and Disability*, who argues that disability 'is a key site of colonial administrative power, a lived experience under colonial control, or a category of difference in place to maintain colonial legitimacy and control (overtly or covertly)'[37]. It is through the hyper-medicalisation inflicted upon disabled people that forms of violence are 'legitimised', leading to atrocities, eugenics, and even genocides[38]. Due to the truly immense extents of the implications for disabled people, it is imperative that the medical lens and acts within medicine are appropriately scrutinised.

The medical lens, as mentioned by Clare, 'catapult[s] us out of our body-minds', making a reductive understanding of disability, where people, and their 'messy visceral selves', can be reduced to symptoms. In 'Reification, Biomedicine, and Bombs: Women's Politicization in Vieques's Social Movement', medical anthropologist, Víctor M. Torres-Vélez, argues that through the internalisation of biological essentialism and ableism, how the body-mind perceives and reacts to the environment(s) is devalued both on a societal and individual level[39]. As a consequence of internalising the medical lens, people tend to overlook their own bodily knowledge and 'natural instinct'.

Through considering disability outside of the medical lens, and dismantling this biological essentialism framework, disability is regarded as an aspect of human biodiversity. Rob Nixon, an environmental humanities theorist, argues in *Slow Violence and the Environmentalism of the Poor* that attempts to creating 'monocultures do an immense amount of damage. So much labour and violence goes into creating and maintaining them. Their

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[36] Anthony J. Nocella II, 'Defining Eco-Ability', in *Disability Studies and the Environmental Humanities: Towards an Eco-Crip Reader* (United States of America: University of Nebraska, 2017) p. 144.
[37] Karen Soldatic; Shaun Grech, *Colonialism and Disability (Dis)encounters and anxious intersectionalities* (Oxfordshire: Routledge, 2017) p. 2.
[38] Karen Soldatic; Shaun Grech, *Colonialism and Disability (Dis)encounters and anxious intersectionalities* (Oxfordshire: Routledge, 2017) p. 2.
[39] Víctor M. Torres-Vélez, 'Reification, Biomedicine, and Bombs' in *Disability Studies and the Environmental Humanities: Towards an Eco-Crip Reader* (United States of America: University of Nebraska, 2017) p. 318.

existence requires hundreds of eradications and removals'[40]. In applying this theory to disability studies, this 'labour and violence' that Nixon describes emphasises how monocultures are not 'natural'[41]—it is a socially enforced idea. Humans have, and always will have, disability within our biodiversity. As a result, in the words of Eli Clare: 'We need to choose between monocultures and biodiversity, eradication and uncontainable flourishing.'[42]

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[40] Rob Nixon, *Slow Violence and the Environmentalism of the Poor* (Massachusetts: Harvard University Press, 2011) p. 133.
[41] Or naturally occurring, as in not appearing without enforcement.
[42] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (North Carolina: Duke University Press, 2017) p. 187.

Disability Poetry vs Crip Poetry

> ‘but the Poems with Disabilities Act
> requires us to make all reasonable
> accommodations for poems that aren’t
> normal. […]’
>
> Jim Ferris[43].

As I have established a definition of disability, I will now introduce the term ‘disability poetry’ and discuss access to the poetry industry and making texts more accessible to wider audiences.

In the United States, disability poetry prospered following the implementation of the Americans with Disabilities Act (ADA), as it provided legal support and a public awareness of disability. Disability literary scholar, Declan Gould, argues in ‘Disability Aesthetics and Poetic Practice’ that despite many poets having disabilities prior to the implementation of ADA, this aspect of identity was often not included in their poetry, likely due to the ableism within the publishing industry. She writes:

> Owing in no small part to the oppression created by the medical model, up until the late 1970s, American poets with disabilities, such as Larry Eigner, Josephine Miles, Hannah Weiner, and Vassar Miller, tended to leave disability out of their poetry or to refer to it only indirectly (one exception to this tendency was the poet Adrienne Rich, who lived with severe rheumatoid arthritis and openly wrote about the pain caused by this disability as early as 1973). Despite their unwillingness to speak directly about disability in their poetry, mid-twentieth-century disabled poets have had a strong influence on many contemporary poets with disabilities, such as Jennifer Bartlett and Jillian Weise, who have found a lineage in earlier poets like Eigner and Miles. […] American poets increasingly began to bring disability into their poetry in a more direct way in the 1980s and 1990s. Along with their embodied experiences living with disability, the work of many of these poets, such as Laura Hershey, Jim Ferris, Kenny Fries and Stephen Kuusisto, represents their involvement in the Disability Rights

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[43] Jim Ferris, ‘Poems with Disabilities’, *Facts of Life* (Wisconsin: Parallel Press, 2005) p. 14, ll. 4-7.

> Movement and disability culture and puts disability at the centre of the poetry by writing primarily for disabled (rather than nondisabled) readers. [44]

The implementation of ADA, along with the growing public consciousness surrounding disability, gave way to the disability literary movement of 'Crip Poetics'. In this movement, disability became the focal point of poetry, with the intended reader being disabled (rather than nondisabled readers). In adapting the poet Jim Ferris' terminology from 'The Enjambed Body: A Step Toward a Crippled Poetics' and drawing upon Sami Schalk's discussion on reclaiming the word 'crip' (from 'cripple'), Gould coins the term 'crip poetry'. She states:

> I call the twenty first-century poets who continue this tradition of disability culture poetry "crip poetry." In contrast, I call the twenty-first-century poets who develop disability poetics that are not written primarily for disabled audiences, and that are often based in other aesthetic movements and/or identities, "disability poetry." Such poetry is more closely affiliated with disability studies – the interdisciplinary field of disability scholarship that has been steadily growing since the founding of the Society for Disability Studies in 1986 – in the sense that, while it is concerned with investigating disability's many valences and with creating new ways of understanding disability, it does not necessarily share crip poetry's allegiance to disability activism or disability culture. The first category that I describe, Deaf poetry, consists largely of American Sign Language (ASL) poems that are performed rather than written and that develop out of and speak primarily to Deaf culture, which has its own rich history apart from the Disability Rights Movement[45].

In the current UK and US publishing industry[46], the differentiation between disability poetry and the continuation of crip poetry can sometimes be quite clear-cut, and other times can be more ambiguous. Whilst it may be distinct whether the poet is themselves disabled and if the poem focuses on disability, there are many poets who consider nondisabled readership, myself included to some extent. For example, in Karl Knights' pamphlet *Kin*[47], Knights both centres his disability whilst addressing the nondisabled readers, forcing readers to question their

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[44] Declan Gould, 'Disability Aesthetics and Poetic Practice', *The Cambridge Companion to Twenty-First Century American Poetry*, edited by Timothy Yu (Cambridge: Cambridge University Press, 2021) p. 106, para. 1.

[45] Declan Gould, 'Disability Aesthetics and Poetic Practice', *The Cambridge Companion to Twenty-First Century American Poetry*, edited by Timothy Yu (Cambridge: Cambridge University Press, 2021) p. 107, para. 1.

[46] As I write in 2023.

[47] Karl Knights, *Kin* (Sheffield: the poetry business, 2022).

assumptions about disabled people and their internalised ableism. For example, in the poem 'How to Wheel'[48], Knights writes about how his mum trying to use his wheelchair, and her assumption that it would be easy to use on all terrains. This poem reads as though it is intended for a nondisabled reader, who is similarly encouraged to change their assumptions. Equally, in 'My Nurses'[49], Knights writes about (and perhaps *to*) all the nurses that have kept him alive throughout his life. As disability and crip poetry develops and becomes more mainstream, albeit slowly, the separation between the two starts to blur regarding disabled poets who centre disability (unlike nondisabled writers discussing disability, who are not crip poets). Crip poetry is notably also more of a North American literary movement, and it is the individual preference of the poet whether they are writing as a continuation of the movement or are simply drawing inspiration from it.

In this thesis, I use the term 'disability poetry' as it is more encompassing of writers who do not exclusively consider disability, and those who may consider a wider readership. The poet I have chosen to analyse within this thesis, Wayne Holloway-Smith, has not publicly stated an interest in being classed as a crip poet. Some argue that disability poetry is not made for disabled people[50], and I want to address that my interest is not in poetry about disability written by nondisabled people, it is exclusively in the work of disabled writers[51]. As Weise argues in 'Disability and Poetry', a journal article for *Poetry*: 'there are certain kinds of disabled poems that some publishers want: the speaker overcomes disability; the speaker's friend/ relative is disabled or diagnosed; the speaker notices a disabled person on the side of the road, I avoid those poems at all costs.'[52]

For me as a writer, I do not identify myself as a crip poet, despite being influenced by work from this movement. This is predominantly a North American movement, and whilst my own writing has been influenced by crip poets, much of my work has an interdisciplinary focus (such as the investigation of environment). Equally, I write my poetry with both the disabled

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[48] Karl Knights, 'How to Wheel', *zoeglossia* ([n.a.]) <https://www.zoeglossia.org/karl-knights> [accessed 11th October 2023].

[49] Karl Knights, 'My Nurses', bath magg ([n.a.]) < https://www.bathmagg.com/karlknights/> [accessed 11th October 2023].

[50] Meg Day at the Keynote Address at the 2018 New Disability Poetics Symposium ('Dis Poetics / Crip Poetics'), for example, argued that 'its primary audience is not disabled people, it does not go far enough toward resisting the "co-opting" of disability by nondisabled poets'. This has been taken from Declan Gould's analysis. Declan Gould, 'Disability Aesthetics and Poetic Practice', *The Cambridge Companion to Twenty-First Century American Poetry*, edited by Timothy Yu (Cambridge: Cambridge University Press, 2021) p. 108, para. 2.

[51] This includes chronically ill, mentally ill, D/deaf, disabled, and neurodivergent writers, all of whom have acknowledged their disabilities or illnesses publicly.

[52]Jennifer Bartlett, John Lee Clark, Jim Ferris, Jillian Weise, 'Disability and Poetry', *Poetry* (2014), vol. 205, no.3, 271-284 (276).

reader and nondisabled reader in mind: I hope that disabled people find their experiences reflected within my work, and I consider how the nondisabled reader can learn and to sit with discomfort. For this reason, I would refer to myself as a disabled poet, but not necessarily a crip poet. I included this section on crip poetry to further uplift the voices of disabled poets and writers, and to demonstrate the poetic contexts I am working within.

Accessing the Page

> 'The exclusion of the past does not have to dictate the future of disabled poets. Now is the time to ask ourselves, what do we want the estate of poetry to be?'
>
> Karl Knights[53].

Whilst poetry itself may not propose restrictions—other than self-imposed formal elements—the industry certainly does. Poets in minorities, whether they are writing explicitly about their identities and experiences or not, may encounter more barriers or discrimination and because of this are at a critical disadvantage in the way of publishing[54].

For disabled writers, this inaccessibility within publishing is extended into the 'poetry scene' of book launches and readings. As disabled poet Karl Knights asks in his essay for Poetry London, entitled ''No Disabled People Wanted Here': Accessing The Estate of Poetry'; 'how often have you seen disabled people at their launch events?' Knights goes on to argue that 'editors and programmers' do not sit around 'like cartoon villains' intending to exclude people, instead they are unaware of how they are making events inaccessible[55]. As Poet and leader of Octavia – Poetry Collective for Women of Colour, Rachel Long, argued in the York Centre for Poetry Series, writing opportunities for minorities are inconsistent and appear as 'windows.' She said:

> From talking to all the poets who have kind of felt like they saw […] this kind of like real sense of like change and hope for a future like this happened in like the mid-to-late 90s, multiculturalism, like new waves of Caribbean poetry particularly [..]. one poet who I admire greatly—and will just tell it like as he sees it […] he referred to is as windows, like this window opened up then, and then it got closed, and he's like who's doing the window opening and closing. Who gets to choose like each—our era, our generation—who gets to be the one who says 'okay, now [blank]' who's the

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[53] Karl Knights, 'No Disabled People Wanted Here: Accessing The Estate of Poetry' (2022), *Poetry London* <https://poetrylondon.co.uk/no-disabled-people-wanted-here-accessing-the-estate-of-poetry/> [accessed 27th April 2023] para. 14 of 14.

[54] Shelly Romero and Adriana M. Martínez Figueroa, *'The Unbearable Whiteness of Publishing' Revisited* (2021) *Publishers Weekly* < https://www.publishersweekly.com/pw/by-topic/industry-news/publisher-news/article/85450-the-unbearable-whiteness-of-publishing-revisited.html> [accessed 28th April 2023].

[55] Karl Knights, *No Disabled People Wanted Here: Accessing The Estate of Poetry* (2022), *Poetry London* <https://poetrylondon.co.uk/no-disabled-people-wanted-here-accessing-the-estate-of-poetry/> [accessed 27th April 2023] para. 14 of 14.

> orchestrator? […] why can't all the windows be open at one time? Who does it serve when one is open, and one is closed? And when they're being opened and closed in those ways across a certain amount of time, does anything really *really* change?[56]

These 'windows' which Long references, highlights inaccessibility and lack of continual opportunities as a structural issue within the industry. The idea of publishers acting as an 'orchestrator' of which minority group gets to be published is a useful metaphor. It raises questions such as, when certain topics are 'open' and others 'closed', if a poet explore multiple dimensions of their identity at once, then would they somewhat be relying on two windows being open?

Gradually, the poetry industry, particularly within the UK, has been shaped by pioneering disabled writers and activists. With the creation of writing prizes such as the Barbellion Prize[57] and the Disabled Poets Prize[58], opportunities which are accessible and are detached from wider industry ableism are provided to disabled writers. These platforms recognise and uplift the work of disabled writers, celebrating voices which are often overlooked within the poetry industry[59]. Equally, there has been an increase in opportunities for professional development, such as the Arvon 'Poetry for D/deaf & Disabled poets' course[60]. With speakers Raymond Antrobus and Jillian Weise, the course was tutored by, and for, D/deaf, disabled and neurodiverse poets, and was made accessible by captions and BSL interpreters. Despite this being the first of its kind to be run by Arvon, the course did face criticism for the inaccessibility of its price (£280).

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[56] Rachel Long, *York Centre for Writing Poetry Series – Rachel Long* < https://www.youtube.com/watch?v=_fnaNtbziWc> [48:28-50:13] [accessed 12th October 2023].

[57] The Barbellion Prize <https://www.thebarbellionprize.com/> [accessed 11th October 2023].

[58] The Disabled Poets Prize <https://disabledpoetsprize.org.uk/> [accessed 11th October 2023].

[59] Stuart Bartholomew, 'Disabled Poets Prize 2023', Spread the Word (2023) <https://www.spreadtheword.org.uk/disabled-poets-prize-2023/> [accessed 11th October 2023] para. 6.

[60] 'Arvon at Home: Writing Week – Poetry', Writers & Artists (2021) <https://www.writersandartists.co.uk/events-and-courses/arvon-home-writing-week-poetry> [accessed 11th October 2023].

Writing for the Wider Audiences

In writing against the canon of historically white, cisgender, straight, nondisabled men—and bearing in mind the publisher's predicted or real readerly critical responses—poets are faced with questions of how much of their identity they are 'allowed', or feel safe, to explore. Readers can be encouraged to learn, and to what extent is dictated by the poet. Encouraging readers to learn about different cultures, ways of life, or experiences, without having too much social context being built into the texts, can allow poets the space to create more nuanced representations[61]. As writers, we are faced with the question: how much context do readers need to be able to understand the message we wish to send, and how much context do we wish to provide?

As I have written in my poem 'The Guts I Have Left', I am working on the assumption that many of the sensations that I attempt to describe are not ones that have a 'universal quality' to them ('there are many things / that I did not know existed / until I was made to feel them'[62]), and so I am trying to explain physical sensations that readers are unlikely to have experienced. This has an impact of the languages choices I make. For example, if I mention a term for a specific symptom, such as 'fatigue' or 'brain fog', the impact it will have on the reader heavily depends on how much the symptom resonates with them, rather than the way this is written. To communicate to a larger audience, and to a readership who do not necessarily have the same disability as myself—I need a language which is carries the emotional and visceral aspects, as well as being able to communicate the concrete images and more technical aspects. I choose, within my poetry, to communicate a sense of what it feels like, for myself, to have this illness, though I choose to refrain from over-explaining what the illness is. Ulcerative Colitis is mentioned once in this collection, roughly halfway through, as a found material. In the poems themselves, I do not refer to the diagnosis. I want readers to be immersed in how this illness feels and affects the speaker, before it is formally revealed. In doing this, the reader experiences the emotional and physical aspects before the dispassionate medical and clinical aspects and is kept closer to the text.

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[61] Mary Jean Chan, 'The Faber Poetry Podcast: Mary Jean Chan & Rebecca Tamás', 2019 < https://www.faber.co.uk/journal/the-faber-poetry-podcast-mary-jean-chan-rebecca-tamas/> [accessed 27th April 2023] 00:36:30.

[62] Lucy Hurst, 'The Guts I Have Left' (p. 53 of this document) ll. 27-29.

Some poets make choices to embed contexts within texts, both in the poetry and in the surrounding pages. In using examples from contemporary and experimental poets, this balancing is shown to be done in a variety of different ways. For example, in Daisy Lafarge's *Life Without Air* (2020), an ecopoetic collection considering Pasteur's study on fermentation, there is a balance between where the context is placed and what this para-text does for readers. In the collection, there are two sections where paragraphs of context are given to the reader; once before the 'Dredging the Baotou Lake'[63] sequence, and on the final notes page, there are passages on 'how Louis Pasteur (1822-95) described the process of fermentation' which provides context for the 'understudies for air' sequence[64]. For the poet, Lafarge, and the publishing team, the writing is negotiated— always asking what does the strategic placement of the context do for the reader and how necessary is it?

Similarly, in Khairani Barokka's *Ultimatum Orangutan* (2020), a collection exploring disability in the environmental contexts of Indonesia and neo-colonialism, context is added in the form of a lexical index[65]. The index provides information on disability terms and the history of Indonesia alike. This means that the poetry can explore these themes in detail, and the reader, who may not be aware of topics, can follow without this information needing to be explicitly explained in the poetry itself. This lexical index can also be interpreted as a method of making the text more accessible to disabled readers.

However, it is crucial to recognise that it is not the sole responsibility of writers to ensure readers can understand any personal, cultural, or traditional significance, it is a shared responsibility with the reader. Good writing takes more than a talented writer, but a willingness to hear. We all toe the line between what we are trying to say, and how we say it; it is the nature of language itself. But for disabled writers, trying to explore our experiences publicly can come with an incredible toll. As an oppressed group, it is inherently dangerous to be addressable, as much of what we say can be potentially weaponised against us[66]. This becomes a difficult conundrum as many aspects of disability are painful, uncomfortable, and indicate a drop in quality of life, and when taken out of their original contexts, can have profound social implications (such as being used to back eugenic arguments). There are a range of experiences and feelings surrounding our own health, yet in exploring this, we are writing against

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[63] Daisy Lafarge, *Life Without Air* (London: Granta, 2020) p. 18.

[64] Daisy Lafarge, *Life Without Air* (London: Granta, 2020) p. 87.

[65] Khairani Barokka, *Ultimatum Orangutan* (Rugby: Nine Arches Press, 2021) p.81.

[66] Sandeep Parmar, 'Still Not a British Subject: Race and UK Poetry', *Journal of British and Irish Innovate Poetry,* vol. 12, issue 1 (2020). Doi: https://doi.org/10.16995/bip.3384 (para. 2 of 70).

profoundly ableist narratives that disability, or a drop in quality of life, makes life not worth living[67]. As crip poet, Laura Hershey, writes in the poem ‘Telling’:

> What you risk telling your story:
> […]
> Your sadness will justify their pity.
> Your fear will magnify their fears.
> Everything you say will prove something about
> their god, or their economic system.[68]

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[67] Joel Michael Reynolds, “I’d Rather Be Dead Than Disabled’—The Ableist Conflation and the Meanings of Disability’, *Review of Communication,* vol. 17, issue 3 (2017) 149-163.

[68] Laura Hershey, ‘Telling’, for the *Unitarian Universalist Association* (2003) <https://www.uua.org/worship/words/reading/telling> [accessed 11th October 2023] ll. 1[…] 14-17.

The Language of OCD

After establishing a definition of disability and of disability poetry, I will now introduce the collection that I will be analysing, the illness discussed in the text, and how I will perform an ecocritical reading.

The example I am analysing is Wayne Holloway-Smith's second poetry collection, *Love Minus Love*[69]. It is an experimental and fragmented text, exploring themes of mental health, masculinity, and family. The collection includes 'a strange layering of time, in which multiple things happen at once', infused with intrusive thoughts of dead dads, dead animals, and food stuffs. With a dark humour running throughout, *Love Minus Love* explores themes of both obsessive-compulsive disorder (OCD) and eating disorders, but within this thesis I will only focussing on the aspects relating most to OCD.

I have chosen to analyse *Love Minus Love* as it is an in-depth exploration into how obsessive-compulsive disorder impacts the speaker, on a more intimate level. The text makes prominent what the intrusive thoughts are, their patterns, and how they relate to the speaker's wider contexts. It is a key text the next two chapters, as I will be considering how, through figurative language, Holloway-Smith discusses the body-mind, and how, when discussing disability away from the medical lens, environment is implicitly discussed. My approach to this text is to perform close language analysis, whilst keeping an awareness of the limitations of the poetic mode and which contexts it is more appropriately used in.

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[69] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020).

Introduction to OCD

Obsessive-compulsive disorder (OCD) is a mental health condition where a person exhibits both anxious and obsessive thoughts and compulsive behaviours[70]. These obsessive thoughts are ego-alien, intrusive, and can feel deeply disturbing to those who have them[71]. The repetitive anxious thoughts are usually of an intense fear that a person will be responsible for *something* immoral. Despite being all-consuming thoughts, they are not in any way wants or desires, and they reflect more on what is immoral within society than the individual[72]. The repetitive behaviours act as a ritualistic attempt to discourage the anxious and intrusive thoughts, though performing them the sufferer will likely manifest more anxiety[73]. Experiences of this can range from mild to debilitating[74].

The onset of obsessive-compulsive disorder is often attributed to traumatic incidents, particularly of incidents within childhood. As noted by the mental health charity PTSDUK, OCD and PTSD are commonly found together. The charity argues that 'any trauma […] severe enough to potentially cause the symptoms of OCD might also have a chance to cause PTSD in the same individual'[75]. OCD may also appear in children following a childhood streptococcal infection, given that they have predisposed biological factors—this is referred to as PANDAS (paediatric autoimmune neuropsychiatric disorders associated with streptococcus)[76] . Typically, OCD has a gradual onset which is 'insidious, taking months or years to manifest, while the dramatic OCD symptoms of PANDAS spring up literally overnight'[77].

There are five notable categories in which obsessions and compulsions manifest: checking, contamination/mental contamination, symmetry or ordering, rumination/intrusive

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[70] NHS, *Overview – obsessive compulsive disorder (OCD)* ([n.a.]) < https://www.nhs.uk/mental-health/conditions/obsessive-compulsive-disorder-ocd/overview/> [accessed 16th March 2023]

[71] OCDUK, *Introduction to Obsessive Compulsive Disorder* ([n.a.]) <https://www.ocduk.org/ocd/introduction-to-ocd/> [accessed 16th March 2023].

[72] OCDUK, *What are obsessions?* ([n.a.]) <https://www.ocduk.org/ocd/obsessions/> [accessed 16th March 2023]

[73] OCD Specialists, *Compulsions in OCD* ([n.a.]) < https://ocdspecialists.com/compulsions-in-ocd/> [accessed 16th March 2023].

[74] Mind, *obsessive-compulsive disorder (OCD)* ([n.a.]) <https://www.mind.org.uk/information-support/types-of-mental-health-problems/obsessive-compulsive-disorder-ocd/about-ocd/> [accessed 16th March]

[75] Ptsduk, *OCD and PTSD – and the relationship between the two* ([n.a.]) <https://www.ptsduk.org/ocd-and-ptsd/> [accessed 16th March].

[76] Moleculera Labs, What is PANDAS? ([n.a.]) <https://www.moleculeralabs.com/what-is-pandas/> [accessed 16th March 2023].

[77] Harriet A. Washington, *Infectious Madness* (New York: Little, Brown Spark / Little, Brown and Company, 2015), p. 85.

thoughts, and hoarding[78]. OCD is a form of mental illness and has more recently been recognised as a form of neurodiversity as the brain processes and behaves differently to what is considered as neurotypical[79]. For many this can become a disability, as it impacts all aspects of life, and because of this, within this thesis I will refer to it as such.

As OCD can be attributed to environmental factors (such as trauma and bacterial infections) and distorts relationships with the nonhuman (fear of germs and bacteria), I will demonstrate how different forms and modes investigate, what appears to be, a significant factor in the causes of, and experiences that stem from, OCD.

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[78] The Gateway Institute, *Obsessive Compulsive Disorder (OCD) Symptoms and Treatment* ([n.a.]) <https://www.gatewayocd.com/related-conditions/obsessive-compulsive-disorder-ocd/> [accessed 16th March 2023].

[79] Spectrum Connections Therapy, *Is OCD Neurodivergent?* ([n.a.]) <https://spectrumconnecttherapy.com/is-ocd-neurodivergent/> [accessed 25th April 2023].

Introduction to Ecocriticism

In this thesis, I will read this collection through an ecocritical lens, and will consider how, through this poetic form, experiences of disability are figured in relation to their environmental factors.

An ecocritical reading is an investigation into the relationship between the speaker of the text and their environmental contexts; this analysis fully considers the impact of nonhuman on the speaker and uses an expansive definition of environment. As ecocritical theorist, Cheryll Glotfelty states in the introduction to *The Ecocriticism Reader: Landmarks in Literary Ecology*, ecocriticism 'takes as its subject the interconnections between nature and culture, specifically the cultural artifacts of language and literature. As a critical stance, it has one foot in literature and the other on land; as a theoretical discourse, it negotiates between the human and the nonhuman'. This approach slightly differs from other approaches; as Glotfelty continues, ecocriticism has an expansive notion of what should be examined critically. She writes:

> Literary theory, in general, examines the relations between writers, texts, and the world. In most literary theory "the world" is synonymous with society—the social sphere. Ecocriticism expands the notion of "the world" to include the entire ecosphere."[80]

I have chosen to draw upon ecocritical theory because of this expansive definition of environment and 'the world'. To analyse environmental factors of disability on a more detailed level, I must go beyond analysis of built environments, to considering the body-mind as transcorporeal, and taking an expansive approach to critical disability studies. In wanting to analyse experiences of disability for their complexity, I needed a suitably complex understanding of environment. The theorists I have used—Morton, Bateson, Hildyard—consider the body and mind as inseparable, and the body-mind as intertwined into environment, which is beneficial to my argument as I want to analyse from a holistic and well-rounded perspective[81]. This way of reading a text is also beneficial as it can be equally applied to poetry as it can the *DSM.*

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[80] Cheryll Glotfelty and Harold Fromm, *Landmarks in Literary Ecology* (Georgia: The University of Georgia Press, 1996) p.xlx.

[81] As to add separation between body and mind is both unnecessary in this analysis and can be actively detrimental as it establishes false dichotomies which I am arguing against.

In the *Love Minus Love* analysis, I how discuss obsessive-compulsive disorder and contamination anxiety shifts the relationship between human and bacteria, what it means to have 'bad bacteria', and how through poetry we can better understand the ecological idea of 'transcorporeality' and the boundaries of the body-mind. I demonstrate how poetic language and form can help us as readers to understand disability and OCD in an emotive way, and to identify how illnesses interact with types of environments. As theorist Garland-Thomson argues in 'Integrating Disability, Transforming Feminist Theory', disability studies and the environmental humanities can work side-by-side, by demonstrating that our bodies are constantly transformed from the moment of conception. She explains that disability is formed when our bodies encounter the world, and this history is registered on our mind-bodies[82]. Though using these theories in conjunction with one another, nuances of health and disability can be explored in greater detail as they identify the exact ways the body-mind is shaped by these encounters.

I want to highlight that when we are not using the medical lens, and are considering own experiences, environmental factors become prominent, even if it not a theme of the text, as all experience is deeply intertwined with environment. This is due to disability, being an embodied experience, always being constructed and experienced in relation to physical and social environments, as well as access needs being met or not. Despite not all conditions having obvious links the environmental factors, all conditions, to some extent will have environmental qualities as this disability is a lived experience and is a form of embodied knowledge which constantly interacts with and reacts to environment. These factors may be attributed to their causality (such as many forms of trauma), are reacted to, or exacerbate conditions and impairments. For example, in narratives about mental health, conditions such as PTSD, when considered through an experience-based and personal lens, many people note newfound and uncomfortable relationships with environments may start to form—a place-based anxiety which did not occur prior to their experiences.[83] Or, when considering forms of neurodiversity, those with Tourette syndrome or obsessive-compulsive disorder may build compulsive geographies through urges to touch objects[84].

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[82] Rosemarie Garland-Thomson, 'Integrating Disability, Transforming Feminist Theory', *NWSA Journal*, Vol. 14 (2002), pp 1-32 (4).
[83] Louise E. Boyle, 'The (un)habitual geographies of Social Anxiety Disorder', *Social Science & Medicine*, vol. 231 (2019), 31-37 (p. 31).
[84] Diana Beljaars, 'Towards compulsive Geographies', *Transactions of the Institute of British Geographers*, vol. 45 (2019), 284-298 (p. 286).

This understanding of disability being ever influenced and caused by environmental factors, I believe, can be applied to any disability but not necessarily any text as the writer may be intentionally exploring certain aspects. Through using different lenses, modes, and models, different information about conditions and disabilities are emphasised. This opens interpretation of disability and embodied knowledge of lived experience.

I am particularly interested in considering poetry to explore from both a language and a formal perspective. Poetry and figurative language can act as a powerful tool for exploring disability and environment as meaning is created by drawing upon a shared understanding, instead of 'plain' symbolic language which may be lacking. As a writer, I am compelled by the idea of inviting readers to engage emotionally with experiences, rather than explaining these experiences in a technical, definitive way. As a reader of poetry, the associations which I draw upon, instead of purely 'plain' or symbolic terms, I feel give the text a clarity of meaning. Through this specificity, poems can read as though the poet is sharing some 'truth', and this reading experience can feel intimate and creates an illusion of connectedness with the poet.

Poetry also does not necessitate a complete logic or an entirely comprehensive book structure. This can allow poets to have creative freedom regarding formatting, whereas in novels, the same structuring may make the reading experience difficult to follow (such as a lack of chronology). For me, poetry is my chosen form of exploration into disability as I do not need to find full conclusions, thoughts can remain as fractured and not fully thought out, or I can explore only a specific aspect in detail. This is particularly helpful for investigating topics which are complex and not fully knowable, as I do not need to grasp the full breadth and intricacy of these topics, only look at aspects that I am able to comprehend.

In this analysis, I have chosen not to investigate ecopoets, and have instead chosen to look at disability poets who explore environment as an intrinsic factor of disability and experience, but not as an explicit theme of the text. Literary critic, Nasrullah Mambrol, states that eco-poetics investigates:

> how the human is situated within its habitat; how "home" is defined and built; where (or whether) borders exist between body and world, human and other, space and place;

> and how sense activities, physical presences, memory, and moments of thinking locate and assist the human desire to navigate the self in the world.[85]

Ecopoetics are, in essence, the exploration of ecocritical ideas and thought through the medium of poetry. Whilst many eco-poets have been influential on my practice—particularly eco-poets considering the intersection with disability, such as Polly Atkin and Khairani Barokka—I wanted to apply an ecocritical lens to see how language shapes our understanding of disability and its intersection with environment, rather than analyse a text which is explicitly exploring this topic. In future projects, I do want to analyse eco-poetics as it is a fascinating and rapidly growing field, yet this is beyond the span of this thesis.

I decided to choose *Love Minus Love* specifically as it does not explicitly consider the environmental factors that are associated with this condition and is not considered as eco-poetry. I am proposing that when poets move away from the medical lens, disability is viewed as influenced by environment as it is an intrinsic aspect of experience.

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[85] Nasrullah Mambrol, 'Ecopoetics' (2021), Literary Theory and Criticism <https://literariness.org/2021/02/19/ecopoetics/> [accessed 16th February 2024].

Chapter 3

Writing Disability and Using Figurative Language to Understand Pain and the Body-Mind

Broader Context of Disability and Metaphor

Before I delve into this argument, I want to establish the parameters of my investigation and situate this work amongst other literary criticism and disability discourse.

Theorists and activists often discuss how disability has been used as a metaphor and the detrimental real-life effects that has on disabled people. I want to specify that I am not considering this angle for this thesis, I am instead looking at how poetry and figurative language can help to enable conversations on experiences of disability and environment.

One of the landmark texts which considers how disability has been used as a metaphorical device, and how metaphor has been used to create negative and inaccurate depictions of illness, is Susan Sontag's *Illness as Metaphor* (2009), Sontag proposes two main arguments—that 'illness is *not* a metaphor'[1] and should not be used as a metaphorical device, and that in using metaphorical thinking, depictions of illnesses create socially constructed views of illness which are damaging to those with the conditions. I want to, here, emphasise that I am not constructing any polemical argument against *Illness as Metaphor*, and the many disabled theorists and activists who have followed, and do not wish to discredit the very valuable work they have done.

The one point that I will be disputing is one of her conclusive points (as noted in the introductory pages), that 'the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking'[2]. Whilst within the context of this book, this conclusion is insightful (when a person has an illness, removing negative metaphors surrounding the illness can help to consider the illness with more accuracy and without social constructions creating a sense of fear and shame), the conversation should not begin and end there.

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[1] Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (USA; Penguin Classics, 2009) p.3.

[2] Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors* (USA; Penguin Classics, 2009) p.3.

Much of the conversation around disability and metaphor which has followed has been in a similar vein[3]—that using disability as a metaphorical device is reductive and detrimental—and this I agree with, and I am conscious of it in my conversational language.

However, given the potential size of the field of study for disability in linguistics and literature, it is disheartening to see that far more attention is given to how language is weaponised against disabled people, whilst how language can be beneficial remains deeply under-addressed. The use of disability as metaphor, and more recently, the 'depathologisation' of disability as metaphor[4], are deeply necessary conversations. Yet as a researcher, I feel that these are reiterated far more often than they are expanded upon, and that as researchers, we are doing a disservice by not paying greater attention to disabled artists and writers, and the endeavour of putting disability into language.

This is not to dispute claims and significance of the work that has been done by theorists and activists on the topic. There have been many in-depth and fascinating studies, such as Mitchell and Snyder's *Narrative Prosthesis: Disability and the Dependencies of Discourse*, in which Mitchell and Snyder thoroughly consider how literary representations of disability have been used as 'an opportunistic metaphorical device'[5] to represent religious punishment and medieval superstition to the 'superhuman' trope, where the disability is depicted as a superpower. I believe texts like these are deeply necessary, yet I also believe that language and disability are both vast and complex issues that can be approached in a myriad of ways, and that there is still a huge amount of terrain left to cover.

In this thesis, I am examining how figurative language can be used as a tool to explore lived experiences, as opposed to how perceptions of illnesses are created by others. I will evaluate the accuracies and inaccuracies of figuration, and how it can be used to consider topics beyond our own knowledge and comprehension. As figurative language plays a fundamental role in communication and as a way of understanding, it must also be critically evaluated for its positive attributes and usefulness. In doing so, the relationship between disability and language can be explored, and ableism within language can be dismantled in meaningful ways. I believe

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[3] This can particularly be seen throughout disability activism.

[4] Dan Goodley, '*Disability and depathologisation are not metaphors'* (2023) <https://thepolyphony.org/2023/05/05/disability-and-depathologisation/> [accessed 26th July 2023].

[5] David T. Mitchell; Sharon L. Snyder, *Narrative Prosthesis* (Ann Arbor: The University of Michigan Press, 1997) p.47.

that these arguments can co-exist, and that it is necessary to keep expanding these conversations as language, as I will demonstrate, is as much of a tool as it is a weapon.

Circle Where it Hurts

The experience of illness or any kind of emotional or physical suffering will always be separate to the language that tries to define it. As essayist and literary critic, Elaine Scarry, argues in *The Body In Pain*: 'physical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned'[6]. When these experiences become too overwhelming, instead of trying to express it in words, we often express it through crying or yelling — these are our 'culturally stipulated responses'[7]. The act of crying, and other non-linguistic communications of bodily sensations and pains, such as expressions, behaviours, and body posture, are an integral part of how we communicate and how we interpret the information given to us[8]. When someone is crying, despite them not using full words or comprehensive sentences, there is a communication of emotion which is almost universally understood. In trying to put experiences into words, the language seems to break down or becomes inadequate, and it proves a challenge to express what we are feeling.

Scarry argues that this resistance to language is not 'incidental or [an] accidental attribute[..]' but reflects the nature of the phenomenon itself. She states, 'it is precisely because [pain] takes no object that [pain] […] resists objectification in language'[9]. In addition, disability, and health more broadly, also have many aspects which are 'unknown', 'unknowable', or escape our comprehension. Due to these phenomenological qualities, and the personal and subjective characteristics of experiences of disability, there is an innate resistance to language which makes understanding disability and health particularly difficult.

The linguist and philosopher, Julia Kristeva, argues in *Desire in Language: A Semiotic Approach to Literature and Art*'[10], in this 'state anterior to language', the body-mind has a mode of non-linguistic communication, which she refers to as the 'semiotic'. The semiotic' is,

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[6] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1987), p. 4.
[7] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1987), p. 4.
[8] 'How Much of Communication Is Nonverbal?', *The University of Texas Permian Basin* ([n.a]) <https://online.utpb.edu/about-us/articles/communication/how-much-of-communication-is-nonverbal/> [accessed 11th October 2023].
[9] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1987), p. 5.
[10] Julia Kristeva, *Desire in Language: A Semiotic Approach to Literature and Art,* ed. Leon S. Roudiez, trans. Thomas Gora, Alice Jardine, Leon S. Roudiez (New York: Columbia University Press, 1980).

as Kristeva argues, the matriarchal aspect of language[11], one which expresses the ‘chora’ through to the ‘mirror stage’. These are the pre-linguistic stages in childhood development, where communication is used to express the body-mind’s drives and impulses[12]. This mode of communication, as Kristeva describes, is based in sound and rhythm as a necessity for survival:

> Vocal and muscular contractions, spasms of the glottis and motor system—all make up for the absence of intrauterine life components. Voice is the vehicle of that call for help, directed at a frustrated memory, in order to insure, first through breath and warmth, the survival of an ever premature human being; and this is undoubtably significant for the acquisition of language, which is soon to be articulated by the same vehicle.[13]

The drives (such as the drive to remain alive) are expressed through the ‘vehicle’ of the voice, using sound and rhythm before using words. Kristeva adds, in *Revolution in Poetic Language*[14], that as the child acquires language, it is often attributed in ‘either metaphoric or metonymic’ ways[15], with ‘generative grammar […] not yet readily equipped to account for them’[16]. The semiotic, however, becomes ‘censored’ by society[17], and is eventually replaced by the patriarchal and rules-based aspect of language, which she refers to as ‘the symbolic’[18]. However, poetic language, unlike the more symbolic language of medicine or law, for example, draws upon these non-linguistic methods of communication. In using the poetic mode, writers are hierarchising the use of sound, rhythm, and figuration; encompassing more aspects of the ‘state anterior to language’, and therefore bringing the reader closer to the state itself.

When approaching writing the body-mind, it is also helpful to consider the act of putting phenomenological experiences into words as an act of translation, rather than replication. In an

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[11] Camelia Talebian Sadehi, ‘*Beloved* and Julia Kristeva’s The Semiotic and The Symbolic’, *Theory and Practice in Language Studies* (2012) vol. 2, no. 7, pp. 1491-1497 (p. 1491) para. 4.

[12] Julia Kristeva, *Revolution in Poetic Language*, trans. Margaret Waller (New York: Columbia University Press, 1984) p 26, para. 2.

[13] Julia Kristeva, *Desire in Language: A Semiotic Approach to Literature and Art,* ed. Leon S. Roudiez, trans. Thomas Gora, Alice Jardine, Leon S. Roudiez (New York: Columbia University Press, 1980) p. 283.

[14] Julia Kristeva, *Revolution in Poetic Language*, trans. Margaret Waller (New York: Columbia University Press, 1984).

[15] The example Kristeva uses is: ‘“woof-woof” says the dog, and all animals become “woof-woof”’ (p 43).

[16] Julia Kristeva, *Revolution in Poetic Language*, trans. Margaret Waller (New York: Columbia University Press, 1984) p 43, para. 2.

[17] Julia Kristeva, *Revolution in Poetic Language*, trans. Margaret Waller (New York: Columbia University Press, 1984) p 48, para. 3.

[18] Camelia Talebian Sadehi, ‘*Beloved* and Julia Kristeva’s The Semiotic and The Symbolic’, *Theory and Practice in Language Studies* (2012) vol. 2, no. 7, pp. 1491-1497 (p. 1491) para. 4.

article entitled ‘Writing is an off-shoot of something deeper’, John Berger writes of how this ‘pre-verbal’ state is deeply influential, especially within literary translation. He writes:

> True translation demands a return to the pre-verbal. One reads and rereads the words of the original text in order to penetrate through them to reach, to touch, the vision or experience that prompted them. One then gathers up what one has found there and takes this quivering almost wordless “thing” and places it behind the language it needs to be translated into. And now the principal task is to persuade the host language to take in and welcome the “thing” that is waiting to be articulated.[19]

Berger proposes that translating is not simply taking a text in one language and directly replicating it in another. It is instead rearticulating in the host language — alike to making an impression of the same ‘thing’ in another language. But what if we consider this ‘pre-verbal’ state that is put into language, as a sort of language in of itself—as a phenomenon which cannot be directly copied as experience and pasted as language, but as something to be rearticulated, or made an impression of?

Author, Cynthia Cruz, writes in the article ‘Notes Toward a New Language: The Body’:

> The body has its language and we each have our own individual language: how we speak (or don't), how we move through space, our gestures, and so. And then we have the written word, another language, one that is often a translation of one's personal language, though this is not always the case. All of these pieces (the body, the voice, our speech, our "mother tongue,") can be *collage*d into a written language--or not.[20]

By considering the body-mind as having its own language, and translation as being less of a replication but more of an impression, the mode that we approach writing the body with starts to shift. Precision of meaning no longer necessitates being made from exact terms, or symbolic

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[19] John Berger, *Writing is an off-shoot of something deeper* (2014) *The Guardian* <https://www.theguardian.com/books/2014/dec/12/john-berger-writing-is-an-off-shoot-of-something-deeper> [accessed 21st March 2023] (para. 4 of 11)

[20] Cynthia Cruz, *Notes Toward a New Language: The Body* (2015) *Poetry Foundation* https://www.poetryfoundation.org/harriet-books/2015/04/notes-toward-a-new-language-the-body- [accessed 21st March 2023] (para. 26 of 27)

‘plain’ language, as the attempt is not a replication, but is an impression of the state into language through evocation.

By evoking a topic or ‘thing’, we can create a sense of specificity that is not easily captured in symbolic language. As philosopher Theodor W. Adorno suggests in *Aesthetic Theory*[21], it is the build-up of images and ideas that create art which feels most real to the reader and may be closest to reality. Adorno argues that ‘only a method that transcends conventional depiction can do justice to the new reality’ that it aims to capture[22]. When we cannot pinpoint the word or feeling through symbolic language, we use evocation till the idea comes across to the reader.

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[21] Theodor W. Adorno, *Aesthetic Theory (trans.)* (Frankfurt am Main: The Athlone Press, 1997, 2002 ed.).

[22] Peter Uwe Hohendahl, *The fleeting promise of art: Adorno's aesthetic theory revisited* (Ithaca; Cornell University Press, 2013). P.106.

‘How Would You Describe the Pain?’

In the essay ‘On Being Ill’, Virginia Woolf contemplates the ‘poverty of language’ that becomes apparent when describing pain to medical professionals. She writes:

> The merest schoolgirl, when she falls in love, has Shakespeare or Keats to speak her mind for her; but let a sufferer try to describe a pain in his head to a doctor and language at once runs dry. There is nothing ready made for him. He is forced to coin words himself, and, taking his pain in one hand, and a lump of pure sound in the other […], so crush them together that a brand new word in the end drops out. Probably it will be something laughable. […] Yet it is not only a new language we need, more primitive, more sensual, more obscene, but a new hierarchy of the passions.[23]

Here, Woolf argues that our lack of ‘ready made’ preconceived dialogues and symbolic words for pain—which stems from our diminishing pain—stunts our communication regarding the body-mind. In using figurative language, we are also avoiding the potential for mistranslation that comes with symbolic language. Words chosen by the writer or speaker may not be specific enough (i.e., covering a technical aspect, and dismissing the emotional aspects) or may not yet exist within the English language. Yet, through figurative language, the gaps left by symbolic language can be filled.

We already use figurative language to describe the body, perhaps without even realising it. In researching the exact words that we most commonly use to describe physical sensations there is a reoccurring list that is used by medical professionals and those with pain alike. These lists usually include stinging, scratching, aching, swelling, burning, stabbing, and so on[24]. Many of these words can also be found in the *McGill Pain Questionnaire*[25] and are used by medical professionals to assess types of pain.

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[23] Virginia Woolf, *On Being Ill* (London: The Hogarth Press, 1930; 2002 ed.) p. 26.

[24] NIH, *How can I describe pain to my health care provider?* (2017) <https://www.nichd.nih.gov/health/topics/pelvicpain/conditioninfo/describe> [accessed 21st March 2023] (para. 4 of 4)

[25] Melzack R., ‘The McGill Pain Questionnaire: Major properties and scoring methods’, *Pain* (1975; 1:3) p. 277-299.

In the 1970s, Dr Ronald Melzack and Dr Warren Torgerson of McGill University, Canada, created the *McGill Pain Questionnaire* to help patients to communicate their experiences of pain in affective and sensory detail[26]. This was one of the first (Western) systems of understanding pain that relies on metaphors ad their emotional connotations to describe the sensations. Many of the pain scales then—and still now—rely on either a numerical system (Numerical Rating System, NRS), a visual analogue scale (VAS, or Wong-Baker), or categorical scales (Brief Pain Inventory, BPI)[27].

The *McGill Pain Questionnaire* is designed to draw upon figurative language to give language to the patient's assessment of their own pain and its patterns. The use of figurative language is particularly beneficial here as it provides language to describe experience with some specificity. Below are two sections of the *McGill Pain Questionnaire*[28]:

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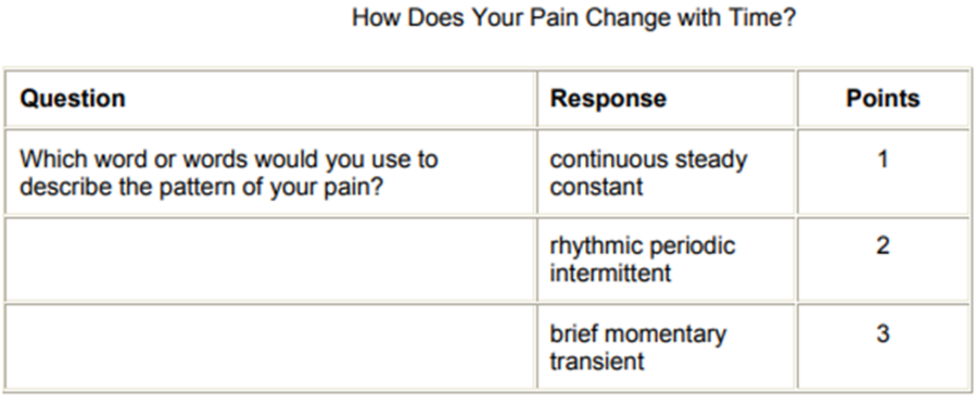
[26] Izze Siemann, *How McGill invented pain: 1970s pain scale still used today* (2017) *The McGill Tribune* <https://www.mcgilltribune.com/sci-tech/how-mcgill-invented-pain-1970s-pain-scale-still-used-today-012417/> [accessed 21st March 2023] (para. 3 of 11)

[27] UF Health, *Pain Assessment Scales/Tools* ([n.a.]) <https://pami.emergency.med.jax.ufl.edu/resources/provider-resources/pain-assessment-scales/> [accessed 21st March 2023]

[28] Melzack R., 'The McGill Pain Questionnaire: Major properties and scoring methods', *Pain* (1975; 1:3) p. 277-299.
(Figure 1 and Figure 2) (2017) <https://www.sralab.org/sites/default/files/2017-07/McGill%20Pain%20Questionnaire%20%281%29.pdf> [accessed 21st March 2023] p. 1, p.4

Group	Descriptor	Points
1 (temporal)	flickering	1
	quivering	2
	pulsing	3
	throbbing	4
	beating	5
	pounding	6
2 (spatial)	jumping	1
	flashing	2
	shooting	3
3 (punctate pressure)	pricking	1
	boring	2
	drilling	3
	stabbing	4
	lancinating	5
4 (incisive pressure)	sharp	1
	cutting	2
	lacerating	3

Figure 4- Taken from the 'What Does Your Pain Feel Like?' section of The McGill Pain Questionaire



How Does Your Pain Change with Time?

Question	Response	Points
Which word or words would you use to describe the pattern of your pain?	continuous steady constant	1
	rhythmic periodic intermittent	2
	brief momentary transient	3

Figure 5 - Taken from the 'How Does Your Pain Change with Time?' section of The McGill Pain Questionaire

The figurative terms chosen are laden with meaning, particularly regarding their emotional connotations. It is through these emotional connotations that readers (or those whom an individual are communicating to, i.e., a medical professional) can creatively imagine what this pain feels like, and conceptualise it, through interpreting its emotional effects on the individual. As linguists Lakoff and Johnson argue in *Metaphors We Live By,* metaphor is a useful tool, for both the writer and the reader, to make sense of phenomena, those such as experiences of illness, as it helps the reader engage 'an imaginative form of rationality'[29]. They write:

> [Metaphor] unites reason and imagination. Reason, at the very least, involves categorization, entailment, and inference. Imagination, in one of its many aspects, involves seeing one kind of thing in terms of another thing—what we have called metaphorical thought.[30]

This bringing together of reason and imagination, allows readers to imagine, creatively, the gaps in the information they are given. So, when an individual cannot find a specific term which accurately pinpoints the sensation, a metaphor can be employed to evoke the sensation. Readers (or in this case, medical professionals) then use a creative rationale; understanding metaphors for their more obvious forms of comparison as opposed to broader (and less rational) interpretations. Through the metaphor's implied emotional intensity, the reader can infer its physical intensity. For example, in using the metaphor of pain as being 'punishing', the reader interprets this as feeling violent, frightening, and deeply concerning to the individual, implying a severity of the pain which is profound enough to cause these psychological fears. Whereas symbolic terms to discuss severity, such as 'high' or 'intense', the reader is made aware of its intensity, but not of what it feels like for the individual.

Through using figurative language which patients will already be aware of, the *McGill Pain Questionnaire* highlights a crucial gap in language where medical specificity and emotional specificity collide. As shown in figure 4, figurative terms that indicate the sensations of pain exist, and again in figure 5, symbolic terms describing the technical aspect of pain (i.e., location, duration, etc) are available to us. Yet, symbolic words which indicate topicality (referred or localized), duration, and emotional intensity all at once are yet to be invented.

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[29] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p. 193.

[30] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p. 193.

The *McGill Pain Questionnaire* does still rely on a numerical system, which helps the medical professional to get an impression of the sense of urgency. In an interview with *The Independent*, Professor Stephen McMahon of the London Pain Consortium remarked that this 'obsession with numbers is an oversimplification.' He continues:

> Pain is not unidimensional. It doesn't just come with scale […,] it comes with other baggage. How threatening it is, how emotionally disturbing, how it affects your ability to concentrate. The measuring obsession probably comes from the regulators who think that, to understand drugs, you have to show efficacy. And the American Food and Drug Administration don't like quality-of-life assessments; they like hard numbers. So we're thrown back on giving it a number and scoring it. It's a bit of a wasted exercise because it's only one dimension of pain that we're capturing.[31]

The need for numerical categorisation and the ever-presence of the wants of the medical-industrial complex, implies that pain scales are not intended to help people to fully understand and communicate pain on a phenomenological level, but to instead are created to communicate the degree of urgency and probable causality. However, in looking at the *McGill Pain Questionnaire*, and its use of both language and numerical systems, there is an implication that this format is to be used by patient and medical professional alike. If medical professionals only need a numerical system and a location, then perhaps this figurative language is more for the benefit of the patient, to be able to express and conceptualise their pain, communicating something more than locality and a ranking of intensity.

The *McGill Pain Questionnaire* includes its own set of metaphors and its own poetic register which has a potential to be used within creative practice. Similar to the formatting of the *DSM-5-TR*, as I mentioned in the 'Play as Process' passage in chapter one, I considered using the metaphors and the form of the questionnaire more explicitly within my practice.

One way I considered using the questionnaire was to collate all of the metaphors used and order them in different ways to see their impact on the reader. I first considered them alphabetically, as I realised that these words span much of the alphabet. This read as the following:

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[31] John Walsh, *How much does it hurt?: The methods used by doctors to measure pain* (2017) *Independent* <https://www.independent.co.uk/life-style/health-and-families/pain-how-much-does-it-hurt-pancreatitus-methods-doctors-measure-a7513101.html> [accessed 21st March 2023] (para. 22 of 56)

> aching, agonizing, annoying, beating, blinding, boring, cold, cool, cramping, cruel, crushing, cutting, discomforting, distressing, drawing, dreadful, drilling, dull, excruciating, exhausting, fearful, flashing, flickering, freezing, frightful, gnawing, gruelling, heavy, horrible, hot, hurting, intense, itchy, jumping, killing, lacerating, lancinating, mild, miserable, nagging, nauseating, numb, penetrating, piercing, pinching, pounding, pressing, pricking, pulling, pulsing, punishing, quivering, radiating, rasping, scalding, searing, sharp, shooting, sickening, smarting, sore, splitting, spreading, squeezing, stabbing, stinging, suffocating, taut, tearing, tender, tension, terrifying, throbbing, tight, tingling, tiring, torturing, troublesome, tugging, unbearable, vicious, wrenching, wretched.

When these words are placed together, and taken out of their original context, they can become an overwhelming readerly experience, both from the amount of visceral sensory associations which are implied, and as prominent through the use of form. In collating these metaphors in this way, the use of alliteration creates a rhythm for the text, which intensifies the harsh sounds of these words, which adds to an auditory intensity to these already intense metaphors. Through alliteration and its musicality, and the only minor variations in syllables per word[32], the text is also given a steady pace, which for the reader, can make this list feel never-ending.

Another way that I experimented with these metaphors was to order them in intensity[33]. As shown below:

> numb, boring, mild, tingling, stinging, itchy, pricking, sore, cool, cold, dull, tender, hot, aching, cramping, annoying, discomforting, rasping, tension, spreading, drawing, tight, heavy, sharp, hurting, freezing, pressing, squeezing, pulling, throbbing, pulsing, flickering, radiating, jumping, flashing, tugging, nagging, pinching, smarting, piercing, tearing, taut, cutting, splitting, tiring, troublesome, lacerating, horrible, miserable, quivering, nauseating, sickening, distressing, gnawing, penetrating, beating, pounding, intense, drilling, crushing, exhausting, lancinating, dreadful, searing, blinding, frightful, fearful, terrifying, gruelling, agonizing, punishing, scalding, torturing, cruel, suffocating, shooting, killing, stabbing, vicious, excruciating, wrenching, wretched, unbearable.

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[32] With predominately two or three syllable words.

[33] As according to how I perceive these metaphors.

This is an uncomfortable reading experience, which starts to become overwhelming as with each word more or new connotations are added. Tension is built throughout the text as these metaphors become progressively more violent. However, these poems ultimately did not end up in my collection as they become too jarring, and I did not want to overpower the text by using too much repetition. I would like to continue this work further, but as a separate project where I utilise the full potential of these scales as inspiration and as found materials.

Life Outside of Figuration

In medical situations and in discussing health and disability, when figurative language is not used, we tend to resort to medicalese or symbols. Both of these lack an emotional or visceral impact on the reader. For example, we are unlikely to use the medical term ‘paraesthesia’ in conversation, partly because not too many of us would know what it means, and partly because it is such a vague and unemotional way to describe your own body. Paraesthesia, meaning the unusual sensations in the skin—the ‘itchy’, ‘pins and needles’, ‘numbness’, and ‘burning’ sensations[34]. In encompassing so many very different physical sensations, and not having emotional connotations, these words can lack the specificity of meaning required for an individual describing their body-mind or experience.

The lack of emotional associations in medical language is emphasised by how poets have chosen to appropriate this language for their own creative practices. For example, poets such as Sylvia Legris and Hannah Hodgson have both used medical terminology, though in radically different ways. Legris, an experimental poet with a distinctive poetic style, draws upon the musicality of medical and technical terms, especially those with Greek and Latin roots. In *The Hideous Hidden*[35], Legris explores human anatomy, making references to Leonardo da Vinci’s Anatomical Manuscripts and the Hippocratic oath. An example of her work, taken from ‘Articulation Points (a preface)’[36]:

i

Renounce the vestibule of non-vital vitals.
Confess the gallbladder,
the glandular wallflowers,
the objectionable oblong spleen.

This play in musicality and obfuscation creates a powerful rhythm and flow which stays with the reader. These words appear to be used not just necessarily for their specific meaning, but for their sound and rhythm. Within this stanza alone, Legris uses the alliteration of ‘V’

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[34] NIH, *‘Paraesthesia’* ([n.a.]) < https://www.ninds.nih.gov/health-information/disorders/paresthesia#:~:text=What%20is%20paresthesia%3F,%2C%20skin%20crawling%2C%20or%20itching.> [accessed 26th July 2023].
[35] Sylvia Legris, *The Hideous Hidden* (New York: W. W. Norton & Company, 2016).
[36] Sylvia Legris, ‘Articulation Points (a preface)’, *The Hideous Hidden* (New York: W. W. Norton & Company, 2016) p. ll. 1-5.

sounds in ‘vestibule of non-vital vitals’, which is quickly followed by ‘G’ sounds (‘gallbladder, / the glandular’), and ‘O’ sounds (‘objectionable oblong’). There are also patterns of stresses which similarly have an alliterative effect (‘Renoun**ce** the v**es**tibule’, and ‘g**all**bladder, /the glandular w**all**flowers’). The poem is made to sound musical and rhythmic, drawing on words heavy in syllables, ordering them in a way which makes the poem read like music, diverting the reader’s attention away from simply the meaning of the word, but to its sound. Without this musicality, these terms (in a symbolic sense) have a limited meaning for the reader, yet when given a musicality, they become sensory to the reader, immersing the readers into the semiotic states of the body-mind.

Hodgson, on the other hand, is a disabled poet who appropriates her own medical literature to juxtapose the blunt ways medical procedures are written up with how they are experienced. In ‘163 Days’, Hodgson writes:

> Friday 17th April
> *My friends have come down on the train.*
> *They know more about this city than I do.*
> *They watch my body, mentally drawing*
> *criminal chalk lines around my changed person.*
> *One starts: “You’ve lost so much weig-um.” She shuffles*
> *in her seat. “I mean you’re so thin. We’ll shop for* clothes
> *when you’re home.” Another says “Can I hug you?*
> *I’m not going to break any of the machines or hurt you, am I?”*
> *I’m so outside of the world I no longer have emotion.*
> *I wish for the days when we hated each other, to feel*
> *such pointless sadness, to be desperate for a snog*
> *instead of survival.*
>
> Ultrasound shows full bladder, patient has no sensation.
> Advice: toilet every 6h. Watch kidney function. Any
> decrease indicative of Kidney Damage/Failure (already
> borderline).[37]

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[37] Hannah Hodgson, ‘Friday 17th April’ from ‘163 Days’, *163 Days* (Bridgend: Seren, 2022) P. 31.

Through juxtaposing speaking and note making in medical settings with how the speaker is feeling whilst in the hospital, Hodgson highlights how the medical lens and language can be reductive of the emotional aspects of experience. In using these appropriated terms and texts, the reader can infer that this mode is not intended to have emotional connotations, and this symbolic medical language is intended to carry minimal meaning. When used to describe the self or a speaker, it is emphasised how reductive this lens is and language is, and how they become counterintuitive outside of medicine.

Similarly, there is a viscerally emotional quality missing in the imagery of pain scales. For example, looking at the Wong-Baker Pain Rating Scale[38], as below:

Figure 3- the Wong-Baker FACES Pain Rating Scale

This scale was designed to help young people articulate the degree of pain they are in without using words. For many, the Wong-Baker Pain Rating Scale is effective in serving its purpose, yet in understanding what pain feels like, these icons cannot be used beyond this setting as it informs the reader of very little.

As a viewer and reader, we are not shown much regarding what it *feels like* to experience it, only the extent to which it makes you want to cry, which is, of course, incredibly subjective. The use of phrases such as 'hurts a whole lot', whilst helpful for children, create a profound sense of ambiguity. The vagueness of the icons and in the language choices, highlights both Scarry's theory that pain resists language (or resists a reduction into specific and emotional terminology, including in this case iconography), and how 'plain' symbolic language can create an unintended openness regarding emotional qualities.

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[38] Wong-Baker, *Wong-Baker FACES* (1983) <https://wongbakerfaces.org/> [accessed 21st March 2023]

The artist Amanda Ross-Ho has appropriated this pain scale in her installation 'HURTS WORST'[39]. In including this in my analysis, we as readers and as an audience can directly compare the use of symbolism with evocation using the same original icons. These pieces have been informed by the artist's personal experience within healthcare, and equally reflect upon the abstract nature of pain[40]. The installation includes both icons and text, examples of which are shown below:

Figure 4- Taken from 'HURTS WORST'

Figure 5- Taken from 'HURTS WORST'

Figure 6- Taken from 'HURTS WORST'

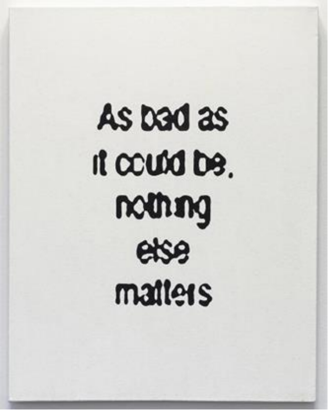

Figure 7- Taken from 'HURTS WORST'

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[39] Kunsthall Stavanger, *Amanda Ross-Ho: Hurts Worst* (2019) <https://kunsthallstavanger.no/en/exhibitions/amanda-ross-ho-hurts-worst#:~:text=In%20HURTS%20WORST%2C%20the%20artist,produced%20by%20our%20contemporary%20moment.> [accessed 26th July, 2023].

[40] Kunsthall Stavanger, *Amanda Ross-Ho: Hurts Worst* (2019) <https://kunsthallstavanger.no/en/exhibitions/amanda-ross-ho-hurts-worst#:~:text=In%20HURTS%20WORST%2C%20the%20artist,produced%20by%20our%20contemporary%20moment.> [accessed 26th July, 2023].

For the viewer, and the reader, of these pieces, the original icons are now given an emotional quality which is more intense than for the original icons. Through this medium of textiles, Ross-Ho there is an evoking emotion, as opposed to literally representing of pain.

In using this medium, there are associations for the viewer which evoke a sense of closeness to the body (as many textiles do out of their function) and are sensory stimuli because of its tactile nature. The tactile properties of the distressed physical nature of these pieces suggests a sense of emotional distress—the feeling of 'falling apart', of being pulled at, and implies haste and urgency in their 'unfinished' appearance. The audience is made to feel, through this evocation, that pain can warp the sense of self and of time. These icons become laden with meaning and implications about pain. Equally, the language choices have a similar sense of specificity in their meaning, both through the associations attached to their artistic formatting[41] (as blurred and emboldened, implying the prominence of the pain and how it can disturb or distort an individual) and the emotional associations connected to these metaphors. I find the phrase 'Unbearable. Torturing / Crushing. Tearing' to be particularly arresting. To the reader, there is a dire sense of being trapped and pain being implied. Between the artist and the audience there is a shared understanding of the intensity of the emotion as drawn from the emotional connotations of these words. Whilst this is still subjective—as we can all interpret how we would imagine 'Crushing' or 'Tearing' to feel—there is something specifically emotive, and even directional which is being implied.

Whilst I do acknowledge each of these icons and pieces of artwork have different contexts and purposes, this comparison demonstrates how figurative language and evocation can exemplify emotional aspects of pain by using pre-established associations, in ways which symbols and icons cannot. In drawing upon figurative language, the emotional aspects of pain and the body-mind can be evoked, and thus, they are viewed in more holistic and multi-dimensional ways.

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[41] As blurred and emboldened text implies the prominence of the pain and how it can disturb or distort an individual's perception.

Just *Like* That

In drawing upon an added layer of meaning by using figurative language, writers can harness readerly pre-established associations to give something form, function, shape etc. In leaning on what the reader already knows, the writer can ask the reader to conceptualise a topic by applying this knowledge to a similar subject. Literature, as professor of literature and the environment, Cheryll Glotfelty, argues *The Ecocriticism Reader*, 'does not float above the material world in some aesthetic ether, but, rather, plays a part in an immensely complex global system in which energy, matter, *and ideas* interact"[42]. Given that everything, including literature, is relational, figurative language becomes fundamental in how we understand the world[43]. We give definition to things through piecing together what they are, and are not, through their similarities and differences to other things. As noted in *Using Figurative Language*, linguist, Herbert L. Colston, argues that common ground between reader and writer is necessary for figurative writing to 'work'[44]. Therefore, the more that the two compared things have in common—such as physical, emotional aspects etc—the more effective the metaphor becomes as the reader can draw upon more association which they then connect to the new subject.

Linguists Lakoff and Johnson state in *Metaphors We Live By*, 'metaphor is how we conceptualise and understand thing, they are not just frilly language, it is a reflection of how we understand'[45]. They argue that '*the essence of metaphor is understanding and experiencing one kind of thing in terms of another'*[46].

An example of how the use of metaphor within my own writing can help readers to better understand a subject, is the comparison to the speaker's (and my own) Ulcerative Colitis, to the intestine feeling like it is in a 'vice-grip'[47]. This metaphor is effective as there are several parallels that can be drawn between this bodily pain and vices, meaning that those without my condition can call upon the connotations of vices and apply it to the body.

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[42] Cheryll Glotfeltly, *The Ecocriticism Reader: Landmarks in Literary Ecology,* edited by Cheryll Glotfelty and Harold Fromm (Georgia: The University of Georgia Press, 1996) p. xix. Italicised in original.

[43] Andrew Bennet & Nicholas Bennett, *An Introduction to Literature, Criticism, and Theory, 5th ed*. (London; Routledge, 2016) p.80.

[44] Herbert L. Colston, *Using Figurative Language* (New York: Cambridge University Press, 2015) p. 103.

[45] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p 9.

[46] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p 5. Italicised in original.

[47] Lucy Hurst, 'The Guts I Have Left' (p. 53 of this document) ll. 27.

- Firstly, there is the imagery of the vice: it is tactile, metal, and hardened, which implies a sense of brutality to the feeling of this sensation.
- Then, there is the function of the vice: it is made to hold things still, and in that, there can be an immense degree of pressure applied to the object. Similarly, there is a feeling of pressure from indigestion within the large intestine.
- Equally, there is a movement to the vice: this pressure can be increased and decreased, and comes from a rotatory action, slowly or quickly. For me, as my intestine does move with Ulcerative Colitis, this can feel like a painful twisting or crushing sensation.

From this the reader, or the person I am talking to, can begin to comprehend and conceptualise the internal pressures, pain, and feelings of motion and rotation that I have from this illness.

In choosing this metaphor, I had to consider which aspects of this condition I wanted to share with the reader. For example, with condition, and in my case, the pain I experience physically comes from the intestine having cuts and ulceration. This generates lots of different sensations for me and can impact my entire body in various ways. I do not need, or necessarily want, my reader to be given exactly what is happening as it is not always entirely impactful, and I may be wanting to explore a specific aspect (such as shame surrounding symptoms).

As a writer exploring my own experiences of disability, I have found using figurative language particularly helpful in expressing complex topics when ‘plain’ symbolic terms feel reductive or restrictive. I find that the topics and ideas I try to translate to the reader are such specific sensory experiences that it would be difficult to convey to an nondisabled reader (or indeed readers without the same illnesses / disabilities as me) without drawing on some shared understanding.

One of the notable issues which arise when discussing symptoms is that—as noted in ‘The Guts I Have Left’—the sensations that I explore are ones which come from a place which ‘I did not know existed / until I was made to feel them’[48]. Meaning that, these sensations, particularly of chronic pain, could be so profound, overwhelming, and entirely unfamiliar to me, that they escape my own comprehension, and therefore I struggle to find ways to translate them into more simplistic or symbolic terms, as it is not a simplistic experience for me.

However, there are limitations to the use of figurative language, as the comparison may have unintended implications. As argued in *Metaphors We Live By,* the very system that

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[48] Lucy Hurst, ‘The Guts I Have Left’ (p. 53 of this document) ll. 28-29.

‘allows us to comprehend one aspect of a concept in terms of another […] will necessarily hide other aspects of the concept […] which are inconsistent with the metaphor’[49]. In this system of metaphors, there will be aspects of the thing described which will not be covered by the metaphor itself, and equally, in using metaphor, there will be aspects which are unintentionally implied. With my example of the vice, there is an implication of this being manmade. Whilst I do not think the association is entirely inaccurate, I was not intending to imply this, but it has been noticed by readers. Whilst metaphors can be incredibly useful, in drawing on a shared understanding, there is a danger of unwanted implications, or indeed making a reference which the reader cannot understand the comparison.

In the example of Wayne Holloway-Smith’s *Love Minus Love*, the reader conceptualises the obsessive thoughts of OCD through the metaphor of ‘illness / in your head going off loud like a / fake studio audience’[50]. This metaphor is used throughout the collection, appearing twelve times in various ways (‘laughing my whole self into my sad sleeve’ pg. 28; ‘the barrel of laughs you can’t get out of’ pg. 31; ‘imminent / laughter’ pg. 33; ‘lip-smacking laughter’ pg. 33; ‘[canned laughter]’ pg. 38 etc). This ‘laughter’ is addressed by the speaker in two sections of the text, on page 31 and again on page 33, as shown below:

> ‘enter canned laughter here
> enter a fist or forehead is crashing through my living room
>   and all over my buttoned-down shirt
> ask me my favourite word: alive
> and thinking of all the ways out of this sitcom I’m in
> and laughter
> not a type that is with you not a type
> you know in the centre of your eardrum to be you
> but the laughter you’re not certain is there   that you have
> to check and strain and check leaning over and over
> the barrel a barrel of laughs you can’t get out of’[51]

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[49] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p 10.

[50] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p. 33, ll. 13-15.

[51] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p. 31, ll. 9-19.

'[…] it's so funny to be
normal so hard to imagine an illness
in your head going off loud like a
fake studio audience'[52]

This metaphor has several layers of meaning for the reader as it has associations attached to its presence in the text, its 'loud[ness]'[53], and the direction of where is sound is coming from (an externality).

The use of laughter in this text is noticeably repetitive to the reader. These repetitions are placed following more serious or harrowing remarks, creating a jarring effect on the reader through their juxtaposition (such as following emotional and explicit references to eating disorders). The reader is made to feel aware of the presence of the laughter, which is reflective of how those with OCD can be made to feel the presence of their mental illness.

In using this metaphor, Holloway-Smith uses the sound associated with the studio audience to explore how intrusive thoughts may 'sound' those with OCD. As I noted in the critical introduction, OCD is a form of neurodivergence. Many neurodiverse people have noted that thoughts, and particularly intrusive thoughts, can feel 'loud'[54]. This is perhaps from how much attention is paid to these thoughts (because of the anxiety attached to it), their feeling of insidiousness or inescapable nature ('the barrel a barrel of laughs you can't get out of').

The 'fake studio audience' also has a directional element, as an audience is distinctly external to the self. This external factor implies an ego-alien nature of intrusive thoughts, where thoughts are not congruent to the speaker's other thoughts, or his wants or desires. The reader also infers that these thoughts are persistent and invasive—as studio audiences are continually present, and their noise impedes upon the performance.

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[52] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p. 33, ll. 12-15.

[53] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p. 33, ll. 14.

[54] Therapy in a Nutshell, *'The 6 Most Common Types Of Intrusive Thoughts'* (2022) <https://therapyinanutshell.com/the-6-most-common-types-of-intrusive-thoughts/#:~:text=are%20intrusive%20thoughts%3F-,Intrusive%20thoughts%20are%20words%20or%20images%20that%20pop%20into%20your,really%20loud%2C%20demanding%20your%20attention.> [accessed 26th July 2023].

In comparing the ‘illness going off in your head’ to a ‘studio audience’, Holloway-Smith implies several aspects of how the speaker is experiencing OCD—from how it operates (as intrusive and ego-alien) to how it feels (distressing).

Chapter 4

Body-Mind and the Environment

Becoming the Environment

> ‘There is no time or place at which genetics ends and environment begins’
>
> Donna J. Haraway[1].

In this chapter, I establish a definition of environment, define the parameters of this study, and explain how disability and environmental humanities can work hand-in-hand.

Environmental humanities scholar, Stacy Alaimo, argues in *Bodily Natures: Science, Environment, and the Material Self*, that our definitions of environment can become reductive, and what is recognisable as ‘nature’ is too often imagined as an inert empty space for human activity[2], which in turn, makes it easier to enslave, colonise, and plunder[3]. Alaimo explains, when redefining the environment, we should be recognising it as ‘a world of fleshy beings with their own needs, claims, and actions’[4]. Not only is the environment a mesh of physical, chemical, and biotic factors[5], formed of flora and fauna which create individual biomes, it is, crucially, inclusive of humans and human activity.

In the West, environment is often viewed as being beyond the boundary of the human body-mind—as conditions we exist in but are ultimately separate from. It may be disconcerting to find out that the boundaries of the human are far more porous than we may realise. As Alaimo argues, we are continually ‘transcorporeal’ beings: our bodies are continually

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[1] Donna J. Haraway, *The Companion Species Manifesto: Dogs, People, and Significant* Others (Chicago: Prickly Paradym Press, 2003) p. 32.

[2] Stacy Alaimo, *Bodily Natures* (Indiana, Indiana University Press, 2010) p. 2.

[3] Timothy Morton, *Dark Ecology: For a Logic of Future Coexistence*, 2018 ed. (USA: Columbia University Press, 2016) p 10.

[4] Stacy Alaimo, *Bodily Natures* (Indiana, Indiana University Press, 2010) p. 2.

[5] *Environment Definition* ([n.d.]), *Biology Online* <https://www.biologyonline.com/dictionary/environment> [accessed 25th April 2023].

transgressed through intra-activity with chemical agents and other actors moving between different sites'[6]. We are not separate from the environment; the environment becomes us.

Environmental writer, Daisy Hildyard, writes on how the human boundaries are continually transgressed through intra-activity, through what she refers to as 'the second body'. This idea can be used to understand what 'transcorporeality' is, and how this impacts us as humans. Hildyard argues that we inhabit two bodies; our first being the 'body you inhabit in your daily life'[7] and the second being 'your own literal and physical biological existence'[8].

In our first body, we consider our the 'human animal' as a 'whole and single individual', where we are encouraged to be 'be yourself and express yourself'[9]. The language we choose to discuss the human reflects this, she argues, that 'this careful language is anxious, […] [it is] threatening in a desperate way'. The language of describing the individual is dictated by definitive boundaries ('you need boundaries, you have to be either here or there') and through this symbolic language, we create define ourselves.

However, the 'second body' that we inhabit— 'our own literal and physical biological existence'[10]—is our biological reality outside of our self-defined individualism. Hildyard writes:

> Nobody in the world can be completely insulated from the atmosphere; the atmosphere can be influenced by any living body. Therefore, each body is involved with every other living thing on earth. Your first body could be digesting a piece of bread in Lagos at precisely the same time as your second body is acting on the internal organs of a seagull in Kamchatka. The activity of a certain species of alga in the south Pacific has determined the composition of the air that you are breathing right now. For the second body, there is no stable boundary between one species and another: we're all in the same boat.)[11].

This 'involvement' with 'every other living thing on earth' demonstrates more than a sense of human permeability, Hildyard emphasises how our existence is dependent upon these things that are seemingly external (such as the 'certain species of alga in the south Pacific'). By being

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[6] Stacy Alaimo, *Bodily Natures* (Indiana, Indiana University Press, 2010) p. 12.
[7] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.25.
[8] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.25.
[9] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.13.
[10] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.25.
[11] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.57.

dependant on clean water and air, on low levels of radiation, the specific degree of heat, the suitability of our food, human bodies are not simply entangled within nonhuman matter, but rather consist of and entirely depend upon nonhuman matter to exist[12].

The language we use to describe the 'second body' or our transcorporeal states, however, can be ineffective. As Hildyard continues:

> The language we have at the moment is weak: we might speak vaguely of global connections; of the emission and circulation of gases; of impacts. And yet, at some microscopic or intangible scale, bodies are breaking into one another. The concept of a global impact is not working for us, and in the meantime, your body has already eaten the distance.[13]

The language used to describe the ways we interact with, and within, our environment is 'weak' in this regard, as health and environment cannot be translated into symbolic language whilst still encompassing the complexity and profundity of these topics.

Hildyard goes on to argue that we tend to become aware of our second body when we are in pain or are having to think about our survival. The example she uses is of 'extreme pains' such as 'headaches; giving birth; and a mechanical tiredness [from intense exercise]'[14], as well as ecological disasters, such as flooding[15]. When she discusses Nadya, a researcher in biology who she interviewed for this book, and her experiences with her own second body, Hildyard comments that it was her 'pain and discomfort in her body which showed her that she was an animal in the world'[16]. Through pain, tiredness, bodily difficulties, and inability to navigate our physical surroundings, we develop a heightened awareness of our body-minds as intrinsically part of the environment.

When this is applied to disability, experiences of disability may come with a heightened awareness of 'the second body' and how body-minds interact with environment (i.e., through access), as well as a greater sense of permeability (i.e., through immunosuppression). A question that Alaimo proposes—in retaliation to the restrictions of the social model of

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[12] Karen Barad, *Meeting the Universe Halfway: Quantum Physics and the Entanglement of Matter and Meaning* (North Carolina: Duke University Press, 2007) p. 184.
[13] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.25.
[14] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p. 87.
[15] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p.91.
[16] Daisy Hildyard, *The Second Body* (London: Fitzcarraldo Editions, 2017) p. 85.

disability—which I seek to answer in this thesis, is: how is disability impacted on a "less perceptible level—that of pharmaceuticals, xenobiotic chemicals, air pollution, etc. [?]"[17]

This topic has also been broached by writers and disability theorists alike. In *When the Sick Rule the World*, writer and essayist, Dodie Bellamy, considers how disabled people can become hyper-aware of how chemicals and pollutants can impact their health. She writes:

> 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 type age carpets heat source paint proximity to industry etc. describe your work environment when your illness began type of building ventilation toxic exposure neighbouring businesses etc. [18]

These factors are highly prevalent in the lives of disabled people as disabled people are at a disproportionately higher risk of exposure to chemicals and pollution, as they are more likely to be affected by poverty and poor housing conditions, and because of susceptibility from pre-existing conditions[19].

In this sensitivity, many disabled people must reckon with factors in the environment which are mostly invisible to the naked eye. These factors may remain unquestioned or even unrecognised by nondisabled people who do not physically feel their impact. This passage shows the mass of the obstacles faced by many disabled people when considering environments, and we as readers are immersed into this world of toxicity. This description of the felt but unseen—the chemicals and toxic exposure—helps readers to comprehend how the body-mind is continually impeded upon. These factors impact everyone, but through this perspective, the reader is brought closer to the 'second body' and can see the mind-body as a transcorporeal state.

Poet and disability scholar, Eli Clare, also explores this 'less perceptible level' of health by discussing how traumatic incidents impede into our body-minds in his hybrid personal memoir and ecological essay, *Brilliant Imperfection*. Clare asks, when investigating 'the moments and locations where disability and chronic pain occur', if we 'can we consider [these bodily consequences as] […] natural, as our fragile, resilient human body-minds interact with

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[17] Stacy Alaimo, *Bodily Natures* (Indiana, Indiana University Press, 2010) p. 12

[18] Dodie Bellamy, *When the Sick Rule the World* (Massachusetts: Semiotext(e), 2015) p. 25.

[19] *Vulnerable groups and toxic exposures* ([n.d.]), *United Nations* < https://www.ohchr.org/en/special-procedures/sr-toxics-and-human-rights/vulnerable-groups-and-toxic-exposures> [accessed 25th April 2023].

the world?'[20]. Here, Clare is asking the reader to challenge the notion of disability and chronic illness to be 'abnormal', and instead emphasises how these are no more 'unnatural' than the 'war, toxic landfills, childhood abuse, and poverty' that causes it[21]. In this investigation, the reader is also made to consider the relationship between social justice and the public health.

In expanding this idea of the body-mind interacting with environment to be inclusive of the 'less perceptible layer'[22], as opposed to simply the built environments which are often considered in the social model, health and disability can be appreciated for its complexities. As disability and environmental scholar, Alison Kafer, notes in 'Bodies of Nature: The Environmental Politics of Disability', the focus on built environments in disability criticism has 'prevented [the field] from engaging with the wider environment of wilderness, parks, and nonhuman nature because the social model seems to falter in such settings'[23]. In considering an ecological definition of environment, and in using a more biopsychosocial model of disability, this thesis investigates the more profound ways in which mind-bodies interact with and become the environment.

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[20] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (USA: Duke University Press, 2017) p. 54.

[21] Eli Clare, *Brilliant Imperfection: Grappling with Cure* (USA: Duke University Press, 2017) p. 54.

[22] Stacy Alaimo, *Bodily Natures* (Indiana, Indiana University Press, 2010) p. 12

[23] Alison Kafer, 'Bodies of Nature: The Environmental Politics of Disability', in *Disability Studies and the Environmental Humanities: Towards an Eco-Crip Reader* (United States of America: University of Nebraska, 2017) p. 201.

Metaphors and Mistranslations

In *Steps to An Ecology of Mind*, philosopher, anthropologist, and poet, Gregory Bateson argues that, like the translation of feeling to language, there is no sufficient direct translation of the nonhuman and the 'species of unconsciousness' to language. It is through metaphor that ecological and environmental writers can begin to describe things which are beyond our limited human understanding, and push at the limits of symbolic language. Bateson writes:

> Today we think of consciousness as the mysterious, and of the computational methods of the unconscious, e.g., primary process, as continually active, necessary, and all-embracing. These considerations are especially relevant in any attempt to derive a theory of art or poetry. […] Art becomes, in this sense, an exercise in communicating about the species of unconsciousness. Or, if you prefer it, a sort of play behaviour whose function is, amongst other things, to practice and make more perfect communication of this kind. It is, in fact, precisely the sort of message which would be falsified if communicated in words, because the use of words (other than poetry) would imply that this is a fully conscious and voluntary message, and this would be simply untrue[24].

Here, Bateson argues that consciousness would be falsified when placed into 'plain' symbolic language. In symbolic terms being definitive and having a precise yet minimal meaning, it becomes ineffective when describing topics which are not definitive and cannot be reduced. Art, and in this case poetry, is a mode of expression which does not seek to address things definitively, but instead seeks to make comparisons, dismantling the attributes of phenomena.

Bateson asserts further on in the text that metaphor has a 'communicative power' which is exemplified in poetry[25]. This sentiment is also reflected in the works of environmental and literary theorist, Hubert Zapf. In 'Creative Matter and Creative Mind', Zapf responds to Bateson's argument by proposing that as 'metaphor is used in the most intense, complex, and self-reflexive ways in poetic language, the discourse of ecology and discourse of poetry and literature are intrinsically related to each other through the shared relevance of metaphor.'[26] He

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[24] Gregory Bateson, *Steps to An Ecology of Mind: Collected Essays in Anthropology, Psychiatry, Evolution, and Epistemology* (Chicago: University of Chicago Press, 2000) p.147.

[25] Gregory Bateson, *Steps to An Ecology of Mind: Collected Essays in Anthropology, Psychiatry, Evolution, and Epistemology* (Chicago: University of Chicago Press, 2000) p. 227.

[26] Hubert Zapf, 'Creative Matter and Creative Mind' in *Material Ecocriticism*, edited by Serenella Iovino and Serpil Oppermann (Indiana: Indiana University Press, 2014) p. 57.

argues that within this ‘shared relevance of metaphor’, creative responses can affirm Bateson’s argument, as well as reimagining and approaching topics from varying viewpoints. He writes:

> ‘In the aesthetic space of art and literature, this immediate relation is suspended, opening up an independent dimension of creativity within language, discourse, and the text. In this self-reflexive imaginative space of cultural creativity, processes of radical de-conventionalization, defamiliarization, but also creative reconstruction, recombination, and reconfiguration are employed to renew ossified and conventionalized forms of thought, perception, communication, and imagination.’[27]

Through writing, there is creative freedom to investigate topics which are too complex to be reduced to symbolic language. Through creative writing and figurative language, we ‘reconstruct’ and ‘de-conventional[ise]’ them, and therefore, we can start to perceive these topics in different ways, further opening how they are approached and understood.

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[27] Hubert Zapf, ‘Creative Matter and Creative Mind’ in *Material Ecocriticism*, edited by Serenella Iovino and Serpil Oppermann (Indiana: Indiana University Press, 2014) p. 57.

Chapter 5

Ecocritical Readings of OCD in Wayne Holloway-Smith's Love Minus Love and the Diagnostic Statistical Manual, 5th ed. (DSM-5)

It is fascinating to consider obsessive-compulsive disorder (OCD) in relation the environment as its onset is often attributed to environmental factors, such as streptococcal infections[1][2] and it can distort the relationship between the human and nonhuman (i.e., anxieties surrounding bacteria). Yet, as OCD is not regarded as an environmental illness, environmental factors have become overlooked and underappreciated in medical literature and popular culture alike.

I am comparing a poetry collection and medical textbook to demonstrate how the environmental factors of OCD are discussed through different modes of language, and what these modes can imply about the condition to the reader.

The texts I am comparing are Wayne Holloway-Smith's poetry collection *Love Minus Love*[3], and the medical textbook, the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (*DSM-5-TR*)[4]. *Love Minus Love* being a contemporary, fragmented, and experimental poetry collection that is based on the poet's own, first-hand experience. This will be compared to the OCD passage found in the *DSM-5-TR*, a popular handbook used by medical professionals in psychiatry. These texts approach the same topic from varying perspectives. *Love Minus Love* being a more intimate and holistic approach, whereas the *DSM-5-TR* being highly medicalised. I want to make this comparison to show how though different lenses and modes of language, environmental factors can be appreciated or diminished. These lenses and modes create different perceptions of OCD for the reader, and through an ecocritical reading, I highlight the extent to which modes of language can be used for an exploration of environmental factors or to reduce them. I will consider the purposes and contexts of each text, respectively.

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[1] OCD can follow childhood infections, this is called 'paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections', or PANDAS.

[2] 'PANDAS-Questions and Answers', National Institute of Mental Health ([n.a]) <https://www.nimh.nih.gov/health/publications/pandas#:~:text=PANDAS%20is%20short%20for%20Pediatric,strep%20throat%20or%20scarlet%20fever.> [accessed 11th October 2023].

[3] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020).

[4] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (Washington, D.C.: American Psychiatric Publishing, 2022).

In performing an interdisciplinary literary reading of a medical text, I am taking an experimental and original approach to advance the medical humanities. It is crucial to perform readings of this text from outside the context of medicine, as this text is often used within everyday life. The language used must be analysed not only for its meaning within medicine, but also for the meaning which is implied to those outside the field who are still impacted by this text.

Performing a close reading of a non-literary text, specifically as a poet, yields different outcomes to other methods of analysis. As a poet, I am interested what it means to be subject to this text, and how language and form shapes readerly interpretation. My approach to this research differs greatly from scientific research; this form of practice research 'value[s] and build[s] upon reflexivity and subjectivity […] appeal[ing] to readers' personal experiences for understanding and interpreting findings' and is concerned predominantly with 'what it means to be human—or ontological concerns' as opposed to scientific accuracy[5] In using a poetic approach, as theorist Debbie McCulliss describes in 'Poetic inquiry and multidisciplinary qualitative research', I seek to 'give a voice back' to those subject to the text, through embracing 'the richness and experience of the people being studied'—the subjective, emotional, and intimate aspects—as opposed to the dispassionate and reductive data of medicine[6].

As Elliot Eisner, a pioneering arts education partitioner, argues in 'On the Differences between Scientific and Artistic Approaches to Qualitative Research':

> In artistic approaches, the particular words chosen, the location of specific ideas within a report, the tone and tempo of the writing the sense of voice that it possesses have no literal equivalent. The potential of form is not regarded as a liability but as an essential vehicle that constitutes a significant part of the content of communication.

Whereas the opposite view is taken in scientific work, where standardization is sought to not obscure any of the content, and thus the attention is diverted away from form[7]. Despite this form being chosen to not distort the content, when viewed through the lens of an arts-based

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[5] J. F, Gilgun, 'Qualitative research and family psychology', *Journal of Family Psychology,* vol. 19, no.1 (2005) 40-50 (43).

[6] Debbie McCulliss, 'Poetic inquiry and multidisciplinary qualitative research', *The Interdisciplinary Journal of Practice, Theory, Research and Education* , issue 2 (2013), 83-114 (83-4).

[7] Elliot W. Eisner, 'On the Differences between Scientific and Artistic Approaches to Qualitative Research', *Visual Arts Research,* vol. 29, no. 57 (2003) 5–11 (8).

practitioner, it is demonstrated to the reader how form and language shape meaning, and how symbolic language should not necessarily be considered as a ‘neutral’ alternative to figurative language in shaping perceptions of illness, which as I will argue, go beyond the setting of medicine.

Love Minus Love

In this section, I will be considering Wayne Holloway-Smith's poetry collection, *Love Minus Love* (2020). This will include a language and formal analysis, as well as an ecocritical reading. This collection discusses themes of OCD, and of mental health more broadly, touching upon other mental illnesses such as eating disorders. *Love Minus Love* explores the poet's own, lived experience with OCD.

Immediately in the text, readers are introduced to lexicons of childhood; challenging ideas of masculinity; eating disorders and meat imagery; and black comedy; creating a multi-layered world of thoughts and ideas. The intimate experiences of obsessive-compulsive disorder and mental illness more generally are given insight through descriptions of the speaker's social settings, details of traumatic incidents, childhood, socioeconomic factors, and relationships. As readers, we follow a layered build-up of narrative which helps us to understand how this mental illness manifests, and how the anxiety changes over time.

I have chosen to look at this passage as it shows a blunt and harrowing account of the speaker's anxiety. It is taken from the middle pages of the text (pg. 28) and is roughly the same length as the *DSM-5-TR* passage that I will be analysing. Holloway-Smith writes:

Dear Anything please let me last across this moment
and on just a bit more
my body is busy thinking itself unwell my body is
thinking itself outside of this moment
what if the soul this moment is cultivating is just an unwell thought I'm piling
on top all of the other very disturbing thoughts until they stand up inside me
someone I love dying from me thinking or not thinking
about the very specific circumstances of it
fear of very specific types of bacteria and cancer of the mouth lung
the brain haemorrhaging all the harm I could do
what I do is I take these and I keep them safe inside me
I have to organise them have to keep them
very tidy each little shit thing
what I have to do is count through each one
what if my body fell away and this soul I'm building was just a thing
left sweating alone in the finicky sun
I'm laughing my whole self into my sad sleeve
at what this has so quickly become but wait:
I can come back from this
everyone loves a comeback so I'm calling myself back
backwards into the lake it can happen
green shadows are all over the place at once here goes
the sun is suggesting I get over myself
and my daughter is laughing I look silly doing it here goes
the water is very calm everyone is dancing the rhythm is in me[8]

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[8] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p.28.

In *Love Minus Love,* the reader learns a few notable qualities about obsessive thoughts in OCD: it is deeply upsetting; the thoughts are ego-alien; and that these anxious thoughts are not tangibly related to the speaker's reality.

The anxiety written into this collection undoubtably reads as an overwhelming experience, as passages like these are most impactful from Holloway-Smith's use of metaphor and imagery. Through language choices that create a closeness to the reader, such as the use of the first person 'I,' and anatomical language and metaphor ('brain haemorrhaging all the harm I could do'), the reader is immersed in the overwhelming and anxious world of the speaker.

Holloway-Smith uses an ontological metaphor to give a form to the 'very disturbing thought'. In doing so, the reader can conceptualise these obsessive thoughts and how they impact the speaker. As Lakoff and Johnson argue in *Metaphors We Live By, '*our experiences with physical objects (especially our own bodies) provide the basis for an extraordinarily wide variety of ontological metaphors, that is, ways of viewing events, activities, emotions, ideas, etc., as entities and substances.'[9] They write:

> Understanding our experiences in terms of objects and substances, allows us to pick out parts of our experience and treat them as discreate entities or substances of a uniform kind. Once we can identify our experiences as entities or substances, we can refer to them, categorize them, group them, and quantify them—and, by this means, reason about them.[10]

In Holloway-Smith's ontological metaphor, the phenomenon of thought is given object, which make them become referable, which Holloway-Smith does through the pronoun 'they'. Through this metaphor, and how Holloway-smith elaborates on it, these thoughts can be quantified, and readers can see how the speaker attends to these thoughts.

In these thoughts now having object, the phenomenon is now given a spatial aspect, where they fill the 'space' of the mind in different ways, which has various implications for the speaker. In this section, this is shown in two ways—thoughts as 'stand[ing] up inside' the

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[9] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p. 25.

[10] George Lakoff, Mark Johnson, *Metaphors We Live by* (London: The University of Chicago Press, 1880, 2003 ed.) p.25.

speaker, and as something to be ‘organised’. Readers can interpret from how they ‘stand up inside’ the speaker, and from the height that is implied from being stood up, that they are overpowering and are not considered small or insignificant by the speaker.

This metaphor continues, with Holloway-Smith describing how the speaker attempts to ‘organise them’ and ‘keep them / very tidy’, ‘count[ing] through each one’. Through this, the reader can interpret obsessive thoughts as taking up ‘space’ in the mind—they are time-consuming, taking up the speaker’s energy, with the speaker feeling as though they need persistent attention. In this demonstration of obsessive thoughts, the reader learns not only what these thoughts are (‘about the very specific circumstances of it / fear of very specific types of bacteria / and cancer of the mouth lung’) but also how they impact the speaker.

As the reader has had insight to the speaker’s thoughts in stream-of-conscious style of writing, there is a noticeable contrast between what Holloway-Smith has established as the speaker (‘I can come back from this / *everyone loves a comeback* so I’m calling myself back’) and the intrusive thoughts. As readers, it becomes clear that these thoughts are more than ‘unwanted’. They are not just ‘bad thoughts’, but thoughts which do not correlate with what the person truly believes / feels. In doing this, Holloway-Smith emphasises that intrusive thoughts are ego-alien and not the actual desires or wants of the speaker. As readers, we are not being persuaded into seeing the speaker as someone who will do any ‘harm’ to others, as these statements do not match of what we already know about the speaker—his losses, his traumas, and his love of his family. This is an important distinction to make, as it allows those with the condition to have control of the narrative—to be perceived as people who have an illness, not as this illness as a true reflection of their character.

Examples, such as ‘someone I love dying from me thinking or not thinking’, also imply to the reader how the anxiety that people with OCD is not tangibly connected to their current situation[11]. Readers can interpret this as the speaker feeling as though these thoughts have high stakes. Yet, as they have no ‘correct’ resolution, we as readers can infer that the ‘threat’ that

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[11] These thoughts are less tangibly related to an individual’s reality than generalised anxiety disorder (GAD). For example, someone with GAD may be anxious about the particular situation they are in (such as catastrophising the situation, i.e., overemphasising the possibility of negative outcomes in a situation), whereas with OCD, an individual’s anxiety can feel more hypothetical, and less connected to their current situation (such as being afraid of harm coming to someone they are about if they do not perform a task in a certain way).

the speaker faces is not one which is connected directly to his situation but is instead his anxiety being projected onto the world around him.

The Body as an Environment

Holloway-Smith breaks down the boundaries of the body-mind and highlights how our fragile body-minds are susceptible to the environment which we inhabit. Throughout *Love Minus Love*, Holloway-Smith describes the body-mind as an internal landscape, one which is moulded by external surroundings, traumas and experiences, and anxieties about other people and relationships. Readers are shown this internal world to be a product of the environment, reflecting and even becoming the physical manifestations of both the love and the traumas the speaker is surrounded by.

In this refracted text, the boundaries of the body-mind and the environment are blurred. This is done through language and form. For example, lines such as ‘I keep them safe inside me’, as taken from this passage, distort the boundaries between the internal and the external—what which is ‘safe inside’ is an anxiety which has been formed and shaped through external forces, such as relationships with others, traumas, and a mix of societal constructs. Once inside, this internalised and hidden thought, cannot stay as internal as now it lives on the page. OCD is shown to the reader as a physiological response to intense stresses and traumatic events, and in doing so, this boundary of what is internal and external to the human body-mind is blurred and the human, especially the mind, is shown as entirely permeable. This is also demonstrated on page 39, a few pages after this passage, when Holloway-Smith writes:

> your heart is in your chest
> your mind in your head
> your eyes are there in their sockets
> in your body
> on this chair
> in this room further back and darker
> than you ever thought possible[12]

In this passage, it is implied to the reader that the speaker has become aware of how he is impeded on, and how this boundary is permeable. It has become part of how the speaker views himself—as constantly in response to the whirlwind of environments and contexts he finds himself in. In this segment, the speaker illustrates how he is not separate to these factors—his

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[12] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p. 39.

body-mind is as much in this room as the chair is; he is made up of these contexts, but also is shown to be becoming part of the environment.

In viewing the speaker's body-mind as an impacted by the environment, and in turn becoming an environment, Holloway-Smith reflects ecological idea of transcorporeality—or as Daisy Hildyard termed, the 'second body'. Whilst what is seeping into the speaker's body-mind is more concerned with the influence of others on his anxiety rather than the impact of physical agents (such as the 'various types of bacteria'), Holloway-Smith invertedly shows ways of thinking about how transcorporeality functions regarding mental health. As ecologist Timothy Morton notes in *Dark Ecology*, our ecosystems are not only made up of physical objects and beings, but they also consist of ideas. He writes 'it's quite logical to argue […] that thoughts themselves are independent entities, reducible to neither brain nor to mind', and that perhaps what we see as 'environment' or as 'mind' are a weird fusion and entanglement of both[13].

The discussion of illness and how it is shaped and formed through a variety of factors is emphasised by the poetic form. In an experimental approach, *Love Minus Love*, is not separated by poem titles, and so the whole collection reads as one long poem. There is an uninterrupted flow throughout the book, which comes from this formal lack of rigidity in its structure, as well as enjambment and a lack of capitalisation and punctuation throughout much of the collection. In having this flow, along with the profound lack of punctuation and capitalisation, the text begins to physically embody the message that it appears to convey—there are very loose boundaries to the body, and to accentuate this, the boundaries within the text are purposely destroyed.

Love Minis Love is written in a vary of styles; from lines of one or two words, sentences without spaces, and capitalised lists. Different pieces of information—memories, feelings, and actions—are be revealed to the reader in different ways. For example, Holloway-Smith includes passages about the speaker's dreams, contextual points, and actions in square brackets ([,]), as shown below:

> [I flung open a random drawer
> in the room

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[13] Timothy Morton, *Dark Ecology: For a Logic of Future Coexistence*, 2018 ed. (USA: Columbia University Press, 2016) p. 67-68.

next to the one
in which he died
and there I found a small ring box
full of my own milk teeth][14]

Whilst, ‘secrets’ are shrouded within the text through a lack of spacing between words, line breaks between words, and are in parts, crossed-out. They are revealed to the reader in a subtle way, formally reflecting the nature of the content:

whenI
firstbe
ganto
speakp
ublicly
aboutm
ydsyfunctional
family
mymoth
er~~was~~
~~enraged~~[15]

Not only are the themes, memories, and ideas in *Love Minus Love* refracted, but as are the forms and styles chosen. For the reader, this formatting emphasises and represents how the speaker is engulfed in a variety of factors which play into how he experiences the world and his mental health. As this collection is composed of mostly fragmented forms and carefully pieced together images and ideas, *Love Minus Love* creates a larger picture when the collection is read in its entirety. Readers are encompassed into ideas of mental illness, and shown how these factors—familial relationships, socioeconomic factors, physical surroundings, and sensory details—form and exacerbate mental illness. *Love Minus Love* formally and linguistically shows readers that OCD does not exist in a void, and that health is not reducible down to one thing but is instead a myriad of components.

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[14] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p.48.
[15] Wayne Holloway-Smith, *Love Minus Love* (Northumberland: Bloodaxe Books, 2020) p. 21.

Markedly with a more experimental structure, poetry does not necessitate the need to have a full or comprehensive narrative, and therefore it is easier to flick between ideas. The reader can still have this build-up of ideas which are implied to be the attributed cause and exacerbation of OCD within the text, whilst the writer does not need to fully fill in all the gaps and can explore the aspects that he sees fit. Through poetic narrative function, Holloway-Smith explores not only what the thoughts are but the specific tangents of anxious thoughts and the more external factors that build up to create this internal world.

‘Bad’ Bacteria

In the polarised anxious world of Holloway-Smith’s speaker, the human sits in one category and the nonhuman in another. In this dualism, the speaker is attempting to separate himself, or assert a separation, from ‘bad’ kinds of bacteria. In having *bad* bacteria, or ‘the very specific types of bacteria’, bacteria are judged in moral terms. This idea means that bacteria start to be viewed as separate to the human, and we begin to perceive and treat it as an external threat, rather than being something that may already exist within us. Whilst the use of *bad* may help us to understand sanitation—such as washing your hands to avoid salmonella—the bacteria itself it not morally bad, but simply dangerous to our bodies in larger quantities.

In the book *On Immunity: An Inoculation* (2015), Eula Biss contemplates on how contamination challenges our beliefs and anxieties about the boundaries of the human body. She writes:

> Fear of contamination rests on the belief, widespread in our culture as in others, that something can impart its essence to us on contact. We are forever polluted, as we see it, by contact with a pollutant.[16]

This idea of contamination as something which impedes an otherwise uncontaminated state of human, she argues, is a false one. Biss continues:

> If we do not yet know exactly what the presence of a vast range of chemicals in umbilical cord blood and breast milk might mean for the future of our children’s health, we do at least know that we are no cleaner, even at birth, than our environment at large. We are all already polluted. We have more microorganisms in our guts than we have cells in our bodies—we are crawling with bacteria and we are full of chemicals. We are, in other words, continuous with everything here on earth. Including, and especially, each other.[17]

In Biss’s words, we are ‘already polluted’; as transcorporeal beings, and indeed ‘contaminated’, from birth, the human and nonhuman dualism is shown to be false. In fact, it is estimated that

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[16] Eula Biss, *On Immunity: An Inoculation* (London: Fitzcarraldo Editions, 2015) p.44.
[17] Eula Biss, *On Immunity: An Inoculation* (London: Fitzcarraldo Editions, 2015) p.82.

humans harbour a mass of around 2 to 6 pounds of bacteria within our bodies, most of which we benefit from[18].

In Holloway-Smith's expression of 'very specific types of bacteria', it is shown to the reader that the speaker's anxiety is not necessarily connected to the biological grounding (as not types of bacteria are specified), but is instead loaded with this social significance, as demonstrated by Biss. The speaker's anxiety is shown through the speaker conflating his self with the 'polluted' and the 'unclean'.

As with OCD, these anxieties are often rooted in social moral discourse and tend to reflect what is considered 'bad' within society. These concerns change throughout different societies depending on what may constitute as immoral, such as divine anxieties in more religious areas or groups[19]. In Holloway-Smith's poetry, we as readers see this connection—these terrible thoughts of things which have a cultural moral position as 'manifesting inside', consuming and being consumed by the speaker. Through this collection, anxiety is viewed as not purely internal or individual, but as an illness which can be induced by or affected external factors, showing the environment of the body to have softer boundaries than we may have first thought.

It is useful here to also draw upon posthuman theory, as it is a more human-specific type of study and centres the self and self-perception[20]. This theory can be applied as an extension of 'eco-philosophy' as it promotes ecocritical thought, such as favouring the complexity of subjectivity'[21] and 'the compassionate acknowledgement of their interdependence with multiple others […] in the age of Anthropocene'[22].

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[18] NIH, *'NIH Human Microbiome Project defines normal bacterial makeup of the body'* <https://www.nih.gov/news-events/news-releases/nih-human-microbiome-project-defines-normal-bacterial-akeup-body#:~:text=The%20human%20body%20contains%20trillions,vital%20role%20in%20human%20health.> [accessed 16th March 2023].

[19] M. T. Williams, L. K. Chapman, J. V. Simms, and G. Tellawi, *'Cross-Cultural Phenomenology of Obsessive-Compulsive Disorder'* < https://drkevinchapman.com/wp-content/uploads/2018/05/Williams_CrossCulturalOCD_2017.pdf> [accessed 16th March 2023].

[20] It is more specific as ecological thought shows the dismantling of the human and nonhuman boundary, but posthuman theory centres around the self, as opposed to the system. Much of ecological thought and posthuman theories work side-by-side and feed into one another. For example, posthuman theory is used throughout Stacy Alaimo's *Bodily Natures: Science, and the Material Self* to create definitions of transcorporeality.

[21] Rosi Braidotti, *The Posthuman* (Cambridge: Polity Press, 2013) p.49.

[22] Rosi Braidotti, *The Posthuman* (Cambridge: Polity Press, 2013) p. 101.

Philosopher, Rosi Braidotti, argues in *The Posthuman*, that what we have socially defined as 'the human' in the Western world is constructed 'in opposition'—it is created within a binary, of what is 'human' and what is 'Other'. This understanding of the human as built 'in opposition', we refer to as 'humanism'. This definition of human is not based on a statistical average but is instead 'posited as categorically and quantitively distinct from the sexualized, racialized, naturalized other and also in opposition to the technical artefact.'[23] Braidotti writes, 'the human is a historical construct that became a social convention about 'human nature'.[24]

Posthumanism, however, as Braidotti argues, is a 'move beyond' the 'lethal binaries'[25] that were established in humanism and is viewing the human as exceeding these socially constructed binaries and boundaries.

In a posthuman reading of this poem, the speaker's attempt to shut down this human boundary can be interpreted as the speaker being met with an unenforceable boundary of the 'human'. The speaker appears to be struggling with, or is having anxiety that relates to, the dualism of the human and bacteria, and is attempting to discourage the anxious and uncomfortable feeling of being 'unclean'.

Through his anxiety, in these 'disturbing thoughts', the speaker conflates himself to what is socially 'bad' in a definitive way—such as being the cause of the death of a loved one ('someone I love dying from me thinking or not thinking'), being 'unclean' ('fear of very specific types of bacteria') and causing harm to others ('the brain haemorrhaging all the harm I could do')[26]. I reiterate here that as readers, we do not interpret the speaker as 'unclean' or 'bad'—readers have been provided enough information throughout this collection to see that these are ego-alien thoughts, not matching the rest of what the reader knows about the speaker.

For the individual with OCD, it is dualisms like these which can become particularly troublesome. Those with the condition often have difficulty with what is known as 'black and white thinking'[27], where thoughts, ideas, and topics etc. are categorised as either '*good*' or

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[23] Rosi Braidotti, *The Posthuman* (Cambridge: Polity Press, 2013) p.26.

[24] Rosi Braidotti, *The Posthuman* (Cambridge: Polity Press, 2013) p.26.

[25] Rosi Braidotti, *The Posthuman* (Cambridge: Polity Press, 2013) p.37.

[26] There is also a mention of 'cancer of the mouth lung' in this section, however, as it cropped up throughout the collection, this thought may be intrusive, but may also be a more general (and potentially slightly more grounded) anxiety of the speaker.

[27] Saya Des Marais, 'OCD and Black-and-White Thinking: What's the Link', PsychCentral (2022) <https://psychcentral.com/ocd/ocd-and-black-and-white-thinking> [accessed 11th October 2023].

bad,' in the most general terms. This extreme of binarized thinking allows the person with the condition to attempt to avoid uncertainty, and only do/think/feel what they consider 'correct'.

In a posthuman reading of OCD through the interaction of the body and bacteria, this attempt at enforcing a boundary around the 'human' and viewing the self as 'uncontaminated' from the bacteria which he is anxious to separate himself from, it is highlighted how detrimental and unenforceable these boundaries are. Through using the phrase 'very specific types', the speaker does not address which types of bacteria he is concerned about. This intentional vagueness shows anxious ruminations to be less about the topic itself, but more about the feeling associated. It appears that the bacteria (as far as anyone can know) is of little danger to him, but the (potentially more damaging) fear of bacteria very much is.

There is an implied acknowledgement (on the part of the speaker) that this categorical thinking is unenforceable—through having enough insight to recognise this as an intrusive thought, rather than being purely reality—which appears to be adding to the distress felt. In this implied recognition of the speaker that these binaries are troublesome, there is a posthuman rejection of individualism, where the self is viewed as separated from its environment, which Braidotti refers to as 'profoundly anti-individualistic'[28]. In this acknowledgement, the speaker realised he cannot close himself off to his environment—he has a heightened consciousness of the boundaries of the human and how it inter-acts with the nonhuman, revealing to the reader that independence from the non-human and the 'bad bacteria' is a detrimental and false dualism.

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[28] Rosi Braidotti, *The Posthuman* (Cambridge: Polity Press, 2013) p. 101.

Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision

In the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*[29], obsessive-compulsive disorder and how it is impacted by environmental factors appears radically differently through the change in mode of language.

When understanding mental illnesses and conditions, one of the first points of reference for clinicians, general practitioners, and those wanting to learn more about their conditions is the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed., text revision (DSM-5-TR).* Over time, The *DSM* has evolved into the established modern diagnostic criteria for mental illness and is recognised as so across much of the globe[30]. Consequently, the *DSM* plays a fundamental role in how we manage and socially perceive mental illnesses. Despite the text's prevalence in the medical field, the *DSM* has been publicly scrutinised for a multitude of reasons. Notably, more recently, as James Davies argues in *Sedated, How Modern Capitalism Created Our Mental Health Crisis*, both the *DSM* and the IAPT[31] assessment criteria (PHQ 9 and GAD7[32]) intentionally set the bar for diagnosis to be low, leading to the medicalization of a number of people who don't warrant a diagnosis[33]. Bearing this information in mind, I will be working on the assumption that many psychologists may be trying to use it in good faith, but I will consider the openness of the definitions.

It is critical to acknowledge that the language of medicine, and especially that of diagnostic criteria, does not strictly remain within medical settings. The readership of the *DSM* goes far beyond its intended audience. This language and clinical perspective infiltrates conversations of identity and human rights, self-help guides, cited and referenced within housing regulations, schooling guidelines, accessibility tools, and 'reasonable adjustments'[34]. Therefore, we must ask, what does the language choice used within the *DSM* imply about the illnesses it defines?

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[29] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (Washington, D.C.: American Psychiatric Publishing, 2022).

[30] Verywell Health, *An Overview of the DSM-5* ([n.a.]) <https://www.verywellhealth.com/an-overview-of-the-dsm-5-5197607> [accessed 16th March 2023].

[31] Improving Access to Psychological Therapies (IAPT).

[32] Patient Health Questionnaire and General Anxiety Disorder (PHQ-9 and GAD-7)

[33] James Davies, *Sedated, How Modern Capitalism Created Our Mental Health Crisis* (London: Atlantic Books, 2021) p. 284.

[34] Psychreg, *Autism: Courts and Tribunals* (2020) <https://www.psychreg.org/autism-courts-and-tribunals/> [accessed 16th March 2023].

I will be analysing the language used within this textbook in the same way I have for *Love Minus Love*. In this section I will consider how the literal medical language of the *DSM* enables discussion on obsessive-compulsive disorder and its environmental factors. This discussion with bear in mind the purposes of the text and the contexts in which it is used and will examine what is explicitly and implicitly told to the reader. This is an innovative, experimental, and interdisciplinary approach to the *DSM-5-TR.* In performing a literary and ecocritical reading of a medical text, this analysis emphasises how these criteria impact those diagnosed through a readerly reception from the perspective of someone outside of the medical field and lens. By performing this study, I am seeking to advance disability studies and the medical humanities.

As the section on OCD runs over seven pages (see Appendix for full diagnostic criterion), I have chosen to analyse passages from the 'Diagnostic Features', 'Associated Features', and 'Risk and Prognostic Factors'. I will first consider the mode of language in 'Diagnostic Features', and after I will analyse the environmental factors in the latter two passages.

The Language of Medicine

According to *DSM-5-TR*, part of the diagnostic features of OCD are the following:

> ## Diagnostic Features
>
> The characteristic symptoms of OCD are the presence of obsessions and compulsions (Criterion A). *Obsessions* are repetitive and persistent thoughts (e.g., of contamination), images (e.g., of violent or horrific scenes), or urges (e.g., to stab someone). Importantly, obsessions are not pleasurable or experienced as voluntary: they are intrusive and unwanted and cause marked distress or anxiety in most individuals. The individual attempts to ignored or suppress these obsessions (e.g., avoiding triggers or using thought suppression) or to neutralize them with another thought or action (e.g., performing a compulsion). *Compulsions* (or rituals) are repetitive behaviors (e.g., washing, checking) or mental acts (e.g., counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly.[35]

Upon first read, the *DSM-5-TR* provides the reader with an all-encompassing framework, one which explains quite simply two different types of symptoms common with obsessive-compulsive disorder. The text is written in a way which aims for clarity, and in many ways, it achieves this. The *DSM* is broken into subheadings and numbered sections to ensure that those reading can find the information quickly and efficiently, which makes the text easy to navigate and use. This organisation follows a similar structure to other medical texts, as it is made to be referenced rather than read in its entirety. In organising the text to read as a more concise definition, then specifiers, diagnostic features, associated features, to prevalence and prognostic factors etc.—or the most to least relevant regarding diagnostic purposes—would be most helpful to general practitioners who have a limited amount of time when referencing.

The text seeks to define what obsessions and compulsions are, provide a brief description on how they impact the individual, and provides an example of intrusive thoughts '(e.g., of contamination)'. The reader greatly benefits from the consistent examples throughout as it helps to ground the text in a form of experience and helps the reader to gain some

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[35] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (Washington, D.C.: American Psychiatric Publishing, 2022) p. 266.

specificity of meaning, as many of the terms used (such as 'compulsions' and 'obsessions') are broad and open-ended. However, the *DSM-5-TR* does not include any citations to the studies in references. This is a particularly dangerous approach to writing scientific information as the reader cannot check the legitimacy of this text or perform further reading.

The language of medicine, and indeed of legal documentation, uses the rules-based[36] 'plain' and symbolic word choices, in contrast to the poetic semiotic. This mode of language is used with the intention of having specificity regarding the technical aspects of obsessive-compulsive disorder, and minimising readerly interpretation. However, with diagnostic criteria, there is a contradiction in what the text needs to do. Diagnoses seek to be specific in what they define, but equally, attempt to encompass a variety of subjective experiences. In attempting to do two opposing things—create precision and open-endedness in the linguistic choices—this precision of technical aspects of the definition come at the expense of the specificity of the emotional and embodied aspects.

In attempting for specificity regarding the technical aspects of obsessive-compulsive disorder (such as defining an obsession), the text focusses on the details that are deemed most relevant, as opposed to a full holistic multi-dimensional perspective of OCD. In *Semiotics and Dis/ability; Interrogating Categories of Difference*[37], childhood education specialist, Nancy Stockall, writes on how the fragmentation of the Self through language can become detrimental to self-perception. She writes:

> This concept of undivided wholeness contradicts the notion of fragmentation so fundamental to our Western culture. It is fragmentation that guides most of our institutions and human work. We fragment and aggregate our time (i.e., work and play), our space (i.e., work and home) […] and life itself (i.e., child, adolescent, adult […]). Indeed, this fragmentation has to some extent been appropriate and sometimes necessary to reduce complex problems to manageable units. However, when we break up both our worlds and ourselves, there is a tendency to seek only those fragments that support our self-world view. Additionally, our ability to separate ourselves from the

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[36] Camelia Talebian Sadehi, '*Beloved* and Julia Kristeva's The Semiotic and The Symbolic', *Theory and Practice in Language Studies* (2012) vol. 2, no. 7, pp. 1491-1497 (p. 1491) para. 4.

[37] Nancy Stockall, *Semiotics & Dis/ability: Interrogating Categories of Difference*, ed. Linda J. Rogers, Beth Blue Swadener (New York: State University of New York press, 2001).

> world sets up a reality that appears to have an autonomous existence, independent of our own making.[38]

Medical language is another example of fragmentation, one which is ‘necessary to reduce complex problems to manageable units’, yet it comes at the consequence of supporting a reality in which we are experiencing an ‘autonomous existence, independent of our own making’. This definition of OCD, which is required to emphasise the technical aspects of OCD, reduces the implied emotional aspects through its use of symbolic language.

In creating a perception of OCD from the medical lens, and through the use of symbolics language, our depiction of illness is one which is static, as not responsive to its environment, as a less so an emotional experience. For example, how emotional aspects of OCD are described as: ‘intrusive and unwanted and cause marked distress or anxiety in most individuals’[39]. Whilst it may be correct to argue OCD is ‘distress[ing]’ and the thoughts are ‘unwanted’, it is diminishing of the visceral effect mental illness has over the body-mind.

In using these semiotic terms, there is no expansion or specificity regarding what the individual may feel for themselves and their thoughts, the paralysing fear for the moral and social consequences of this anxiety, and how these ego-alien thoughts confuse perceptions of the self. Here, readers see a drastic reduction of personal experiences. The text reads as not encompassing the same emotional elements of this illness; ones which were expressed earlier in *Love Minus Love*. In being a medical text, and indeed one for referencing, many may argue that the text does not need to include these qualities, or that they may be considered as less relevant to those using the text, but there are consequences of this. Whilst there is specificity created regarding in the technical elements of this illness (what is OCD [?]), it comes at the cost of losing specificity regarding the emotional and embodied elements (what does OCD *feel like*[?]).

There is also a danger to diagnoses clustering together many different subjective experiences. Whilst the case can certainly be made that expansive definitions encompass different experiences of those with an illness, open definitions also lead to the unnecessary

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[38] Nancy Stockall, ‘A Mother’s Reconstruction of the Semiotic Self’, *Semiotics & Dis/ability: Interrogating Categories of Difference*, ed. Linda J. Rogers, Beth Blue Swadener (New York: State University of New York press, 2001) p. 120.

[39] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (Washington, D.C.: American Psychiatric Publishing, 2022) p. 266.

medicalisation of emotional distress. This breadth does not provide any further insight into symptoms or realities mentally ill people face; in fact, the definitions are made vaguer. This can mean that those being diagnosed, or the psychiatrist involved, can find in harder to recognise these symptoms. Vague definitions lead to more diagnosed patients with anxiety and depression (whether a psychiatric diagnosis is entirely warranted or not), and the under-diagnosis of conditions which may require more accessibility support rather than medical intervention, such as ADHD and autism. An example of this is girls and women going undiagnosed for autism and ADHD much longer than their male counterparts because of a lack of recognitions that behaviours show can differently depending on your gendered socialisation[40].

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[40] National Autistic Society, Autistic Women and Girls ([n.a.]) <https://www.autism.org.uk/advice-and-guidance/what-is-autism/autistic-women-and-girls> [accessed 16th March 2023]

‘The Voice of Reason’

In the *DSM-5-TR,* the speaker’s voice reads as authoritative and emotionally distanced, as to reflect the dispassionate science. This scientific voice is not an accidental attribute—it is designed to reflect objective, rational, and impartial information.

The *DSM* is an ever-changing text and is updated roughly every 5-7 years. In doing so, the *DSM* seeks to be the most up-to-date document on mental illnesses and conditions, but by its very nature, the *DSM* is non-definitive and has huge potential to be laden with flaws. In psychiatry, the biological causes of mental illnesses are still not understood[41], and so the text has a basis of evidence from clinicians, but much of the nature of mental illnesses remain beyond our understanding. By using a definitive tone to describe a non-definitive topic, there is a great danger of misconstruing the subject and there being serious real-life consequences. This is both from a technical perspective—of including and excluding certain aspects of the condition—and the influence of internalised bias of the author, now written as objective truth.

An example of how detrimental this bias translates into medical language can be seen in Psychologist Paula J. Caplan’s (1992) feminist argument against ‘Self-Defeating Personality Disorder’ being put into the *DSM-4*[42]. The passage suggested by the *DSM-4* council is as follows:

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[41] National Library of Medicine, *Information about Mental Illness and the Brain* ([n.a.]) para. 24 <https://www.ncbi.nlm.nih.gov/books/NBK20369/#:~:text=Although%20scientists%20at%20this%20time,whether%20someone%20becomes%20mentally%20ill.> [accessed 26th July 2023].

[42] Paula J. Caplan and Maureen Gans, ‘Is There Empirical Justification for the Category of ‘Self-Defeating Personality Disorder?’, *Feminism & Psychology* (London; Sage Publications, 1991) vol. 1, iss. 1, p. 179-319.

Diagnostic criteria for Self-Defeating Personality Disorder

A. A pervasive pattern of self-defeating behaviour, beginning by early adulthood and present in a variety of contexts. The person may often avoid or undermine pleasurable experiences, be drawn to situations or relationships in which he or she will suffer, and prevent others from helping him or her, as indicated by at l least five of the following:

   1. Chooses people and situations that leads to disappointment, failure or mistreatment even when better options are clearly available;
   2. Rejects or renders ineffective the attempts of others to help him or her;
   3. Following positive personal events (e.g., new achievement), responds with depression, guilt, or a behaviour that produces pain (e.g., an accident);
   4. Incites angry or rejecting responses from others and then feels hurt, defeated, or humiliated (e.g., makes fun of spouse in public, provoking an angry retort, then feels devastated);
   5. Rejects opportunities for pleasure, or is reluctant to acknowledge enjoying him or herself (despite having adequate social skills and the capacity for pleasure);
   6. Fails to accomplish tasks crucial to his or her personal objectives despite demonstrated ability to do so (e.g., helps fellow students write papers but is unable to write own);
   7. Is uninterested in or rejects people who consistently treat him or her well (e.g., is unattracted to caring sexual partners);
   (8) engages in excessive self-sacrifice that is unsolicited by the intended recipients of the sacrifice.

B. The behaviours in A do not occur exclusively in response to, or in anticipation of, being physically, sexually, or psychologically abused

C. The behaviours in A do not occur only when the person is depressed.[43]

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[43] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 3rd ed.* (Washington, D.C.: American Psychiatric Publishing, 1987) p. 373-4.

Self-Defeating Personality Disorder (SDPD) appeared in the appendix of the *DSM-3* (*DSM-III-R*) in 1987 but was not formally admitted into the *DSM*. Paula J. Caplan made the case that the diagnosis of a Self-Defeating Personality Disorder would have horrific real-life implications for women, especially in court cases[44]. Caplan argued that this diagnosis would be weaponised primarily against women—as women were, and still are, more likely to be victims of domestic abuse, sexual assault, and child sexual assault[45].

In the *DSM* passage stating that people who have this disorder are actively and intentionally engaging in 'behaviour[s] that produce pain', it is possible to make an argument that all crimes committed against this person are desired and consented to. Caplan states that this diagnosis would make persecution of abusers more difficult, as victims are actively seeking mistreatment through being 'uninterested in or rejects people who consistently treat him or her well'. As it is noted towards the end of the passage that these 'behaviours […] do not occur exclusively in response to, or in anticipation of, being physically, sexually, or psychologically abused', the *DSM* committee show an awareness that these behaviours are linked to trauma, but disregard for the sufferer's safety. Paula J. Caplan's case against Self-Defeating Personality Disorder highlights how medical language and diagnosis play a crucial role in the lives of mentally ill and disabled people, and how they can have dangerous implications for the individual when applied callously.

In using a 'rational' and authoritative voice, the biases of the author are not eliminated, they are simply made less explicit. Readers of the text are not supposed to question the integrity and the biases of the author and are instead encouraged to take this information as factually accurate, despite the text continually needing revision. The use of this 'rational' voice raises the question, what are the implications for the care of the individual when readers [clinicians] are emotionally distanced from the subjects [patients] of the text?

To begin to answer this question, I am turning to Val Plumwood's *Environmental Culture: the ecological crisis*. In this text, philosopher and ecofeminist, Plumwood, makes the argument that when scientists are emotionally distanced to their subjects, and use this dispassionate approach, they can be perpetuating violence. Whilst Plumwood is discussing the use of

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[44] Paula J. Caplan and Maureen Gans, 'Is There Empirical Justification for the Category of 'Self-Defeating Personality Disorder?', *Feminism & Psychology* (London; Sage Publications, 1991) vol. 1, iss. 1, p. 265.

[45] 'Facts and figures: Ending violence against women', UN Women ([n.a.]) <https://www.unwomen.org/en/what-we-do/ending-violence-against-women/facts-and-figures> [accessed 11th October 2023].

scientific language of the nonhuman, there are helpful parallels in the way this language operates, and how this impacts those who are subject to this use of language. She argues that:

> We hyper-separate ourselves from nature and reduce it conceptually in order to justify domination [and because of this] we not only lose the ability to empathise and to see the non-human sphere in ethical terms, but also get a false sense of our own character and location that includes an illusory sense of autonomy.[46]

Whilst Plumwood's analysis is regarding the non-human, much of the how the scientific language mode operates remains the same. Through the emotional distancing of the dispassionate speaker, and the hierarchy stemming from the subject / authority dynamic, the reader is not asked to empathise in 'ethical terms'. This lack of empathy required from the reader creates an Othering effect of the individuals described in the text, whether it is intentional or not, and in turn can be used to justify ableism. In this inherent lack of empathy, the perceptions of those described within these diagnoses will also be 'reduced conceptually' and therefore will always be somewhat misrepresented—as whole experiences cannot be encapsuled into clinical, emotionless symbolic language.

In using a dispassionate speaker, much of the responsibility for how this text is used is placed on the reader. Whilst it is noted in the *DSM* that it should not be taken out of context[47], this choice of language can be interpreted in violent ways even within its appropriate contexts ('clinical, educational, and research settings'[48]). Many medical professionals will be approaching these criteria with their own knowledge and with empathy, but it would be irresponsible not to recognise the prevalence of racism, misogyny, and ableism are still throughout the medical industry[49]. Through this mode of language, those described within the text are made Othered, and with this comes a violence that medical professionals must remain vigilant of, as to not perpetuate it.

In writing this analysis, I find myself asking the question, why does the *DSM* not want the reader to feel empathy? Whilst, historically, the intentions behind the *DSM* have been

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[46] Val Plumwood, *Environmental Culture: the ecological crisis* (Oxford; Routledge, 2001) p. 9, para 1.

[47] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (Washington, D.C.: American Psychiatric Publishing, 2022) p. 23, para 2.

[48] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision*. (Washington, D.C.: American Psychiatric Publishing, 2022) p. 266.pg 23, para 2.

[49] Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present* (New York; Harlem Moon, 2008).

questionable due to how this text is used throughout the medical-industrial complex[50], I believe the *DSM* is focussed on technical accuracy and readerly reception is simply de-prioritised.

Literary analysis of medical texts is critical as, when compared to other forms of writing, such as poetry, there is a lack of external editing[51] regarding the readerly reception. As this study has highlighted, the language choices made in medical texts both do not always remain within this context and can cause considerable harm to those subject to it. There are many ways which the DSM could shift away from the violent implications of its voice, including input from those with the conditions[52] or sensitivity readers.

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[50] James Davies, *Sedated, How Modern Capitalism Created Our Mental Health Crisis* (London: Atlantic Books, 2021) p. 284

[51] As noted in the introduction of the *DSM-5-TR,* it is noted in the 14 pages of staff that have worked on the issue, that they have a two-person team of editorial and coding consultants.

[52] An example of how this can be done can be seen on the MIND website.

Environmental Factors

One of the primary ways the *DSM-4* was revised in anticipation of the *DSM-5* was the inclusion of environmental factors. In the duration of performing this study, the *DSM-5* was updated to the *DSM-5-TR*, and in this revision the environmental factors section was updated. Below I have included both the original *DSM-5* environmental factors section and the updated version:

> **Environmental.** Physical and sexual abuse in childhood and other stressful or traumatic events have been associated with an increased risk for developing OCD. Some children may develop the sudden onset of obsessive-compulsive symptoms, which has been associated with different environmental factors, including various infectious agents and a post-infectious autoimmune syndrome.[53]
>
> (DSM-5)
>
> **Environmental.** Different environmental factors may increase the risk for OCD. These include adverse perinatal events, premature birth, maternal tobacco use during pregnancy, physical and sexual abuse in childhood, and other stressful or traumatic events. Some children may develop the sudden onset of obsessive-compulsive symptoms, which has been associated with different environmental factors, including various infectious agents and a postinfectious autoimmune syndrome.[54]
>
> (DSM-5-TR)

Initially, when I considered these factors, I was shocked by their profound ambiguity and lack of analysis (such as, what defines a ‘stressful event’ and what are these ‘infectious agents’?). Whilst the acknowledgement is certainly necessary, it still did not parallel with the other existing information on OCD. In reading the original text, the two sentences of environmental factors—out of five pages (not including any introductory material)—feels disproportionate compared to other subsections.

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[53] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed.* (Washington, D.C.: American Psychiatric Publishing, 2013) p. 239-240.

[54] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision.* (Washington, D.C.: American Psychiatric Publishing, 2022) p. 269.

Incorporating environmental factors should give psychologists and those with mental illnesses insight into how the illness functions, which then allows them to work out possible sources of unresolved traumas and potential triggers which are impacting their health.

However, this section does not address the influence of trauma and environmental factors (physical, mental, social, built etc.) and how the illness changes and evolves in any real detail. The passage includes some environmental factors for causality of OCD but not how environment can exacerbate the condition—and what is written reads as if it were written hastily. It is also unspecified as to what the 'various agents' and which 'autoimmune syndrome' the passage is referring to. In the updated version, more details have been added, yet the general principal of my initial analysis still applies.

In revisiting the text after its revision, I have been particularly struck by how much environmental factors have been implicitly discussed when considering how the individual navigates the world. Below is a passage taken from the 'Associated Features' section of the *DSM-5-TR*:

> ## Associated Features
>
> *Sensory phenomena*, defined as a physical experiences (e.g., physical sensations, just-right-sensations, and feelings of incompleteness) that precede compulsions, are common in OCD. Up to 60% of individuals with OCD report these phenomena.
> Individuals with OCD experience range of affective responses when confronted with situations that trigger obsessions and compulsions. For example, many individuals experience marked anxiety that can include recurrent panic attacks. Others report strong feelings of disgust. While performing compulsions, some individuals report a distressing sense of "incompleteness" or uneasiness until things look, feel, or sound "just right."[55]

OCD, and mental illnesses more generally, can be deeply influential in the way that individuals engage with the world. This is something that the *DSM-5-TR* is beginning to imply through its inclusion of '*sensory phenomena'*. Yet in this inclusion, the reader is intentionally distanced from the individuals within the text through the 'rational' dispassionate voice, and so is not

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[55] American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision.* (Washington, D.C.: American Psychiatric Publishing, 2022) p. 267.

made to understand how these phenomena feel. In this literary reading, I am left with questions such as, what does this ‘disgust’ feel like? What does the feeling of ‘incompleteness’ feel like? To anyone who does not have OCD, the idea of something being incomplete may not cause any substantial negative feeling at all. Through close textual analysis, readers can interpret that through using symbolic and dispassionate language to discuss highly subjective emotional experiences, the *DSM* creates an unintended openness in meaning, which further separates the reader from the subject.

Conclusion

In using different modes of language, the speaker is shaping perceptions of OCD and those with the condition.

Within the poetry collection, *Love Minus Love,* figurative language is used to bring the reader closer to the speaker, and to demonstrate how the speaker is impacted by intrusive thoughts. Through using figurative language and ontological metaphors, Holloway-Smith gives form to the phenomena of thoughts, making them quantifiable, and now possible for the reader to see how the speaker interacts with them. Holloway-Smith shows how these intrusive thoughts are formed (as influenced by many external factors), how they occur (as repetitive and disruptive), and what they feel like to the speaker (overwhelming and threatening).

In *Love Minus Love*, OCD is shown as being created and exacerbated by a myriad of factors of external influences impacting the internal life of the speaker, through how the speaker engages with their world. This is enabled through the use of form, with reflects and emphasises the content of the poems (as refracted, and with uninterrupted flow throughout the book). Through this refracted poetic form, it is demonstrated to the reader how the speaker is immersed in an ever-changing world of factors which impede on him.

In performing an ecocritical reading of this collection[56], readers are informed of how the speaker's experiences of disability are moulded to an environment, and how his relationships with the nonhuman become strained and intensified. The speaker interacts with ecological ideas through expressing anxieties around 'specific types of bacteria' and viewing his own body as an environment—where the internal dialogue and OCD is in constant conversation with physical and social environments.

Whereas the *DSM-5-TR*'s use of symbolic medical language creates a perception of OCD as obscured through the medical lens. This mode of language is chosen to convey the technical aspects of OCD as it restricts interpretations of this text. As with symbolic language having minimal meaning, further meaning for the reader of the *DSM-5-TR* is provided through the addition of more details and examples (such as defining an 'obsession').

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[56] With the additional support of posthuman theory as an extension of ecocriticism.

However, in using this mode of language—and only using words with a restricted meaning—the authors must create a hierarchy of different types of information on OCD. The authors cannot use words which imply several meanings in one (as figurative can), so instead they must choose which aspects to describe, and in how much detail. Through this process, technical aspects of OCD are hierarchised for the purposes of this text (to diagnose). Yet, this comes at the detriment of sensory and emotional aspects of OCD. The language itself, as being minimal in meaning, and in conjunction with the dispassionate 'rational' voice of science, prevents the reader from having a closeness to the speaker of the text. Which, in turn, can have dangerous implications for those described within the text.

Consequently, when the *DSM* discusses environmental factors, there is a vagueness in how these can feel for the individual, as the reader is intentionally distanced from speaker and their potential experiences. Whilst the recent addition of 'Environmental Factors' is welcome; it is also unfortunately vague. These environmental factors are presented as potential causes, and not considered for how they may exacerbate the condition. Crucial elements of embodied knowledge, emotional aspects, and in-depth consideration on how environmental factors impact the condition can become over-looked from simply being de-hierarchised. In the 'Associated Features' section, how the individual may navigate the world is mentioned through the idea of '*sensory phenomena*'. Yet, through this choice of voice, the reader is still given minimal information, and is not expected to emotionally engage with the text (and thus, not with those described).

When critically analysed from a literary and ecocritical perspective, this symbolic and dispassionate language is shown as a reductive minimisation of personal embodied knowledge, the intimate ways it impacts an individual, and of how illnesses can react to different environments and the real-life implications of illnesses changing relationships with the nonhuman. This symbolic medical language, as used in the *DSM*, does not do justice to the visceral emotional aspects of illness simply because it is designed to have a restricted meaning and interpretability. Whilst, figurative language, on the other hand, can carry multiple meanings, and therefore can imply more aspects in conjunction—such as how intrusive thoughts come to the speaker, and what his emotional responses are to them are.

Within this example of *Love Minus Love* and the *DSM-5-TR*, readers are presented with two different perceptions of OCD, and are asked to engage in different ways.

In *Love Minus Love*, readers are immersed into the world of the speaker through formal elements and are asked to engage emotionally with the topic. As readers, we understand the complexity of OCD through its relationality—such as how the speaker's anxiety reacts to social taboos (uncleanliness) or relationships. In using figurative language, writers do not need do not need to hierarchise certain aspects over others, as many can be implied at once, and thus, topics do not need to be so greatly reduced in their complexity.

Yet, in the *DSM-5-TR*, the readerly response is not that of emotional engagement, it is to remain distanced to the subject of the text. This, as I have demonstrated, can become detrimental. The language used within the DSM, as symbolic medical language, is not designed for complexity—it has limited meaning and interpretability. Whilst the text is not intended to be open for interpretation, it does make implications though what it does not say, and through its use of voice.

This cross-comparison emphasises that symbolic language is not one which is 'neutral' in comparison to semiotic language. Both modes of language make implications—intended or otherwise—through what is said, what is not said, and through form (i.e., voice and tone). We may, as readers, be under the impression that when passages are written in symbolic words (and through the use of an authoritative voice) they are depicted as entirely accurate, unbiased perceptions. However, through this comparison it is highlighted that in using symbolic words which carry limited meaning, the perception of the 'thing' that we describe must be reduced. When we use symbolic language to describe complex topics, we reduce them to the aspects we consider most prominent and overlook others.

Environment, which has a considerable impact on OCD, is continually overlooked when it is de-hierarchised. In this example, it is demonstrated how through using different modes in language, the environmental factors which cause and exacerbate OCD are either appreciated or are dismissed. The perceptions of OCD that we socially use, as adapted from the *DSM*, are not accurate reflections on what like the lives of those with OCD are like, how OCD operates in the world, and what these experiences are like, as this is inherently a medical perspective. Yet, through figurative language, readers are brought closer to the text, and are reminded that illness is not simply a list of symptoms but is an embodied experience that is not experienced in a vacuum.

Chapter 6

Thesis Conclusion

Disability and the environment have a relationship which is deeply complex, entangled, and goes far beyond our human comprehension. In encompassing a huge variety of impairments, illnesses, and neurodivergence, and the multitude of ways disabled people engage with the world, this topic is bountiful in intersections and intra-activity.

Though it remains under-discussed, disabled people are often made aware of how ecological factors (from access through to the need for clean air) moderate the embodied experiences of disability. These experiences become deeply inter-related, with disability being formed in relation to its culture, socio-political and historical contexts, as well as biological and environmental factors (and their intersections). To expand upon disability studies, I drew upon ecocritical thought to include an expansive definition of environment, to not become reductive of the complexity of environment, and to highlight the 'less perceptible' ways our bodies inter-act and become transcorporeal (Alaimo).

In this thesis, I argue that when we attempt to put these complex ideas into words, the limitations of symbolic language become apparent. These topics resist language for their phenomenological qualities (Scarry); we may create inaccurate depictions of illness (Sontag); and there can be dangerous implications for those who are the subject of the text (Clare). I argue that, with translating these phenomena into *symbolic* language, these topics must be reduced in complexity in order to be defined. For objects, this translation is simple—we prescribe a label that we socially agree on its meaning (i.e., a chair is a chair; to be a chair it must have the defining characteristic of being designed to be sat on). Yet, for phenomena, as they lack object and have many unknowable properties—as with our limited understanding of health in the environment—to prescribe a symbolic term would be to reduce its complexity so far that it becomes inaccurate.

These symbolic words come with a 'censorship' (Kristeva); it is laced with rules in order to categorise the world around us. It prioritises limited meaning of each word over the sound and rhythm-based language we used to express our drives and needs as children (as Kristeva defines as 'semiotic' language). It through this language of the *semiotic*—the poetic, sound-based, rhythmic, figurative language—that we can express the needs of the body-mind and, through this we can begin to express the intimate and visceral experiences of disability, as these words bring us closer to the experiences of the body-mind.

To demonstrate exactly how figurative language can communicate aspects of obsessive-compulsive disorder (OCD), and the ways OCD interacts with ecological ideas, I compared Wayne Holloway-Smith's poetry collection, *Love Minus Love*, to the *Diagnostic and Statistical Manual of Mental Disorders, 5th ed, text revision* (*DSM-5-TR*). In this analysis, I contrasted the differences between figurative and symbolic language, as well as the perceptions of OCD created for the reader.

What can be concluded from this cross-comparison is that, despite the potential to create inaccurate depictions of illness, figurative language can be deeply beneficial to the reader and writer in conceptualising illness, and how they inter-act with environment.

In this example of *Love Minus Love*, Holloway-Smith helps readers to conceptualise ideas through the terms of another, in more detail than symbolic words allow. In using the ontological metaphor of thoughts as objects (ones which 'stand up inside' the speaker), the phenomenon of thought is now given object—directly contrasting Scarry's argument that sensations resist language. These thoughts can then be quantified, and the reader can understand how the speaker interacts with them. Readers are asked to engage in a form of creative rationality, an imaginative and rational reasoning to conceptualise complex topics (Lakoff and Johnson). Figurative language is often used within medicine (such as the *McGill Pain Questionnaire*) for this very reason; not only does it help patients to communicate location and intensity of sensation, but also how this sensation makes them *feel*.

Through the form of poetry, the reader is brought closer to the text, and is asked to engage emotionally with the speaker. In this immersion, ecological ideas come to the fore as these experiences do not occur within a vacuum—they are shown as stemming from the world of the speaker. These ecological aspects—which are quite significant for this condition—are shown to the reader through fragmented social contexts, the body becoming an environment, and how the relationship with the nonhuman changes (such as with bacteria).

Poetic language is not only a means to an end regarding communication; it is an act of expression. Not only does this mode help the reader to learn, but poetry can enable the poet by acting as a research and investigative method. In this, the poet can explore parts of themselves through writing. This is something which became prominent within my own practice, as I use poetry to explore my relationship with disability and how my health inter-acts with environment, in my collection, *Gut Feeling*.

In analysing the *DSM-5-TR* from a literary perspective, as a point of comparison, it can also be concluded that in using symbolic terms to describe illness, we are equally shaping a perception of illness—one which is not purified from bias. Symbolic language, despite having less meaning in each word, still creates implications through that is said, how it is said (i.e., tone and voice), and what goes unsaid. Texts are not often without purpose or aims, and as highlighted in the example of the *DSM-5-TR*, different perceptions are created depending on these intentions.

Through symbolic language, and particularly with the 'rational' voice of medicine, we as readers can be under the impression that the perceptions made through this mode of language are 'whole' and unbiased. In using symbolic language, and attempting to make concise technical definitions, aspects of OCD must be hierarchised, to the detriment of others. Perhaps without realising it, these texts can be over-looking or depreciating the importance of certain aspects (as environment) which seeps into our broader public understanding and perception.

This creates versions of OCD which are simplistic and reductive—and whilst this may be helpful for practitioners who are referencing the text, it is unhelpful for those who are the subject of the text. Given that environmental factors are attributed to both causing and exacerbating OCD, it then becomes dangerous to adapt our social understanding of OCD, and broadly of disability, from texts which devalue environment. In the *DSM-5-TR*, when environmental factors are described, the lack of emotional connotations from symbolic language does not require the reader to emotionally engage with the subject of the text, and therefore this emotional aspect of illness is also devalued.

The most significant conclusion of this thesis is that figurative language and metaphorical thinking are not innately detrimental to discussing disability. Metaphorical thinking is a not simply making comparisons; it is how we understand the world. It can be particularly helpful for understanding phenomena which are as complex and nuanced as disability and environment, as I have proven in both the critical portion and within my practice.

What is detrimental, however, is not necessarily figurative language, but instead the implications we make through language (intentional or otherwise, both with symbolic and semiotic language). Whilst I do recognise the dangers that come from a poorly chosen metaphor—or using a metaphor in violent ways—the danger does not stem from it simply being a metaphor, but instead the motivation behind choosing it, and the implications it has. *Metaphors can be dangerous because they are so effective*. Instead of attempting to strip our dialogues of metaphor (which would be easier said than done) we must remain vigilant and re-evaluate our choices of language for what they imply, assessing how ableism intrudes our language. In discussing ourselves and our own disabilities, poetic language can be as liberating, helpful, and as I have demonstrated, as much of a tool as it is a weapon.

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Appendix

- Obsessive-Compulsive Disorder in the DSM-5-TR (page 203-213).

Obsessive-Compulsive Disorder

Diagnostic Criteria

A. Presence of obsessions, compulsions, or both:

Obsessions are defined by (1) and (2):

1. Recurrent and persistent thoughts, urges, or images that are experienced, at some time during the disturbance, as intrusive and unwanted, and that in most individuals cause marked anxiety or distress.

2. The individual attempts to ignore or suppress such thoughts, urges, or images, or to neutralize them with some other thought or action (i.e., be performing a compulsion).

Compulsions are defined by (1) and (2):

1. Repetitive behaviors (e.g., hand washing, ordering, checking) or mental acts (e.g., praying, counting, repeating words silently) that the individual is driven to perform in response to an obsession or according to rules that must be applied rigidly.

2. The behaviors or mental acts are aimed at preventing or reducing anxiety or distress, or preventing some dreaded event or situation; however, these behaviors or mental acts are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive.

Note: Young children may not be able to articulate the aims of these behaviors or mental acts.

B. The obsessions or compulsions are time-consuming (e.g., take more than 1 hour per day) or cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.

C. The obessive-compulsive symptoms are not attributable to the physiological effects of a substance (e.g., a drug of abuse, a medication) or another medical condition.

D. The disturbance is not better explained by the symptoms of another mental disorder (e.g., excessive worries, as in generalized anxiety disorder; preoccupation with appearance, as in body dysmorphic disorder; difficulty discarding or parting with possessions, as in hoarding disorder; hair pulling, as in trichotillomania [hair-pulling disorder]; skin picking, as in excoriation [skin-picking] disorder; stereotypies, as in stereotypical movement disorder; ritualized eating behavior, as in eating disorders; preoccupation with substances or gambling, as in substance-related and addictive disorders; preoccupation with having an illness, as in illness anxiety disorder; sexual urges or fantasies, as in paraphilic disorders; impulses, as in disruptive, impulse-control, and conduct disorders; guilty ruminations, as in major depressive disorder; thought insertion or delusional preoccupations, as in schizophrenia spectrum and other psychotic disorders; or repetitive patterns of behavior, as in autism spectrum disorder).

Specify if:

With good or fair insight: The individual recognize that obsessive-compulsive disorder beliefs are definitely or probably not true or that they may or may not be true.

With poor insight: The individual thinks obsessive-compulsive beliefs are probably true.

With absent insight/delusion beliefs: The individual is completely convinced that obsessive-compulsive disorder beliefs are true.

Specify if:

Tic-related: The individual has a current or past history of a tic disorder.

Specifiers

Individuals with obsessive-compulsive disorder (OCD) vary in the degree of insight they have about the accuracy of the beliefs that underlie their obsessive-compulsive symptoms. Many individuals have *good or fair insight* (e.g., the individual believes that the house definitely will not, probably not, or may or may not burn down if the stove is not checked 30 times). Some have *poor insight* (e.g., the individual believes that the house will probably burn down if the stove is not checked 30 times), and few (4% or less) have *absent insight/delusional beliefs* (e.g., the individual is convinced that the house will burn down if the stove is not checked 30 times). Insight can vary within an individual over the course of the illness. Poorer insight has been linked to worse long-term outcome.

Up to 30% of individuals with OCD have a lifetime tic disorder. This is most common in men with onset of OCD in childhood. These individuals tend to differ from those without a history of tic disorders in the themes of their OCD symptoms, comorbidity, course, and patterns of familial transmission.

Diagnostic Features

The characteristic symptoms of OCD are the presence of obsessions and compulsions (Criterion A). *Obsessions* are repetitive and persistent thoughts (e.g., of contamination), images (e.g., of violent or horrific scenes), or urges (e.g., to stab someone). Importantly, obsessions are not pleasurable or experienced as voluntary: they are intrusive and unwanted and cause marked distress or anxiety in most individuals. The individual attempts to ignored or suppress these obsessions (e.g., avoiding triggers or using thought suppression) or to neutralize them with another thought or action (e.g., performing a compulsion). *Compulsions* (or rituals) are repetitive behaviors (e.g., washing, checking) or mental acts (e.g., counting, repeating words silently) that the individual feels driven to perform in response to an obsession or according to rules that must be applied rigidly. Most individuals with OCD have both obsessions and compulsions. Obsessions and compulsions are typically thematically related (e.g., thoughts of contamination associated with washing rituals; thoughts of harm associated with repeated checking). Individuals often report that they perform compulsions to reduce the distress triggered by obsessions or to prevent a feared event (e.g., becoming ill). However, these compulsions either are not connected in a realistic way to the feared event (e.g., arranging items symmetrically to prevent harm to a loved one) or are clearly excessive (e.g., showering for hours each day). Compulsions are not done for pleasure, although individuals may experience temporary relief from anxiety or distress.

The specific content of obsessions and compulsions varies between individuals. However, certain themes, or dimensions, are common, including those of cleaning (contamination obsessions and cleaning compulsions); symmetry (symmetry obsessions and repeating, ordering, and counting compulsions); forbidden or taboo thoughts (e.g., aggressive, sexual, or religious obsessions and related compulsion); and harm (e.g., fears of harm to self or others and checking compulsions). Some individuals also have difficulties discarding and accumulate objects as a consequence of typical obsessions and compulsions (e.g., fears of harming others); such as compulsions must be distinguished from the primary accumulation behaviors seen in hoarding disorder, discussed later in this chapter. These themes occur across different cultures, are relatively consistent over time in adults with the disorder, and may be associated with different neural substrates. Importantly, individuals often have symptoms in more than one dimension.

Criterion B emphasizes that obsessions and compulsions must be time-consuming (e.g., more than 1 hour per day) or cause clinically significant distress or impairment to warrant a diagnosis of OCD. This criterion helps to distinguish the disorder from the occasional intrusive thoughts or repetitive behaviors that are common in the general population (e.g., double checking that a door is locked). The frequency and severity of obsessions and compulsions vary across individuals with OCD (e.g., some have mild to moderate symptoms, spending 1-3 hours per day obsessing or doing compulsions, whereas others have near constant intrusive thoughts or compulsions that can be incapacitating).

Associated Features

Sensory phenomena, defined as a physical experiences (e.g., physical sensations, just-right-sensations, and feelings of incompleteness) that precede compulsions, are common in OCD. Up to 60% of individuals with OCD report these phenomena.

Individuals with OCD experience range of affective responses when confronted with situations that trigger obsessions and compulsions. For example, many individuals experience marked anxiety that can include recurrent panic attacks. Others report strong feelings of disgust. While performing compulsions, some individuals report a distressing sense of “incompleteness” or uneasiness until things look, feel, or sound “just right.”

It is common for individuals with the disorder to avoid people, places, and things that trigger obsessions and compulsions. For example, individuals with contamination concerns might avoid public situations (e.g., restaurants, public restrooms) to reduce exposure to feared contaminants; individuals with intrusive thoughts about causing harm might avoid social interactions.

Many individuals with OCD have dysfunctional beliefs. These beliefs can include an inflated sense of responsibility and tendency to overestimate threat; perfectionism and intolerance of uncertainty; and overimportance of thoughts (e.g., believing that having a forbidden thought is as bad as acting on it) and the need to control thoughts. These beliefs, however, are not specific to OCD. The involvement of family and friends in compulsive rituals, termed *accommodation*, can exacerbate or maintain symptoms and is an important target, especially in children.

Prevalence

The 12-month prevalence of OCD in the United States is 1.2%, with a similar prevalence internationally (including Canada, Puerto Rico, Germany, Taiwan, Korea, and New Zealand; 1.1%-1.8%). Women are affected at a slightly higher rate than men in adulthood, although men are more commonly affected in childhood.

Development and Course

In the United States, the mean age at onset of OCD is 19.5 years, and 25% of the cases start by age 14 years. Onset after age 35 is unusual but does occur. Men have earlier age at onset than women: nearly 25% of men have onset before age 10 years ago. The onset of symptoms is typically gradual; however, acute onset can also occur.

If OCD is untreated, the course is usually chronic, often with waxing and waning symptoms. Some individuals have an episodic course, and a minority have a deteriorating course. Without treatment, remission rates in adults are low (e.g., 20% for those reevaluated 40 years later). Onset in childhood or adolescence can lead to a lifetime of OCD. However, 40% of individuals with the onset of OCD in childhood or adolescence may experience remission by early childhood. The course of OCD is often complicated by the co-occurrence of other disorders (see section “Comorbidity” for this disorder).

Compulsions are more easily diagnosed in children than obsessions are because compulsions are usually observable. However, most children have both obsessions and compulsions (as do most adults). The pattern of symptoms in adults can be stable over time, but is more variable in children. Some differences in the content of obsessions and compulsions have been reported when children and adolescent samples are compared with adult samples. These differences likely reflect content appropriate to different developmental stages (e.g., higher rates of sexual and religious obsessions in adolescents than in children; higher rates of harm obsessions [e.g., fears of catastrophic events, such as death or illness to self or loved ones] in children and adolescents than in adults).

Risk and Prognostic Factors

Temperamental. Greater internalizing symptoms, higher negative emotionality, and behavioral inhibition in childhood are possible temperamental risk factors.

Environmental. Different environmental factors may increase the risk for OCD. These include adverse perinatal events, premature birth, maternal tobacco use during pregnancy, physical and sexual abuse in childhood, and other stressful or traumatic events. Some children may develop the sudden onset of obsessive-compulsive symptoms, which has been associated with different environmental factors, including various infectious agents and a postinfectious autoimmune syndrome.

Genetic and physiological. The rate of OCD among first-degree relatives of adults with OCD is approximately two times that among first-degree relatives of those without the disorder; however, among first-degree relatives of individuals with onset of OCD in childhood or adolescence, the rate is increased 10-fold. Familial transmission is due in part to genetic factors (e.g., a concordance rate of 0.57 for monozygotic vs 0.22 for dizygotic twins). Twin studies suggest that addictive genetics affects account ~40% of the variance in obsessive-compulsive symptoms. Dysfunction in the orbitofrontal cortex, anterior cingulate cortex, and striatum have been most strongly implicated; alterations in frontolimbic, frontoparietal, and cerebellar networks have been reported.

Culture-Related Diagnostic Issues

OCD occurs across the world. There is substantial similarity across cultures in the gender distribution, age at onset, and comorbidity of OCD. Moreover, around the globe, there is a similar symptom structure involving cleaning, symmetry, hoarding, taboo thoughts, and fear of harm. However, regional variance in symptom expression exists, and cultural factors may shape the content obsessions and compulsions. For example, obsessions related to sexual content may be reported less frequently in some religious and cultural groups, and obsessions related to violence and aggression may be more common in settings with higher prevalence of urban violence. Attributions of OCD symptoms vary cross-cultural, including physical, social, spiritual, and the supernatural causes; specific compulsions and help-seeking options may be reinforced by these cultural attributions.

Sex- and Gender-Related Diagnostic Issues

Men have an earlier age at onset of OCD than women, often in childhood, and are more likely to have a comorbid tic disorders. Onset in girls is more typically in adolescence; among adults, OCD is slightly more common in women than in men. Gender differences in the pattern of symptom dimensions have been reported, with, for example, women are more likely to have symptoms in the cleaning dimension and men more likely to have [end of page 268] symptoms in the forbidden thoughts and symmetry dimensions. Onset or exacerbation of OCD, as well as symptoms that can interfere with the mother-infant relationship (e.g., aggressive obsessions such as intrusive violence thoughts of harming the infant, leading to avoidance of the infant), has been reported in the peripartum period. Some women also report exacerbation of OCD symptoms premenstrually.

Association With Suicidal Thoughts or Behavior

A systematic literature review of suicidal ideation and suicide attempts in clinical samples with OCD from multiple countries found a mean rate of a lifetime suicide attempts of 14.2%, a mean rate of lifetime suicidal ideation of 44.1%, and a mean rate of a current suicidal ideation of 25.9%. Predictors of a greater suicide risk were severity of OCD, the symptom dimension of unacceptable thoughts, severity of comorbid depressive and anxiety symptoms, and past of suicidality. Another international systematic review of 48 studies found a moderate to high significant association between suicidal ideation / suicide attempts and OCD.

A cross-sectional study of 582 outpatients with OCD from Brazil found that 36% reported lifetime suicidal thoughts, 20% had made suicide plans, 11% had already attempted suicide, and 10% presented with current suicidal thoughts. The sexual / religious dimension of OCD and comorbid substance use disorders were associated with suicidal thoughts and suicidal plans, impulse-control disorders were associated with current suicidal thoughts and with suicide plans and attempts, and lifetime comorbid major depressive disorder and posttraumatic stress disorder (PTSD) were associated with all aspects of suicidal behaviors.

In a study using Swedish national registry data involving 36,788 individuals with OCD and matched general population control subjects, individuals with OCD had a higher risk of suicide risk (OR=9.8) and suicide attempt (OR=5.5), and the increased risk for both outcomes remained substantial even after adjusting for psychiatric comorbidities. Comorbid personality or substance use disorder increased suicide risk, whereas female gender, higher parental, education, and a comorbid anxiety disorder were protective factors.

Functional Consequences of Obsessive-Compulsive Disorder

OCD is associated with reduced quality of life as well as high levels of social and occupational impairment. Impairment occurs across many different domains of life and is associated with symptom severity. Impairment can be caused by the time spent obsessing and performing compulsions. Avoidance of situations that can be trigger obsessions or compulsions that can also severely impair functioning. In addition, specific symptoms can create specific obstacles. For example, obsessions about harm can make relationships with family and friends feel hazardous; the result can be avoidance of these relationships. Obsessions about symmetry can derail the timely completion of school or work projects because the project never feels "just right," potentially resulting school failure or job loss. Health consequences can also occur. For example, individuals with contamination concerns may avoid doctors' offices and hospitals (e.g., because of fears of exposure to germs) or develop dermatological problems (e.g., skin lesions due to excessive washing). Sometimes the symptoms of disorder interfere with its own treatment (e.g., when medications are considered contaminated). When the disorder starts in childhood or adolescence, individuals may experience developmental difficulties. For example, adolescents may avoid socializing with peers; young adults may struggle when they leave home to live independently. The result can be few significant relationships outside the family and a lack of autonomy and financial independence from their family of origin. In addition, some individuals with OCD impose rules and prohibitions on family members because of their obsessions (e.g., no one in the family can have visitors to the house for the fear of contamination), and this can lead to family dysfunction.

Differential Diagnosis

Anxiety disorders. Reoccurring thoughts, avoidant behaviors, and repetitive requests for reassurance can also occur in anxiety disorders. However, the recurrent thoughts that are present in generalized anxiety disorder (i.e., worries) are usually about real-life concerns, whereas the obsessions of OCD usually do not involve real-life concerns and can include content that is odd, irrational, or of a seemingly magical nature; moreover, complulsions are usually present and usually linked to the obsessions. Like individuals with OCD, individuals with specific phobia can have a fear reaction to specific objects or situations; however, in specific phobia the feared object is usually much more circumscribed, and rituals are not present. In social anxiety disorder, the feared objects or situations are limited to social interactions or performance situations, and avoidance or reassurance seeking is focussed on reducing feelings of embarrassment.

Major depressive disorder. OCD needs to be distinguished from rumination of major depressive disorder, in which thoughts are usually mood-congruent and not necessarily experienced as intrusive or distressing; moreover, ruminations are not linked to compulsions, as is typical in OCD.

Eating disorders. OCD can be distinguished from anorexia nervosa in that in OCD the obsessions and compulsions are not limited to concerns about weight and food.

Tics (in tic disorder) and stereotyped movements. A tic is a sudden, rapid, recurrent, nonrhythmic motor movement or vocalization (e.g., eye blinking, throat clearing). A stereotyped movement is repetitive, seemingly driven, nonfunctional motor behavior (e.g., head banging, body rocking, self-biting). Tics and stereotyped movements are typically less complex than compulsions are not aimed at neutralizing obsessions. However, distinguishing between complex tics and compulsions can be difficult. Whereas compulsions are usually preceded by obsessions, tics are often preceded by premonitory sensory urges. Some individuals have symptoms of both OCD and a tic disorder, in which case both diagnoses may be warranted.

Psychotic disorders. Some individuals with OCD have poor insight or even delusional OCD beliefs. However, they have obsessions and compulsions (distinguishing their condition from delusional disorder) and do not have features of schizophrenia or schizoaffective disorder (e.g., hallucinations or disorganized speech). For individuals whose OCD symptoms warrant the “with absent insight / delusional beliefs” specifier, these symptoms should not be diagnosed as a psychotic disorder.

Other compulsive-like behaviors. Certain behaviors are sometimes described as “compulsive,” including sexual behavior (in the case of paraphilias), gambling (i.e., gambling disorder), and substance use (e.g., alcohol use disorder). However, these behaviors differ [end of page 270] from the compulsions of OCD in that the person usually derives pleasure from the activity and may wish to resist it only because of its deleterious consequences.

Obsessive-compulsive disorder. Although obsessive-compulsive personality disorder and OCD have similar names, the clinical manifestations of these disorders are quite different. Obsessive-compulsive personality disorder is characterized by intrusive thoughts, images, or urges or by repetitive behaviors that are performed in response to these intrusive symptoms; instead, it involves an enduring and pervasive maladaptive pattern of excessive perfectionism and rigid control. If an individual manifests symptoms of both OCD and obsessive-compulsive personality disorder, both diagnoses can be given.

Comorbidity

Individuals with OCD often have other psychopathology. Many adults with the disorder in the United States have a lifetime diagnosis of an anxiety disorder (76%; e.g., panic disorder, social anxiety, generalized anxiety disorder, specific phobia) or a depressive or bipolar disorder (63% for any depressive or bipolar disorder, with the most common being major depressive disorder [41%]); a lifetime diagnosis of an impulse-control disorder (56%) or a substance use disorder (39%) is also common. Onset of OCD is usually later than most comorbid anxiety disorders (with the exception of separation anxiety disorder) and PTSD but often precedes that of depressive disorders. In a study of 214 treatment-seeking adults in the United States with DSM-IV OCD at intake, comorbid obsessive-compulsive personality disorder was found in 23%-32% of individuals followed longitudinally.

Up to 30% on individuals with OCD also have a lifetime tic disorder. A comorbid tic disorder is most common in men with the onset of OCD in childhood. These individuals tend to differ from those without a history of tic disorders in the themes of their OCD symptoms, comorbidity, course, and pattern of a familial transmission. A triad of OCD, tic disorder, and attention-deficit / hyperactivity disorder can be seen in children.

Several obsessive-compulsive and related disorders, including body dysmorphic disorder, trichotillomania, and excoriation (skin-picking) disorder, also occur more frequently in individuals with OCD than those without OCD.

OCD is also much more common in individuals with certain other disorders than would be expected based on its prevalence in the general population; when one of those other disorders is diagnosed, the individual should be assessed for OCD as well. For example, in individuals with schizophrenia or schizoaffective disorder, the prevalence of OCD is approximately 12%. Rates of OCD are also elevated in bipolar disorder; eating disorders, such as anorexia nervosa and bulimia nervosa; body dysmorphic disorder; and Tourette’s disorder.