Merry-Go-Sorry

An Autoethnography of Chronic Illness

A thesis presented in partial fulfilment of the requirements for the degree

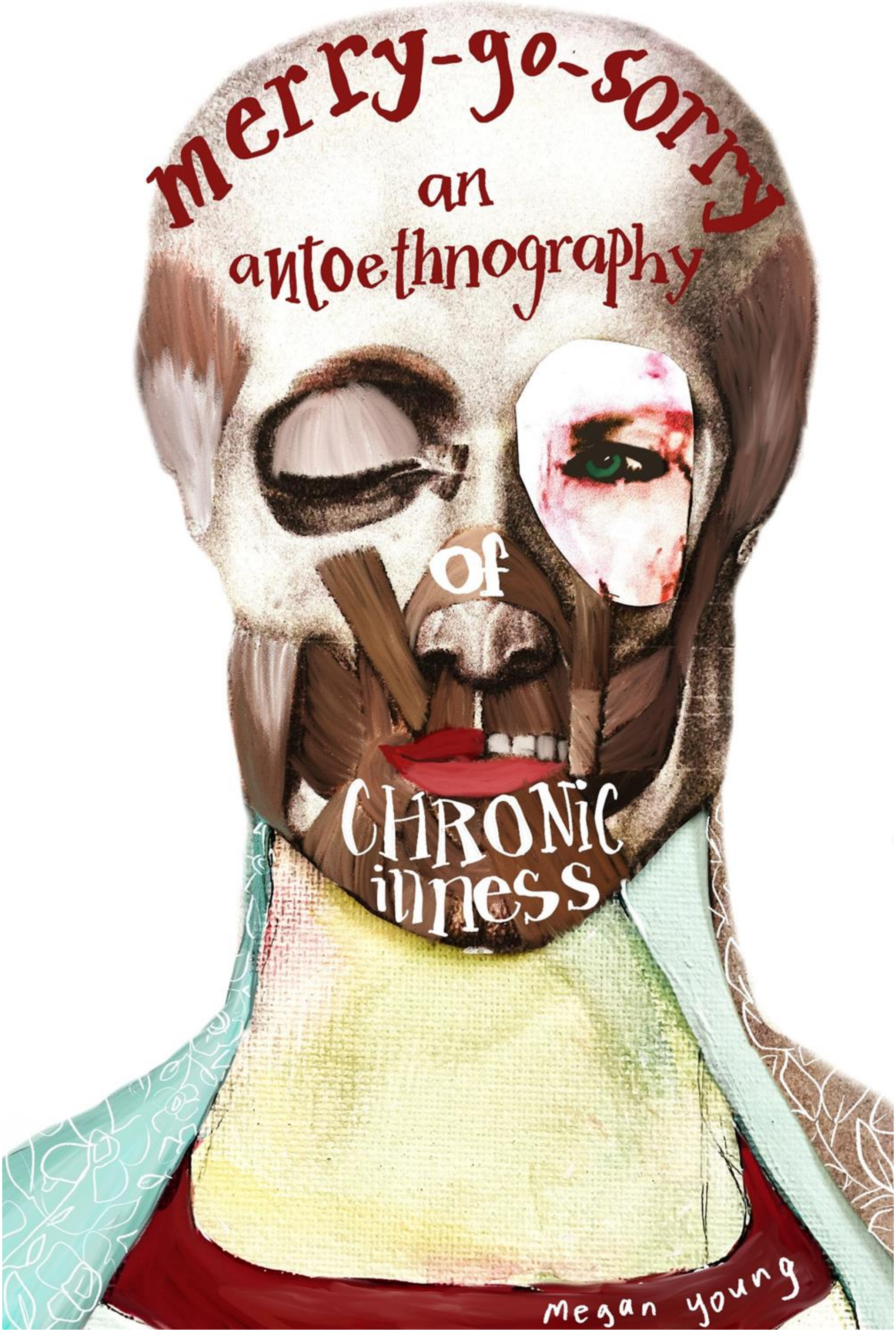
of

Doctor of Philosophy in Psychology

at Massey University, Auckland, New Zealand.

Megan Young

2023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ABSTRACT

Merry-Go-Sorry is an autoethnography of chronic illness. It seeks to embrace the depth and complexity of the lived experience of pain and fatigue as they move through the quotidian frustrations, joys, and challenges, as set against the social narratives which seek to fix, cure, pity, judge and quantify chronically ill bodies.

This research is situated within the evocative style of autoethnography, which seeks to connect with the reader at both an intellectual and emotional level. To this aim, Merry-Go-Sorry uses creative non-fiction and visual arts techniques to enrich the narratives, including layered narratives, a braided essay, poetry fragments and figurative self-portraits.

Methodological innovations are made by theorising the autoethnographic self as a textual character to support authorial reflexivity, and writing the personal story as an autoethnographic metasynthesis to illustrate how this methodology may talk with and to other texts. On a theoretical level, embodied pain is conceived as a non-linear wave like experience, and chronic fatigue as a form of amoral desire. Autoethnographic slippage in these stories are modified by the presentation of figurative portraits as an ethical and evocative way to evoke “thick performance”.

Contributions to knowledge in this area include the addition of lived experience to the brachial neuritis literature, in understanding “embodied time” as important in pain, the cultural burden of shame in fatigue. Taken as a whole, this research broadens the

understanding of chronic illness as a disruptive and disrupting experience, but one that does not equate an unwell body with a body that is in any way less whole.

ACKNOWLEDGEMENTS

For Kerry Chamberlain and Veronica Hopner. As first readers, your suggestions strengthened, clarified, and improved the work greatly; as supervisors, your ongoing patience and support kept me moving forward every time I stalled; as mentors, your encouragement and advice has brought me further into a career I enjoy than I ever thought would be possible. It was a lucky day when I walked into your joint classroom as a newly minted post-graduate student, and I am ever and beyond thankful.

For Warren. Thank you once again for the formatting maestroship; also patience, making dinner, and wanting to do whatever is best.

For Nathan, Eilidh, and Jack. Thank you, babies, for the tea and commiserations, the lols and the thumbs up. No-one gets the point of all this like you three; and it’ll be nice to finally wear the funny hat.

your life is your life.

know it while you have it.

you are marvelous

the gods wait to delight

in you.

Charles Bukowski

CONTENTS

FIGURES

CHAPTER 1

An Introduction

Brachial Neuritis, n.

(Also known as Parsonage Turner Syndrome and Neuralgic Amyotrophy)

A nerve disorder characterised by bouts of extreme pain, weakness, and muscle wastage in the upper limbs.

(Adapted from Smith & Bevelaqua, 2014)

Background

The genesis of this research began on an ordinary weekday morning with an extraordinary discovery. Following weeks of severe pain in my shoulder, I found that I could not move it at all, the whole joint was completely paralysed. I could move my hands, my forearm, but anything that required the use of the muscles in my shoulder, I was simply unable to do. Much time and many doctors' visits later, it was finally diagnosed as peripheral neuropathy with the ungainly name of brachial neuritis, cause unknown (Smith & Bevelaqua, 2014).

I have a somewhat mild (I am assured) genetic immunodeficiency which makes me vulnerable to collecting an assortment of chronic diseases, and I mention this only to say that I was well practiced in the care and maintenance of illness before brachial neuritis ever raised its inflammatory head. It was a surprise and a confusion, therefore, to find that I was unable to wrest this particular disease under my full control. She is wild and untamable, and we live together in an uneasy merry-go-sorry of recurrence and recovery. There is, as my physiotherapist once cheerfully told me, nothing I can do about that.

Not exactly nothing. As an academic researcher, I have the privilege of a voice to tell about it, and in that telling perhaps come to understand the nature of our chronically embodied dance a little better.

Aims and Objectives

As White (2023) states, “temporal trajectories of health, illness, and disability … are important strands within …disability studies” (p. 1259), while Birk (2013) suggests that to understand a health phenomenon, it is important to have access to the stories of those who are living that phenomenon. My aim in writing an autoethnography of chronic illness and disability is to contribute such a direct and experientially grounded story, one that resists shame without inviting admiration (Berger, 2016), is nuanced and ambiguous (Simplican, 2017), a timescaped narrative of brachial neuritis, of multimorbidity, of a vulnerable merry and a complex sorry. In doing so I hope to break the silence and add to the body of knowledge of brachial neuritis as a challenging disease (Smith & Bevelaqua, 2014).

There is very little information on brachial neuritis in the research literature, and what research has been done is always from a healthcare provider biomedical point of view: I could find no published articles to date that described the lived experience of brachial neuritis from the perspective of those with lived experience of this disease. From the point of view of a sufferer, the lack of information is a frustration, from that of a researcher it highlights not so much a gap in the literature, but a void and a silence. This absence of embodied stories means that there is a very limited understanding of the quotidian needs and limitations of brachial nerve damage, of what ongoing pain and fatigue means for sufferers at an experiential and existential level. This limitation was a principal motivating factor for choosing to tell my own story of brachial neuritis as a doctoral research project.

The lack of research on the lived experiences of brachial neuritis also reflects the sense of alienation that accompanies this disease. While chronic illness in general is known to erode connection (Brown, 2002), when the embodied consequences of your illness are not well understood even among medical personnel, it is the burden of the sufferer to always explain and justify their experience. Brachial plexus, axillary nerve, muscle atrophy, fatigability, winging scapula, shoulder instability; just a collection of words that describe both everything and nothing at all. Finding a constructive way to tell my story better, in order to add to the understanding of this disease better, became an important secondary motivating factor.

Choosing Autoethnography

Reginato (2021) describes the kind of silence encountered in people’s stories of illness as a social object, and as such the experiential solitude that I describe above lies not only in my experience of illness, but in my experience of the social as it relates to my illness, a story of self as it is embedded in a wider cultural narrative.

Many qualitative research methods seek to give voice to illness experiences (Stam, 2000), but autoethnography is particularly suited, as Cotter (2017) suggests, to uncovering the private story, the salient details in the personal (Bochner & Ellis, 2003). Autoethnography views the subjective not as a weakness but a resource (Gough, 2017), and as such is anchored in a social constructionist epistemology that suggests we make sense of lived experience through the lenses of intrapersonal and interpersonal relationality (Giacomini, 2012).

Autoethnography is an important methodology in health research as it is able to resist the common realist approaches (Denshire & Lee, 2013) that can restrict stories of health to the public experience (Cotter, 2017). It can also be viewed as a form of insider research, where those who live with illness and disability can tell of their experience without mitigated interpretation (Birk, 2013), a particularly important value of disability research (Bulk & Collins, 2023). So too, it can challenge negative frameworks (Boylorn & Orbe, 2014), frameworks that are commonly and detrimentally applied to people with chronic illness and disability (Patrycja, 2012). It is also an accessible methodology for those whose illnesses and disabilities may limit participation in more conventional research (Patrycja, 2012) increasing diversity of knowledge and experience within the academy. Autoethnography, in other words, creates an avenue for the chronically ill and disabled to "speak back" (Denshire, 2014, p. 841).

Examples of Autoethnography in Health Research

The ability of autoethnographic accounts to challenge the oversimplification of experience in chronic illness (Richards, 2008), to increase representations of embodied heterogeneity (Kasnitz, 2020) and resist easy classification of individual experience (Denshire, 2014) mean that there are many examples of these kinds of accounts in the literature. One of the first that I came across was Jennifer Esposito's (2014) "*Pain is a social construction until it hurts: Living theory on my body*". Esposito writes of her experiences with extreme pain following a car accident, and interrogates the embodiment of pain, disability and the impact on identity. As part of this interrogation, Esposito utilises poetic exposition, which suggested to me the idea and importance of including creative literary tools in research, and their analytical potential.

I have also been inspired by Carolyn Ellis' (2014) *"No longer hip: Losing my balance and adopting to what ails me.* In particular, the interrogation of arthritis as it relates to societal views on aging was influential in my thinking about the representational value of autoethnography in greater depth. There is also a stated purpose to this research of Ellis' utilising it to understand her own story better, which clarified for me the value of this process in an academic work, a value I particularly explore in my article *Witches Dance Backwards.*

Els' (2017) autoethnography is an exploration of her experience with chronic pain, and describes her concomitant spiritual journey as a form of labyrinth. I was intrigued here by the idea of the labyrinth as a metaphor, and the use of the cognitive tools of imaginary knowing to highlight the non-linear nature of experience and to interpret embodied meaning. This article was an important prompt in my interrogation of experience as visual metaphor in *Circles of Hell*, and to interrogate the potential for the epistemololgical significance of the imagination in *Witches Dance Backwards.*

Parker's (2021) *Diagnosis, Prognosis and Caregiving: An Autoethnography* described her experience as a caregiver for a partner with a terminal illness. This work was also influential in my understanding of the potential for art and research to not just coexist, but expand on each other’s interrogative value. In her autoethnography, Parker (2021) includes examples of the paintings she created as a caregiver, paintings that don’t just illustrate the accompanying narrative, they add a psychologically complex and relationally important one of their own. This narrative quality was an important consideration in creating the work of *A Cipher for the Falling* also.

O’Grady’s (2021) description of early menopause in *An autoethnographic performance: The researcher’s story of hysterectomy and menopause as act of resistance and activism* utilises both poetry and artwork as a type of performance ethnography. This autoethnography includes both poetry and the visual arts as pieces that both compliment and increase the communicative power of the other. When I was struggling with a problem in my planned format for *A Cipher for the Falling*, this combination of painting and poetry suggested a solution that enhanced both my work and my understanding of the place and value of the arts in autoethnographic research. In addition, her work here on women’s bodies and medical narratives was influential my development of *Witches Dance Backwards* as a braided narrative.

Harvey’s (2023) autoethnography *Short and locked down: The impact of Covid-19 on a person with dwarfism* tells the story of experiencing even greater social alienation of disability in general, and dwarfism in particular, during a Covid-19 pandemic lockdowns. Harvey’s work is an excellent example of the ‘othering’ experienced by the disabled, and the moral and practical imperatives of epistemic justice. As Harvey says, her article highlights “how the vulnerabilities and imbalances exposed by the COVID-19 pandemic reproduce and intensify existing disability-related embodied and spatial inequalities.” (p. 390), and it was this work in particular that shifted my perspective of epistemic justice as a research ideal to societal necessity.

These examples stand testament to the value of autoethnographic research as a methodology for interrogating embodied experiences of illness and disability. I am indebted to all the women mentioned here for the various ways they guided and shaped my work as I learned how to craft an autoethnography that was both academically sound and personally useful.

Including Arts-Based Research

The above examples of autoethnographic research also highlight the natural affinity of autoethnography and arts-based research. I justify the inclusion of *A Cipher for the Falling* in greater detail in the introduction to this work, and highlight the academic context in the exegesis, but as an introductory note, I would suggest that if the doing of an autoethnography reflects the autoethnographer (Bochner & Ellis, 2016) then as an artist who relied on her art to understand and cope with the pain, fatigue and resultant disabling effects of brachial neuritis, it was an imperative to include aspects of these artwork in a research project of lived experience. As Gannon (2021) says, “we do not speak from nowhere” (p. 42) and the place from which I speak is firmly rooted in the notion of art as a way of knowing (Archibald, 2022).

Research Position

There is no one way to “do” autoethnography, yet there are commonly applied categories that signal a broad methodological approach. Two regularly used terms are evocative autoethnography and analytical autoethnography (Denshire, 2014), and within this paradigm, *Merry-Go-Sorry* is situated firmly in the evocative mode of autoethnographic research. Evocative, in that it seeks to evoke, to resonate, to creatively express; evocative in that it embraces vulnerability, aesthetic pleasure, and the often turbulent nature of internal experience (Ellis & Bochner, 2006). Evocative, in that it seeks to show rather than tell (Ellis et al., 2011).

I agree with the sentiment too, however, that calling an autoethnography "evocative" is a redundancy (Ellis & Bochner, 2006). With its roots in both anthropology and the literary (Denshire, 2014), and its emphasis on the conventions of narrative techniques (Bochner & Ellis, 2003), on "thick description" (Adams & Herrmann, 2023), to 'evoke' is simply what an autoethnography does. Further to this idea, I also agree with Denshire (2014) that autoethnography is both evocative *and* analytical. This idea is a position I hold strongly as an autoethnographic arts-based researcher, and one an argument I seek to develop further throughout the rest of the thesis in general, but particularly in the article "*Crafting Autoethnography and the Problem of Self as Story".*

Though there are many terms to describe autoethnographic studies from a positionality frame of reference, with its emphasis on the techniques of creative non-fiction and arts-based research, *Merry-Go-Sorry* can be considered a form of performative autoethnography (Bartleet, 2021). It also utilises layered, personal narratives (Bochner & Ellis, 2003) as a storytelling tool in both the written articles and the arts-based book, with the intention of helping to communicate the complex psychological experiences of temporality and embodiment in chronic illness and disability. Another way to express this is to think of

Merry-Go-Sorry as an assembled critical narrative that is composed from the artefacts of memory and material objects, artefacts collected from the personal wreckage of a brachial neuritis diagnosis. I made what I could out of what I had.

Ethical Considerations

As consistent with Massey University's ethical processes, this research was granted a Low Risk Notification, which means it was not required to go through the University's ethical consent process.

Autoethnography considers ethical choices outside the realm of institutional guidelines, however (Tullis, 2021), including that of relational ethics (Ellis, 2007). It is impossible to write personal narratives without touching on broader relationships also; family, friends, work places, work colleagues, medical staff. While few family members, friends and colleagues will read this doctoral thesis, they nonetheless deserve consideration of how they are represented to those who will.

As I could find no personal stories of brachial neuritis in the academic research, and as both pain and fatigue are the two main chronic impairments of this disease, I decided that interrogating my embodied experiences of both through a broader cultural lens would be a productive and personally interesting research goal. From a relational ethics position, this allows me to conduct this research project without the more problematic social lens of close relationships. This was also important for the relational ethics of this particular piece of research, because as it was a new illness, there were many impacts of the disease on and with my close relationships that were still unfolding, and working these out through a formal piece of research before I had worked them out with the people concerned, was an untenable ethical position to me.

Edwards (2021) calls this respect for a researcher's own needs and values as an ethic of the self. While an autoethnographer has a responsibility to authenticity, we must also consider the risks of disclosures in personal narratives as published in a professional setting. Tollich (2010) suggests treating autoethnographic writing as permanent as a tattoo, that is, what is written about oneself stays written and remains accessible. This aspect of autoethnographic ethics was certainly a concern to me as a doctoral student and an early career researcher, and the fear of limiting future employment and opportunities was, and remains, not insignificant. However, along with the personal and vulnerable discussions of pain and fatigue, there was also the considered choice to write a methodological piece that theorises the value of craftsmanship and the nature of the textual self in autoethnographic writing, along with a layered and emotionally evocative collection of artwork that showcases the fragmented complexities of the multimorbid experience. As such, the collected thesis aims to balance personal vulnerability with professional strength.

In a similar vein, Tullis (2021) also mentions the often overlooked area of our ethical responsibility to the readers and viewers of our written and visual narratives. Autoethnographies commonly detail personally traumatic and intimate details of the researcher's life, and these details have the potential to cause unintentional harm to the reader or viewer of the research. This is not to suggest that the chronically ill and disabled need 'protect' others from the realities of their lived experiences, a position I find unsupportable and at odds with the evocative and inclusive goals of autoethnographic research, but can be simply understood as a reflexive consideration that there *will be* an impact.

It is my view that the techniques of creative non-fiction writing and the visual arts have a psychological buffering effect on such potential ethical harm. The creative arts have long been used to evoke and illustrate intimate human details for collective consumption, they are expressive and empathic forms of communication (Eisner, 2008) but also offering interpersonal emotional distance (Minge, 2006). That is, a creative story is about a textual version of me, while a piece of art represents a creative imagining of me.

This is especially true for the abstract nature of the artwork and the fragmented pieces of poetry represented in *A Cipher for the Falling* and this is a significant reason that many of the more intimate, narratively important, aspects of my lived experiences are included here.

Finally, research in New Zealand is required to consider ethical implications of Te Tiriti o Waitangi, a foundational document of bi-cultural governance and Māori sovereignty. Though I whakapapa NZ European, and this is a personal narrative, I nonetheless ascribe to the values of representation and epistemic diversity that are foundational to co-governance, and these values are embedded throughout the entirety of this research.

The Road Ahead

This is a thesis by publication. In the following pages I present three research articles, one exegesis, and a book of narrative artwork. The first article, *Crafting autoethnography and the problem of self as story* discusses the difficulty of writing the autoethnographic self. It turns to ideas from fiction and creative non-fiction writing to help theorise one particular way that this might be done. The next article, *Circles of Hell: Brachial Neuritis and the Chronification of Pain* is a story of the embodied experience of pain as it unfolds over time, and it uses a unique structure of the personal story as a form of autoethnographic metasynthesis of pain research. *Witches Dance Backwards* is the third article, and focuses on the lived experience of fatigue. It highlights the historical roots of somatophobia in western medical culture, particularly with regards to women's bodies, interweaving personal anecdote and imaginative inquiry in the form of a braided narrative. Finally, the broader situation of a multimorbid body, through which the experience of brachial neuritis as a chronic illness is firmly embedded, is presented as a book of paired figurative collage and poetry fragments, *A Cipher for the Falling*. This is accompanied by an exegesis to give academic, artistic, and personal context to the work.

CHAPTER 2

An Introduction to Crafting Autoethnography and the Problem of Self as Story

I wrote *Crafting Autoethnography and the Problem of Self as Story* to fill a gap I perceived in the literature on some of the pragmatic aspects of writing about 'self' that I would like to have read as someone new to this methodology. As noted in the following article, I had unwittingly entwined aspects of my identity with the experience of chronic fatigue, and this was making it difficult for me to write about it with sound analytical judgement. Everything I experienced seemed equally important, and parsing notes, anecdotes, and memories down to a representative but manageable number proved elusive. I was also reluctant to share some of the useful but less flattering aspects of chronic fatigue for fear of how I would be perceived. There was too much protective evasion, too much mindless slippage.

Slippage is the information lost between a wholly true account of an experience and a mindfully truthful one (Medford, 2006). Autoethnography acknowledges that there can be no one single Truth when recounting stories of self, because self-knowledge is contingent, culturally situated, tendentious (Gannon, 2021), fluid and ambiguous (Richards, 2016). Being aware of this difference in a critical and thoughtful manner is, therefore, important to creating an authentic and rigorous autoethnographic account (Medford, 2006).

I had read a lot of work on the nature and purpose of reflexivity by the time I was struggling with the question of how to "do self" in autoethnographic writing (Short et al., 2007, p. 771). As Tuval-Mashiach (2017) suggests, it is a concept that can mean different things in different qualitative traditions, but a core explanation seemed often to involve some version of Le Roux's (2017) definition of "self-awareness and agency within that self-awareness" (p.

200). Being mindful of the need for self-awareness in a reflexive research story was a useful critical tool for coming to understand that I had absorbed aspects of the fatigue experience into aspects of my identity, and one consequence of this was unmindful slippage that was moving me further away from a truthful account of my experiences rather than pushing me closer toward it.

This speaks to Edwards' (2021) ethics of self, the responsibility we have as autoethnographic practitioners to balance honest accounts with protective boundaries, vulnerable revelations with sensible restraint, and thoughtless slippage with mindful omission. I was unsure on the balance I needed between these ethical tensions, how to find it, the process I should use in order to be satisfied that I had told a truthful story, but not a personally harmful one.

What was missing, I think, was a form of agency, a mechanism by which I could move awareness of the problem to an enactable solution, a "methodological reflexivity" if you like (Olmos-Vega et al., 2023, p. 245). If ethnography borrows from literary studies, has a fictive tradition (Denshire, 2014), and if evocative autoethnography favours storytelling methods over conventional explanatory ones (Bochner & Ellis, 2016), then I believed it might be fruitful to look to these traditions and methods for guidance.

There were clues in the literature that this approach would be helpful in moving my writing forward. Holley and Colyar (2012), for instance, encouraged the use of narrative elements such as plot, character, point of view and authorial distance in qualitative writing; Abdallah (2017) discussed the creation of an authorial persona; and Narayan (2012) suggested looking for elements of ethnographic writing in a broad range of literature. Though they vary in their specific approaches, the common element in all of these suggestions is the underlying proposition that the craft of narrative writing can be a useful cross-disciplinary resource to develop the craft of autoethnographic writing.

As *Crafting Autoethnography* explains, reflecting on different methodological processes found in fiction and creative non-fiction writing led me to develop an authorial distance that then allowed me to decide the story of self I needed to tell, which did indeed move my stalled writing forward. It also helped me further develop an understanding of what *auto-ethno-graphy* means for me, how self and culture and expression are defined in my own research as they relate to writing truthful and useful stories of self. It provided me with the agency I was seeking to construct the research boundaries I was needing.

At its core, this process is one of autoethnographic craftmanship, an ideal that is a cornerstone of my methodological approach throughout this thesis as a whole. Craftmanship is a research value that I have become deeply committed to developing and exploring further in my nascent research career, and one I have worked hard to establish in all elements of this collective work. If craft is what we can see of art (Bayles & Orland, 2001), then it is also, I believe, what we see of autoethnographic rigour, methodological reflexivity, and trust in the mindful slippage of our narrative accounts.

As Holley and Colyar (2012) point out, “...the construction of the text [is] a central task in the research process” (p. 117), and it was through writing *Crafting Autoethnography and the Problem of Self as Story* that I developed a relationship with autoethnographic methodology that took guidance from more experienced practitioners but remained distinctly my own.

For this reason, it sits here at the beginning of my research story as a form of manifesto, a statement of belief. There may be, as Garrett (2013) suggests, a limit to how reflexive we can ultimately be, but there is not, I contend, an equal limit to how much craftmanship we can cultivate to strengthen and polish the visible edges of the art of autoethnography.

Crafting Autoethnography

And the Problem of Self as Story

Megan Young

Massey University

Albany Village, Albany, N.

Crafting autoethnography and the problem of self as story.

Abstract

For a beginning autoethnographer, the non-prescriptive nature of this methodology can be overwhelming. This article examines ways creative non-fiction and fiction writing techniques can help novice autoethnographers craft their research well, and write about ‘self’ in both an evocative and academically rigorous manner. It also asks questions on whether more discussion of the technical craft of writing would be helpful to highlight some of the ways autoethnographers bring an analytical lens to their research, an aspect of autoethnographic rigor that is often hidden behind the curtains of our presented work.

There is no doubt that storytelling serves an important societal function (Orr et al., 2021) even, arguably, a fundamental one (Storr, 2019; Zaidel, 2018): formal or informal, recorded or lost in the layers of time, every human culture in every age has its myths and mythologies, its heroes and villains. Stories are how we make sense of our place and our purpose, our origins and our belonging.

Not every story, however, is granted the privilege of being heard. This is at least as true in the culture of academia as it is anywhere else (Evans-Winters & Esposito, 2018), and there are few methodologies where storytelling is possible, let alone desirable. Autoethnography promotes itself as one of these, not least in part to amplify those voices and experiences that might otherwise remain buried or dismissed (Au, 2022). It is an inclusive methodology, and as such it is not a prescriptive methodology (Adams & Herrmann, 2020), and the diversity this encourages is one of its biggest strengths.

And also, sometimes, when you lack experience, when your story is perhaps a little too large and complicated for your technical skill set, the breadth of possibility can be one of its weaknesses. In the spirit of autoethnographic storytelling, I offer the following account of some challenges I faced in writing up a particularly difficult section of my research, where the non-prescriptive nature of autoethnography, combined with my own inexperience, worked against me. I do not believe the answers I found were the only possible way to overcome the difficulties I was facing, and I certainly don't offer them as a restrictive technical requirement that act as a gatekeeper to exclude anyone from participation. My purpose here is simply to show what worked for me, to explain why it worked, and how it fits into the autoethnographic toolbox. To be an outstretched hand through an open research door.

And it is also, without apologies, an appreciation of the work, knowledge and skill so many writers of so many different kinds of genres have built and passed on for the rest of us to make use of. The original meaning of the word "craft" is of strength, of physical might ("craft", n.d.) and I like to think that the more we practice the skills of writing research well, no matter our methodology, the more heft we wield in crafting excellent research, and the more impactful we become.

Strengthening my own ability in both of these areas is certainly a continued personal aim and a great professional joy.

I am writing my autoethnographic Ph.D. and I am stuck. Stopped in my tracks, stranded, lost, bogged down, mired, befuddled, perplexed. By every metric of anything I have ever written before, I should be only one or two weeks away from completing this current section, but I have been one or two weeks away from completing this current section for a while, and I will be one or two weeks away from completing this current section for a good while more. There are confounding variables outside my control that are making things harder and slower than they would otherwise be - a recurrent exhausting and painful nerve condition and a global pandemic as chief among them - and perhaps I am underestimating how much they are constraining my ability to put words to paper. Even so. Things are not going well.

The section I am currently stuck on is an autoethnographic piece about the fatigue associated with chronic pain. I have, at last count, 7 chronic pain conditions that interfere with my daily functioning: inflammatory arthritis, osteoarthritis, cluster headaches, fibromyalgia, hypermobility syndrome, Bertolotti's syndrome, and recurrent brachial neuritis. Mostly these are only bothersome in the way all entropic ageing bodies are bothersome, and are generally managed and contained with various medications and lifestyle modifications. I brace my joints, I take pain relief, I rest, I get by. But the nerve damage caused by recurrent brachial neuritis knocked my life sideways from the moment it first struck, and I have never quite settled back into my body since. Many years and significant muscle atrophy later, I am unsure if I ever will.

This is not the prognosis I was given in the early days, but research on the condition is slowly catching up with the reality that many sufferers face long term pain, fatigue and disability, and that recurrence is not as uncommon as first believed (van Alfen et al., 2009). I feel it important to use my academic voice to help put flesh and sinew onto the bones of this research, to show what long term pain and fatigue and disability can mean in this context.

But I lack the craft to do so well. Everything I have written reads as unfocused, self-centered, bitsy, tedious.

What do I mean by craft in the context of my autoethnographic project? At a basic level I mean it to include an understanding of autoethnographic theory and the resultant methodological implications, and some knowledge of creative non-fiction techniques. The latter is not a requirement for autoethnographic writing, but it is compatible with it (Bartleet, 2021), and a method I have chosen to utilise. I enjoy the literary, I have a useful academic background in it, and I appreciate the way it can invoke the seeing of meaning (van Manen, 1997).

The writer Annie Proulx once said that she looks on writing “as a craftsman would making a table” (Rock, 2016, para. 26), and it has similarly been described by others as a construction

(Dürig, 2017; Gutkind, 2006; Holley & Colyar, 2012), as a tool (Colyar, 2009), as scaffolding (Dürig, 2017). You don't need to be a master craftsman to build a functional table, or even a beautiful one, but you do, I believe, need a certain level of practice, a few relevant tools, and a basic level of instruction.

As Bochner and Ellis (2016) point out, instruction for the various kinds of narrative and creative writing commonly utilised in autoethnography are not often taught at Universities. It's difficult to develop a strong and supportive scaffolding appropriate to the story you want to tell without learning the purpose of that scaffolding and the different ways it can be constructed, difficult to know how to find and strengthen areas of weakness. Without knowledge of writing as a craft we risk building a wobbly and poorly supported autoethnographic "table".

I also agree with Salesses (2021) who says that craft is "a set of expectations" (p. 16). Autoethnography shares many expectations, many different theoretical and methodological elements, with a range of other qualitative methodologies. It embraces the creative (Bartleet, 2021), it favours complexity (Denshire, 2014), it can include arts-based methods (Daly, 2021; Piercy, 2022), it is evocative (Bochner & Ellis, 2016), and it is embodied (Spry, 2001).

But where autoethnography differs, where it claims a unique research space of its own, is in the purposive centrality of the self (Muncey, 2010). It challenges the traditional research values of the neutral and the objective (Au, 2022) by consciously blurring the line between the researcher and the researched (Keleş, 2022) with stories that don't just reflect the storyteller (Pelias, 2021), but build their entire narrative foundation upon the close-up, the personal, the “I” (Caulley, 2008).

And here I find at least one source of weakness in my precarious story construction: I simply don’t understand enough yet about who this autoethnographic “I” is, or how I should go about writing one.

I didn’t have the same difficulties with writing an earlier section about my experience with chronic pain. Though complicated, it was not overwhelming or confusing in the way writing about chronic fatigue is proving to be. I suspect there is something about the nature of the topics themselves that is at least part of my current troubles.

Pain is an acceptable (if unwelcome and difficult) way to have a body, especially when the source of that pain is medically verifiable. I have a specialist diagnosis and an MRI scan showing the fat curling nerves that are wreaking havoc on my body, all lit up like a string of Christmas lights. My pain is legitimate, the source medically verifiable and socially acceptable. I feel I have a right to claim it.

Fatigue is more problematic. It is broad and murky as a concept, and more a subjectively felt illness than an objectively verified disease (Primdahl et al., 2019). It is synonymous with lethargy and dullness, antonymous to vigour and vitality. It feels shameful, and more perilous at both a personal and professional level to discuss out loud; an admittance of failure, a character flaw.

That is, I have entwined my identity with the idea of chronic fatigue, with a belief, real or imaginary, of negative social judgement. Pain was happening to me, but fatigue was part of me, something at some level I *was* rather than something I was *experiencing.* Because of this, I believe it may be helpful to understand further how to separate identity from experience, the noun from the verb, before I can write this story as effectively as I would like to.

Another way to understand this problem, is to understand the difference between a situation and a story.

The difference between a situation and a story can be described thus: a situation is the setting, the background, the circumstances we find ourselves in (Gornick, 2001), alternatively it can be understood as our “awareness of the world” (Salesses, 2021, p. 87).

A story, however, is a series of events, a narration of things that have happened, the meaning found within the situation, the “thing one has come to say” (Gornick, 2001, p. 13). I regularly use the word “story” when both writing and thinking about how to construct an autoethnography and I use it advisedly because story can be differentiated from a report with this inclusion of embodied experience. Not just what happened, but how I felt about what happened, what it means to me, the impact it had.

Fatigue is the situation I am writing about, but it is not the thing I have come to say, it is not my story. Because I have not clearly distanced my identity from my situation, my emotional focus has become centered on how I feel about who I am, rather than how I feel about what I am experiencing. This lack of psychological distance makes it difficult to find, interpret, and analyse meaning.

But what does analysis mean in an autoethnographic context anyway? I see the query raised of what constitutes enough analysis (Allen, 2020; Stahlke Wall, 2016) but not the question asked about what analysis *is* an autoethnographic context; I have certainly never asked it for myself.

At a basic level analysis just means to investigate, to inquire, to reason (“analysis”, n.d.), and it is perhaps the latter that most academic writing is focussed on; a sustained and reasoned discussion arising that argues for a particular interpretation of that data. The critique of lack of analysis in autoethnography certainly seems to be focussed on this meaning of the term.

I believe this is mistaken, though, because there is not one sole valid autoethnographic approach (Piercy, 2022), and some approaches are less suited to including an overt critical analysis than others. It does not follow, however, that this necessarily means they do not include any form of analysis if we understand analysis to encompass the idea of craftsmanship also, to include the conscious and particular choices a researcher has made to build a structure that is suited to, and strong enough to contain, the story being told. To make art out of chaos (Pelias, 2019), to find and organise meaning (Salesses, 2021). Analysis in this context can be conceived of as assessing and separating the things we have come to say into the constituent parts of what is important to the story and what is not (Caulley, 2008), before putting them back together into a structurally sound, compelling, evocative, and synthesised story of lived experience (Pelias, 2019).

In other words, one form of analysis within autoethnography is to investigate, examine and reveal our situation, the way we see our world (Salesses, 2021).

* * *

A year into writing my Ph.D. I had a confirmation examination, a ritual all candidates at my university must go through to show their subject is of sufficient depth and breadth to sustain an extended research project, to confirm that the candidate understands their own research approach adequately. While my examiners had no difficulty with autoethnography as my chosen research methodology, they did ask me how I was going to avoid the problem of self-centredness, or self-indulgence, what some have called the uncensored self (Stahlke Wall, 2016). I had read a lot on autoethnographic methodology by then and had a confident answer ready: I would avoid the problem of too much *me*, I said, by avoiding the construction of a “protagonist” identity (Simplican, 2017).

A confident answer, but a misguided one, or perhaps just poorly understood. The more experience I gain writing my own stories, the more I come to understand that we are all the protagonists of our own lives, we are all central to our own story. We can experience ourselves in no other way. Identifying as the protagonist within our own lives *is* our authentic experience.

Rather than a protagonist identity, I think what I really meant in my confirmation examination is more akin to a *hero* identity, the beau ideal. A paragon, or an exemplar; someone who is being affected by a particular social context, but is innocent of the affecting.

As many autoethnographers have pointed out, it is easy to romanticise experience (Short et al., 2007; Simplican, 2017). To whitewash it, to leave out the grit, the grime, the contradictions and unflattering angles. This doesn't always mean to paint ourselves in the best light possible, we can romanticise our experience in ways that flatter the story we want to tell as well. I think of what author Adriane Howell (2022) termed "miserableism" (p. 3) as an example of this, where we paint everything outside of ourselves in shades of awful, and every encounter as bleak.

It is a trap I know I am prone to, particularly when I think about chronic fatigue. But it is not the full truth, and I know it is not the full truth because my life is not one shade of one colour, my experience is not one shade of one colour, and my situation is not one shade of one colour. Be they rose coloured glasses, or tinted with ash, these are flat and misleading interpretations of experience (Karr, 2015), turning the self we have described on the page as an overcoming hero or a martyred one, but not reflecting the messy, complex, nuanced, light and shadowed, experiences that we actually live (Pelias, 2019).

This is, I believe, where accusations of self-indulgence in autoethnographic writing can be accurate. A unidimensional representation of ourselves or our experience is a propaganda, not a story, an exhortation, not a piece of research. It is only when we pry into the hidden, the forgotten, the contradictory aspects of both our story and situation that we begin to investigate story without sentiment or guile.

Knowing that I need to separate myself from my situation, to gain some kind of authorial distance (Holley & Colyar, 2012; Narayan, 2012) in order to examine my situation more clearly has been extremely useful in my quest to move my writing forward. But I still don't know enough of the practical and pragmatic *how* to go about actually doing this.

The problem is that I am with my conscious mind *all* of the time. All the feeling, thinking, experiencing, noticing, reacting, assuming, worrying, predicting, remembering, is noisy and constant and repetitive. The excess of information feels simultaneously important and exceedingly trivial.

The problem is this familiarity means that I walk through the world assuming I *do* know and understand myself, but memory is mutable and unreliable (Au, 2022), and it is difficult to tell if I am simply interrogating something that happened, or changing it by the interrogation (Karr, 2015).

The problem is I can't see what another person might see when they look back at me. It's uncomfortable to share useful but potentially disadvantageous information, and the border between what is too much and not enough is murky and mercurial. Easier, instead, to hide under obfuscation and partial truths.

The problem is I know too much about myself. The problem is I don't know my "self" at all.

The problem is there are too many selves to possibly ever know.

In her book, Unquiet, novelist and literary critic Linn Ullmann (2021) labels her childhood self as "girl", her parents as "father" and "mother". The girl is never given a name, and is not, entirely, representative of Ullmann herself; indeed, when a journalist suggests otherwise, she "gently corrects" him (Clark, 2020, para.9). Ullmann is the daughter of filmmaker Ingmar Bergman and actress Liv Ullmann, and as one might expect from a storyteller born of storytellers, what presents as an ostensible memoir of her childhood memories is also something a little creatively more.

I am reading this book primarily for my own enjoyment, and am surprised to find the technique of writing one's self as a character is an epiphany for my research. Ullmann's work excites me not because I wish to blur the lines between fact and fiction as she does (Clark, 2020) but because I think if I were to think of the self I am writing about as a character, I might be able to move past the overwhelm, to see the line between useful and tangential more clearly, to take the broader more analytical view, much as I would if I were sorting through data about somebody else.

This sounds suspiciously like I am trying to argue my way back into the famed (if illusory) ideal of research objectivity, but it's a subtler shift than that. Observation, rather than objectivity, distance rather than neutrality. If autoethnography blurs the lines between the researcher and the research (Keleş, 2022), it still needs, I believe, to be clear on the difference between being a story and telling one.

I decide to try writing about myself in the third person as a way to find the observational distance I need. I substitute "I" for an Ullmann inspired "she", to see where it takes me, to see how it fits.

She sits in her rheumatologist's office holding her handwritten list of the top 3 things she has come to discuss. She knows she only has 20 minutes, and 10 of those will be taken up with an examination of every single joint in all of her limbs, and always in the same order: fingers, wrists, elbows, shoulders, toes, ankles, knees, hips. She always forgets to give important information in the limited time she has the rheumatologist's attention, at least information which is important to her, and she hopes having a written reminder means she won't forget anything this time.

He welcomes her into her office with a ubiquitous "how have you been?", and she says she's been good, and she reads him the list of things that she needs help with. He holds his hands up to stop her before she gets to the end. "We don't have time to look at everything", he *says, "so just pick the one thing that's most disruptive right now". Her heart sinks and her body literally folds down into something smaller, takes an unconscious decision to inhabit less physical space. She picks her painful shoulder because it keeps her awake, and her painful ankle and her swollen knee will have to fend for themselves for at least another six months until one of them climbs the problem ladder to become the most worst thing.*

The steroid he injects into her shoulder is helpful, but she never bothers to bring a list again.

The technique proves itself useful in providing cognitive distance, and as it suits the story I am writing, I keep it. I also tuck the idea away for future projects. But it is not something appropriate to every piece of autoethnographic research, and it would be a nonsense to suggest otherwise. I need to understand what separating my identity from my situation, and my situation from my story, means in much greater depth so I can know how to do this in any future autoethnography too. The search continues.

Authorial distance is a well established idea in many genres, academic writing among them. As George Orwell once wrote (2004), effective writing requires us to "efface one's own personality" (p. 10), and Bochner and Ellis (2016) describe this as avoiding self-consciousness, and Gannon (2021) states that we can be "too full of self-identity" (p. 42). This falls into the ethnographic concept of reflexivity, or, as Adams and Herrmann (2020) write, as autoethnographers we need to "engage in rigorous self-reflection" (p. 2).

Something in Ullmann’s fictionalisation of experience reminded me of a problem discussed in a writing book I own, bought years earlier with the delusional hope that simply amassing enough information will somehow endow me with extra skill. It has been a vain hope, but in this one instance, not an entirely useless one; I find the specific chapter in the specific book I am after fairly quickly as the bold claim made by the author (Reiken, 2011) has stayed with me.

Reiken (2011) states that the biggest faults within the stories he encounters as a teacher of fiction writing are a result of what he calls the “Author-Narrator-Character” (ANC) merge (p. 5). He suggests it is also true of non-fiction writing, and the idea resonates with my search for authorial distance and my ongoing struggle to construct some load-bearing walls (Holley & Colyar, 2012) of self within my research text.

Reiken (2011) breaks down the differences between the author, character and narrator thus:

Author - the whole of me, the conscious mind, the mother, the academic, the reader, the thinker, the one who is outside the text wondering which point in my notes fit best with what I want to say. The wizard behind the curtain, the editor, the decision maker.

Narrator - the teller of the story, this voice you are reading, the rhythm, and style, and shape of the words.

Character - the focus of the story, the remembered, imagined self who experienced (and within the text, eternally experiences) the phenomenon being written about.

These are all “I”, but they are not the same “I”, and writing as if they *are* the same in a work of autoethnography is problematic because when we write about ourselves, we are remembering a version of the past, and memory is filtered through the imagination (Salesses, 2021). Imagination sounds precariously close to just making anything up, which is not what academic writing is purposed to do. However, memories *are* mutable, *are* unstable, *are* constructed (Au, 2022; Karr, 2015; Salesses, 2021), and to tell my story as if the me remembering, and the me remembered, are the same, are absolute factual unbiased truth rather than contextual mutable memories? *That* would be making things up.

I decide to take an on-line course about creating characters in fiction (Bell, 2023), because, I reason, understanding how to create a character better will help me understand how to craft my autoethnographic self, and perhaps give me some more of the *how* I separate my author self from my textual self. Though choosing a third person perspective was helpful in cultivating distance, and this character of ‘she’ does not seem to be overly idealised, or mired too deeply in distress, equally I can see that there is very little depth to her. She is flat, and uninteresting. If I can’t connect to her on an emotional, evocative, level, I have no right to expect that a reader will want to either, and one goal of the kind of autoethnography I aspire to write is to connect with any potential reader (Bochner & Ellis, 2016).

The writing workshop includes a technique for finding your character's fatal flaw (Storr, 2019) in order to write that character's story with depth and emotional resonance. It begins simply enough with just noting down a few biographical details. Age, birthday, these are easy, uncontroversial, not overly insightful. What I (she) likes, dislikes, my (her) favourite colour, also simple, also not greatly relevant. I assume that the next step of discovering a fatal flaw for myself will be an exercise in futility too, because how could it matter? I'm telling a story, not creating a plot.

I try it for myself anyway because I believe that you can't understand creative non-fiction techniques if you don't understand the fiction techniques that underlie them. I also believe that even fictional characters are "only somewhat fictional" (Leavy, 2012, p. 253) and that the tools of story writing are tools of human communication, so what would help me create a realistic fictional character is also likely to help me understand how to craft an authentic autoethnographic character.

What is meant by the term "fatal flaw" in fiction writing is simply the main value, or motivating factor, that steers a character's action, even, and especially, where it also steers them into conflict with their goals in the context of the story they are being written into (Storr, 2019). A psychological Achille's heel. One well known example would be Elizabeth's Bennett's pride as it clashes with Mr. Darcy's prejudice (Austen, 2014). To find this cognitive weak spot, we need to think about what is so important to that character that they would protect it against all costs, what is it that they hold supremely sacred (Storr, 2019). Elizabeth Bennett's love for her family is what leads her to act with such unbending pride; Mr. Darcy holds his personal reputation as so important it causes him, in turn, to act with an imperious social prejudice.

When I think about my experiences with chronic fatigue, I believe that my own character weakness in this context is that I want too much to be liked. Not to be a hero, nor even admired, but valued and respected. Especially respected. And this need is what is ultimately clouding my judgement, muting important aspects of the fatigue experience so that when I sit down to write with my piles of notes and ideas and references, I simply don't have much to contribute to the conversation, because I want too much to hide what I perceive are the shameful, unlikeable, aspects about it.

It is important to note that this would not be, and was not, a vulnerable psychological weakness when writing about chronic pain, because it did not come into conflict with my lived experience of chronic pain, as I had not entangled aspects of my identity with it. Or if I had, they were positively felt, not something I believed would lower my social value. When we think about the fatal flaw, the defining limitation of our textual self, we are not imagining what might be a useful conflict to make the story more interesting, as we would in writing fiction, we are thinking about how our own personal vulnerabilities relate to the specific situation we are writing about.

The reason this can be a useful thing to do, because a character's role is to illuminate (Gornick, 2001), to animate a story (Pelias, 2019), not to layer it under a fog of obfuscation. Learning to watch for and take account of ways our psychological makeup can interfere with insight and honesty in our writing is important, whatever technique we use to do it, and fiction's idea of the fatal flaw is one technique that worked for me, and would work whatever point of view we choose to write our textual selves from. In my own writing, it enabled me to see how integral this aspect of my character was in the medical and professional encounters I experienced, how deeply it affected my responses, how it shaped my work, my family, my friendships. How it had begun to shape me. Knowing this about my authorial self and putting this knowledge into practice when writing my textual self did indeed mean that this part of my character illuminated, animated, invigorated my story.

No magic solution. Just a small collection of useful tools that finally worked together to help me craft a piece of writing about my experiences with chronic fatigue I could feel was both truthful and useful. That was all. And that was all I needed.

Endings, I am told, are equally important as beginnings (Caulley, 2008), so let me begin my ending by acknowledging that this is, of course, a highly edited and curated story of how I dug myself out of the research hole I had inadvertently fallen into. The reality was much less linear and more confused than this account would suggest, and a paradox of communicating a complex experience clearly is that we must also condense it greatly. To do so means making considered choices about what aspects of our experience to amplify or compress, which parts to examine closely and which to leave quietly in the background (Holley & Colyar, 2012; Narayan, 2012), and this requires consideration of the craft of writing as much as consideration of the experience itself. Learning to be competent in any kind of craft is an ongoing and challenging enterprise that takes time and practice, time and practice that can sometimes be lacking in our teaching and research praxis (Bochner & Ellis, 2016).

What autoethnography is claimed to mean is regularly discussed in terms of the Greek roots of the three elements that make up the word: auto (self), ethno (race, culture) and graphy (write). Much less often talked about, however, are how we define these terms as they are applicable to writing up our research, and learning how to do this for myself was a large part of how I was able to move forward in my own stalled work.

Narayan (2012) suggests that it is helpful to gather insight from the ethnographic elements of other kinds of writing. It was reading an eclectic selection of authors that led me to Ullmann's use of her childhood self as a character in her memoir, which then led me to Reiken's (2011) discussions of the ANC merge, which, in turn, brought me to Gornick's (2001) differentiation between situation and story, and forward on to Storr's (2019) work on understanding character. These disparate elements from very different writers, all of whom are well outside my area of academic speciality, gave me clarity on what was missing and what was needed to finish my troubled piece of research. I came to understand the "auto" as a combination of myself as author and narrator and character, the "ethno" as (very broadly) the situation I was experiencing, and the "graphy" as the story I had come to tell (Gornick, 2001).

I also came to understand that although these concepts were all inextricably linked, it was the 'character' aspect of my autoethnographic self that was key to crafting my research well, evocatively, and with rigour. A character brings life to a story (Gornick, 2001; Pelias, 2019), and when we conceive of the “I” that is writing as different to the “I” that is being written about, then we are more readily able to serve the authentic research story, rather than having that story serve us. This authorial distance makes it easier to write complexity and depth into our research, to analyse the disparate parts as they speak to the whole; to reveal “the world in its twisted beauty” (Abdallah, 2017, p. 181).

Judging the value of autoethnographic research without taking account of this kind of craftsmanship is to misunderstand the process and value of the methodology itself. When we don’t talk openly and often about the craft of writing in autoethnographic research, we also do not show how much critical thinking, depth and rigour has gone into building our work. When we don’t provide adequate discourse around the use of narrative tools in autoethnographic writing, this can sometimes mean that the non-prescriptive nature of the methodology may be misinterpreted as a lack of structure, that evocative writing is misconstrued as containing little analytical content, and that purposeful vulnerability is mistaken for unreflexive oversharing. Good writing is hard to achieve (Caulley, 2008), and crafting a textual world that exposes, informs, explains or acknowledges important aspects of a lived experience requires good writing (Gregersen, 2022; Holley & Colyar, 2012). As such, more public discussion around the possibilities and processes involved in the crafting of autoethnographic research can only be of benefit to researchers and readers alike.

Finally, what is meant by “good writing” can be different for every autoethnographer. The “narrator” of the ANC triumvirate, the one who represents the style and language and rhythm of our writing, is as unique to us as our authorial and textual selves are. This is why autoethnography is not, and can never be, a prescriptive methodology: language, craft, and our concept of self are all situated in culture (Abdallah, 2017; Carroll, 1988; Gannon, 2021; Pelias, 2019; Salesses, 2021), and culture is neither neutral nor homogenous. Good autoethnographic writing means that we narrate our stories with careful effort and consideration, but it also means to narrate them as if they are *our* stories.

Salesses (2021) expresses this best when he says that "...one way the teaching of craft fails is to teach craft as if it is one" (p. 34). To paraphrase Walt Whitman (2017), the craft of writing is large and multitudinous, and learning to do it well can be challenging (Holley & Colyar, 2012). This can be overwhelming to an inexperienced practitioner, as I was overwhelmed. This overwhelm can tempt us to look for easy solutions in place of practice and attention to detail (Caulley, 2008; Pelias, 2019; Storr, 2019), which in turn can lead to problematic autoethnographic research (Gregersen, 2022).

Understanding autoethnography as both a researcher and a reader is a "never-ending story" (Short et al., 2007, p. 781). If I found my own solutions reading the writers mentioned in this story, they were not the only solutions to be found, nor the only writers to be read. There is a wealth of craftspeople who have learned some aspect of the art of storytelling and are willing to pass their knowledge on in books, in articles, in workshops, and in their classrooms. We should, as Narayan (2012) suggests, make use of this wealth of experience, make efforts to seek it out, try it on. And when it doesn't quite fit, adapt it.

As autoethnographic writers, our academic training in research design and critical analysis makes us well suited for seeking and sorting through disparate knowledge sources in order to find what is useful and relevant in our own research. And as autoethnographic writers we also have the privilege of having our story heard, of passing all this knowledge on.

Because in the end, we write not just for the sake of autoethnographic rigour, but for Orwell's "…joy of mere words…" (2004, p.3), for our fellow human travellers (Gutkind, 2006; Richardson & Motl, 2021), and for the struggling researchers like me who are in desperate need of guidance to help strengthen the construction of our rather wobbly research tables. So, yes. Most especially, we write to pass it all on.

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CHAPTER 3

Introduction to Circles of Hell: Brachial Neuritis and the Chronification of Pain

The experience of pain is a ubiquitous one, and chronic pain a common presenting health complaint (Bushnell et al., 2013), and this is certainly true of brachial neuritis, where ongoing pain is a prevalent reported problem (Cup et al., 2013; IJspeert et al., 2021; Van Eijk et al., 2016). Though there is a large body of literature that seeks to understand the causes and effects of pain as a physical sensation, it remains a poorly understood phenomenon at the experiential level (Ojala et al., 2015), with a paucity of research stories written from the chronic pain sufferers point of view (de Montalk, 2014). It is in this research space that *Circles of Hell: Brachial Neuritis and the Chronification of Pain* is situated.

Such stories are important for a variety of reasons, not least because those who suffer chronic pain are often not believed (García-Rodríguez et al., 2023), particularly if they are women (Schäfer et al., 2016). As women are also more likely to experience a chronic pain condition (Skuladottir & Halldorsdottir, 2011), this becomes a matter of epistemic injustice, in that an important source of embodied knowledge has been too readily and too often overlooked. In the western biomedical paradigm, expertise in chronic pain resides with the healthcare provider, and medical practitioners' discourse becomes focussed almost exclusively on "patient education" (Ram et al., 2023, p. 41), which in turn often leads to a sense of embodied disempowerment for chronic pain sufferers (Schäfer et al., 2016).

Evocative autoethnography considers lived experience as an important source of knowledge (Pelias, 2019), one that can address personal experience at a deep holistic level (Cotter, 2017), and as such is particularly suited to counter this epistemic injustice by highlighting the value of the sufferer's own understanding of their chronic pain. In doing so, I believe it also encourages what Buchman et al. (2017) calls epistemic humility: that is, increasing awareness of insider knowledge of chronic pain can also challenge the hegemony of medical conceptions of chronic pain.

This challenge is not necessarily to dispute medical knowledge, but to expand it; as Chang (2016) suggests, autoethnographic texts can, and perhaps should, speak with other forms of research. This was my aim for writing *Circles of Hell,* to develop a story that conveyed the ways chronic pain developed, shifted, and changed over time, how it impacted daily living and quotidian experience. As I read research in this area, I found my experience alienated from each individual "finding", perceiving them as too narrow, too exclusionary. However, and as noted in the article introduction, when I took a reflexive step back and considered the research as a combined whole, I could see that many of these same findings mirrored important singular aspects of my chronic pain story. In this sense, *Circles of Hell* can be considered a form of autoethnographic metasynthesis, where academic citations signal the points in time where my personal experience corresponds with findings in the chronic pain literature.

I believe this to be a useful, if somewhat unorthodox, method of situating research findings in a broader interpretive context. Useful, because it highlights the wealth of knowledge contained within insider accounts of lived experience, supporting the idea of epistemic humility, and useful too because the analogous accounts warn against privileging one singular research finding over the more integrative context of personal experience.

This is not an argument for lived experience as truth, but for lived experience as epistemically important.

This epistemic significance is further highlighted in this article’s consideration of the temporal nature of pain. Common definitions in the literature measure chronicity by clock time (Caldas & Bertero, 2012), where a minimum of 3 months experience of symptoms differentiates a diagnosis of chronic pain (Ram et al., 2023), from acute pain. However, the change from acute to chronic is not experienced as a single demarcation by the sufferer, but as a continued and continuous temporality (Osborn & Smith, 2006), an expression of lived time (Caldas & Bertero, 2012), or “egenzeit” (Fuchs & Detmers, 2017, p. 257), the body’s own time.

As Hoerl (2014) argues, it is what we *remember* of what we experience that registers as the passing of time, and in this context we can say that one way to describe temporality is as the collected differences found in such memories (Caldas & Bertero, 2012). *Circles of Hell* seeks to illustrate the embodied temporality of chronic pain through a series of these temporal viewpoints as set within a storied timescape (Holland, 2011), viewpoints remembered from the onset of brachial neuritis pain through the first few years of learning how to live with it. As a way to illustrate the temporal nature of chronic pain, and because an evocative autoethnographer’s task is also to be mindful of narrative form (Narayan, 2012), the resultant timescape is reflected in the article’s narrative construction, where repetitive but disparate experience is mirrored in repetitive but disparate stories.

Utilising language artistically (Eisner, 2008) in this way is important because, as Pelias (2019) writes, “the literary … has the potential to … bring the affective into shared space with the cognitive” (p. 121) and this combination of evocative storytelling with analytical engagement is the conceptual heart of *Circles of Hell: Brachial Neuritis and the Chronification of Pain.* In telling my story, I aim to combine lived experience with a synthesis of research findings, to use narrative creativity as a mirror on temporal complexity, and to highlight representational agency (Asad, 2008) as a way to promote epistemic humility. Though the sensation of pain may be unseen (McGowan et al., 2007), solitary (de Montalk, 2014) and ineffable (Ratzan, 2014), it is my aim to show that stories of the lived experience of chronic pain need not be.

Circles of Hell:

Brachial Neuritis and the Chronification of Pain

Megan Young

Massey University

Albany Village, Albany, N.Z.

Circles of Hell: Brachial Neuritis and the Chronification of Pain

Abstract

Pain is a changing and changeable embodied experience, a shift in temporalities, non-linear and unpredictable. It is always new, and ever familiar, sometimes picking us up in a large and looming calamitous wave, sometimes pushing us out onto a new and unfamiliar shore. This autoethnographic article imagines one such possible collection of pain experiences based on the author’s own familiarity with an acute pain disorder as it develops into a chronic one, combining creative writing techniques with a synthesis of academic research as a method to examine personal experience within a collective context.

Introduction

In mid-2016 I was in the middle of writing up my Master’s thesis when I began to feel an increasingly severe pain in my left shoulder. As someone with inflammatory arthritis, I was used to joint pain as part of my everyday experience, and so ignored it and carried on. After a few days this same shoulder became suddenly paralysed, a shocking experience that eventually led to the diagnosis of brachial neuritis.

The paralysis resolved itself within a few months, though the resultant instability and nerve damage caused significant ongoing pain, particularly in the first few years. As I began my doctorate, I found no research on this disorder from the sufferer's point of view, and I also found very little in the research on chronic pain that I could relate to. Though many findings and discussions spoke to one aspect of my experience at one particular point in time, I felt alienated by this compartmentalisation, felt the complicated and temporally dynamic nature of a chronic pain disorder was not represented in a way I could personally access, nor relate well to.

As I started to write my story, I came to understand that this was not wholly true; assembled together they did indeed mirror parts of my experience and reflect how it changed over time. This autoethnographic narrative utilises a methodological technique born from this understanding: my experience is written as I lived it, drawing on the autoethnographic technique of evocative storytelling to help unify and convey the narrative in an accessible manner, but it also references the research that I found to be reflective of disparate elements of the experience at a given point in time along the way.
If autoethnography conceives of "the self as a valid gateway to the social world" (Khan, 2022, p. 755), then the narrative which follows also conceives of the synthesis of qualitative research as a valid gateway to the self; something of an autoethnographic meta-synthesis, if you will. To this end, I have conceptualised the development of my own chronic pain disorder as a palimpsest, a series of experiential waves that ebb and flow through space and over time, waves that are both predictable and unexpected, waves that uncover and obscure.

But who can remember pain when it’s over? – Margaret Attwood.

I would like to take the King’s advice (Carroll, 2009) and begin our story at the very beginning, but there is no beginning. Rather, there are only beginnings; every pinch and ache and stab and twist a sensory wave of its own discrete experience. Always new, and always familiar; we are literally born knowing pain.

But this particular pain, it is more of the new and less of the familiar. I can’t sit still, I can’t sleep, I feel I have been cast into one of the circles of hell. (*On a scale of 1-10, how much does it hurt? 12 demons, 3 serpents, and 100 fiery furies*). I have a disease so poorly understood there is no consensus even on its name: introducing Parsonage-Turner Syndrome, Neuralgic Amyotrophy, Brachial Neuritis. By any other name, what it means is that a complex circuitry of nerves in my shoulders and upper back have become inflamed, set on fire by my own immune system. Seventh circle of hell, second ring (Alighieri, 2012). Recovery can be lengthy, the pain persistent (Cup et al., 2013; van Alfen et al., 2009), and so it goes for me. Daily, hourly, an infinity of minutes (Leder, 2016), the pain is persistent.

I find myself living in parallel temporalities (Leder, 2016). There is one where, fatigue aside, life is as it always has been. I buy groceries, mark assignments, distract myself with mindless television. And there is another where there is no past, no future, just the unintelligible torment of this painful moment (Caldas & Bertero, 2012). Clock time (Caldas & Bertero, 2012) versus existential time (Thomas, 2000). Some moments I find myself wholly in one temporal experience, then the other, switching back and forth between them in a constant pull of attention, both worlds loud, both worlds insistent. One of my children asks me a question; an imaginary knife is plunged into my shoulder. I swear, I take a breath, I answer the question, I swear again. Other moments, I become imprisoned in the experience of the painful now, pushing hard through some imperceptible veil to connect again with the world on the other side. There is something I need to do out there, but I can't focus long enough to quite remember what. And in still other moments, the ebb of pain lasts long enough for me to settle back into the rhythm of a day, the existential temporal state receding as a dream, as an uncertain memory. It's not that bad, really. I'm fine.

I have read that the body in health is quiet (Osborn & Smith, 2006) but I don't agree. Hungry, lustful, cold, hot, relaxed, tired; my body speaks in all manner of ways, at all manner of times. We are the same woman, of course (Biguet et al., 2015, Ojala et al., 2015) but also separate (Medford, 2006), removed experientially by the languages we use and the perspectives we take. I have my words, she has her senses (Skuladottir & Halldorsdottir, 2011). I have memory and expectation; she has the forever now. In pain, her loudest, most demanding voice, I become her. Outside of pain, I become capable of forgetting her. But with so many days, weeks, and months of the back and forth and forth and back of my parallel temporal existence, I begin to lose my footing, my bearings, my sense of being one whole self.

This is how I experience pain. Not as sickness (Thomas, 2000), but as a disorientation.

I did not care what it was all about. All I wanted to know was how to live in it. – Ernest Hemingway

Pain is a cacophony. It is noise, meaningless (Leder, 2016) unbearable noise. Sartre called it a kind of melody (Svenaeus, 2015) but this is no music I know. (*One a scale of 1-10, how much does it hurt? 3 squealing tyres, 8 piercing alarms, and 12.67 amplified jack hammers*). So much noise, it is hard to sleep, and even when I do, the pain follows me into my dreams. There is little rest, anywhere. I read of pain and a head in chaos (Ojala et al., 2015). I have a head in chaos.

I am not safe to drive, I cannot remember things, and my words, they start losing, I am not sure is making sense. I don't notice how confused both speech and writing have become. Lack of sleep (Ramlee et al., 2018), excess of pain, temporal shifts (Gergel, 2013; Leder, 2016; Caldas & Bertero, 2012; Thomas, 2000) noise, noise, noise. I have a diagnosis. I have medication. But I can't make any sense. My doctors, they all want details I can't clearly remember; how long, how much, what kind, where? I don't know. I don't know, I don't know. If pain is my body speaking to me (Skuladottir & Halldorsdottir, 2011), she is doing so in an encrypted code (Morlion et al., 2018; Tsay et al., 2015). I can't translate what I don't understand.

If I keep still for long enough, sometimes the noise will recede. Just a little. But a little is room enough to think beyond the present moment, to reach back into a larger, more integrated sense of self. I pick up a pen and I scribble. The noise recedes some more. I doodle flowers and faces, notes and lists, I doodle some small sense of order.

It’s a cacophonous kind of order, an illusory one. I don’t care. It helps. I start a new sketchbook, return to an old one, draw in school books, doodle on research papers. I dig out old watercolours and ink pens, I find more sketchbooks. I have work to do, work I won’t admit that I can’t do well, work I am ignoring in order to build this enormous tower of incoherent, incomplete, ridiculous babble.

I read Frida Kahlo’s diaries. They are not babble, but in them I think I see something of pain’s cacophony. She said that she could stand the pain as long as she could paint (Kahlo, 2005), and I think I understand, or at least I understand something in her words for myself. Her magnificent paintings, my chaotic scribblings, they are structure enough within this unpredictable (Persson et al., 2011; Smith & Osborn, 2007), distorted (Tsay et al., 2015) and distorting sensory experience to give a little pause, some room to breathe, a small place of focus. They are a dot on the wall on which we can concentrate, I can concentrate, while the next sensory wave tumbles me over and around.

I can’t bear this pain. Also, I must bear it.

In the face of pain, there are no heroes. – George Orwell

Pain is a bully. By name it translates as ‘punishment’ (Jackson, 2005), by nature it signals threat (Risdon et al., 2003). Unwelcome, an interference (Broom et al., 2015), an assault

(Charmaz, 1995; Smith & Osborn, 2007), chronic pain can change the brain's physiology (Bushnell et al., 2013). It promotes loneliness (Ojala et al., 2015), elicits helplessness (Thomas, 2000), creates an unfriendly (Risdon et al., 2003), intolerable (Svenaeus, 2015), alien (Tsay et al., 2015) body.

Or so the story goes, and the story itself feels like an assault (Jackson, 2005). Where the demands were first only internal, now I feel bombarded from all sides (Jackson, 2005). Do these exercises, take this medication, have these blood tests, visit this specialist, get an MRI, change your diet, it's probably something else, have an ultrasound, I'm sure you'll be fine, try Pilates, see a chiropractor, a naturopath, let me pray for you, try this medication, that supplement, swear more, swear less, it's not so bad, don't catastrophise (Beunaver et al., 2007), learn to meditate, acceptance is key. (*On a scale of 1-10, how much does it hurt? 3,691 words of unsolicited advice, 18 unwelcome judgements, 22 blithe dismissals*). I want to take a cattle prod and use it on the next person who says something, anything, about pain to me, follow them around for the week, and prod them every time I hurt, and for as long as I hurt. Now you try Pilates, now you stop catastrophising.

The words I come to resent the most are also some of the most kindly meant; I hope you get better soon. As if this is a possible choice, as if I have a cold, a sprain, a temporary ache. The more I hear it, the more invisible, the more dismissed, I start to feel. The more the intended blessing becomes a received curse.

Curse because such advice is aiming me toward an ideal, an embodied perfect, infering that my current direction is imperfect. If perfect is my aim, then I have choice, and if I have choice, then I also have responsibility (Kugelmann, 2017). If I have responsibility, I can also be blamed. To remain in daily pain for so long must somehow, at some level, be my own damned fault.

I don’t understand this consciously at first, but I feel it: worse, I believe it. I try to keep working, to stop moaning, to get off the couch and do something. Anything. I become bully to myself. What else am I to do? Staying still keeps the shifts in temporal experience, the confusing cacophony to a minimum, but living and working and loving, these do not involve a great deal of staying still. Hello, Scylla; welcome, Charybdis.

An MRI shows eight inflamed nerve roots, their fat white tendrils curling out and around from my neck like the face of a medieval Green Man. He is celebrated for the cycles of nature, death and rebirth, growth and renewal (Basford, 1978). This belies his earlier, more sinister origins; some even name him as the devil (Basford, 1978). I think he is the devil, this ghostly accuser, this dramatic figment of my overwrought imagination. I think he is a devil who names me as fallen, who names me as weak, and who names me as the one to blame. I spend far too long taking part in this awful conversation, first to defend myself, and then again to accuse. I come to understand that arguing a premise is to accept a premise, and as the pain continues and continually renews, I become weary of the argument. It’s demeaning, and unhelpful, and not even very true.

I decide on a new premise. I decide that pain is not a punishment, and that there is no ‘perfect’ toward which I can turn.

Every person is defined by the communities she belongs to. – Orson Scott Card

Pain is a breaking thread, breaking threads, an unravelling. It is strained relationships (Broom et al., 2015), disrupted connections (Gergel, 2013), a struggle to belong (Skuladottir & Halldorsdottir, 2011).

I sit in a café, uncomfortable in the hard chair, the ache in my body growing slowly louder, sharper, bolder, and more insistent. I force my shoulders to relax. I twist in my seat to find a better position. I sit on my hands, in case it helps. I bring my focus back to the ongoing conversation, and I bring it back again.

"Did you hear about …"
But it hurts.
"Oh my lord, they never…"
It hurts.
"So I told them that…"
It really bloody hurts.

I want to be here, I am desperate to leave. There are things we are taught from childhood to never say out loud, and I understand that this desire to abandon my friends, now, right now, right in the middle of everything, is one of those things. I keep my silence. I know that no-one else can hear my body (Johansson et al., 1999) and though every pain is new to me, it is an old, repetitive, monotonous complaint to those around me (Johansson et al., 1999). To show this pain and to talk about it, over and again, is uncomfortable and inappropriate (Charmaz, 1995), a burden of perpetual empathy on those who know and care for me. It is walking around with my skin on inside out, much too raw, and much too intimate. So, I perform a different body, an untruthful body. An acceptable and concealed body (Esposito, 2014).

It wears me down (Hunhammar et al., 2009), and my performance becomes increasingly flawed; the pain leaks out into my posture, my face, my tone of voice. I am forgetful, impatient, my inattention palpable. A playful slap to the arm doubles me over in shock and fear; I sob hysterically in a large room full of strangers. They pretend not to notice. I pretend not to be furious (Werner & Malterud, 2003).

I begin to resent the need to keep this secret, to move at all, to go outside the comfortable borders of my own home (Smith & Osborn, 2007). (*On a scale of 1-10 how much does it hurt? 4 broken friendships, 82% loss of confidence, 1 boundless ocean of concealed grief*). I despise myself for it, I push myself outward, keep trying to hold on to those strands of connection for as long and as well as I am able. One by one they start to break, to pull out and away from my weakened, grasping, hands. If pain engenders helplessness (Thomas, 2000), this is where I feel helpless: I am not, was not, strong enough to hold on.

I no longer understand my place (Jackson, 2005; Leder, 2016) in this fast, physical, unrelenting world. I want an ordinary body (Smith & Osborn, 2007), a quiet body, a body that belongs (Charmaz, 1995) but this is not the body I have and there is no peace for me in pretending otherwise (Jackson, 2005). I am always vulnerable, always performing (Esposito, 2014). It hurts, and it’s no-one’s fault that it hurts, there is no-one to rage against except fate, or chance, or some random vengeful god. There is no-one to rage against except my self.

I learn to keep another secret, one more of those things that you must never say out loud. I am lonely. Just that. Alone and utterly lonely.

We are always only in our own company. – Frederick Nietszche

Pain is a desolation. I am sure that were I screened for it, I would be labelled as depressed, but this would be to misinterpret my sorrow. I have lost my sense of place (Jackson, 2005; Leder, 2016), belonging (Charmaz, 1995), and home (Thomas, 2000) and I grieve for that (Ojala et al., 2015). But I *should* grieve for that.

Such an emptiness here. I find it more difficult to explain than the pain itself; how does one describe an absence? How does one define this paradox of a smaller world to inhabit, with a larger space to fill? It feels much like a hunger, or a longing, or a thirst, and also it feels like none of those. I have come to hide the daily intense conversation between me and my pained body by hiding myself, I lose patience with other people’s sickness, with other people’s pain. (*On a scale of 1-10, how much does it hurt? 93 yearnings, 12 silent voids, and*

652 unwarranted hostilities). It's tiring enough just to carry my own. I am not proud of this. It is an ugly person to be (Korn, 2017).

I try to quieten the noise another way; I seek out stronger pain medication, take it to the upper limits, see if I can trick this dissonant body into silence, into sleep. It works, but too well. Everything sleeps. I am not in pain, I am not in anything but a fog of numbed oblivion. I don't care for work, for people, for my future, for anything. It's tempting to stay here, to retreat to the darkness as a quiet, peaceful, spectre; still alone, still lonely, just unable to give a damn about it.

But, there are people I love. Some strong and stranded threads of connection, they stay intact, and they keep my desires tethered to the world. I want to give a damn. I reduce the medication, and the pain returns. I lie about this to one of my doctors who would not understand (Esposito, 2014), because what matters to him stories of ghosts and oblivion against double-blind studies and the need for cure? (Webster & Harden, 2013). In that culture, if I reduce the medication, perhaps my pain is rendered illegitimate (Jackson, 2005), and I am no longer worthy of medical attention concerning it (Broom et al., 2015). I lie to avoid these kinds of judgements (Buchman et al., 2017) and the dismissal of my particular needs. But I also tell the truth to another doctor who does understand. *The thing with you*, she says, *is that it's more important you keep your thinking sharp*.

It is important, at least sharp enough to function, sharp enough to read and to write and to draw and to make. Sharp enough to carry on being me. There are worse things than pain, and losing my identity, not caring about anyone else, these are two of them. I don't welcome the physical discomfort, but shutting myself off has solved nothing. A freedom comes in embracing that. The landscape here, it remains desolate, but I am no longer so alone.

You must not ever stop being whimsical. – Mary Oliver

Pain is a three year old. A tired three year old in need of food and an afternoon nap. She is still unpredictable (Smith & Osborn, 2007), cacophonous (Biguet et al., 2015), still something of a bully (Charmaz, 1995), but she is also smaller now, quieter, and harder to take so seriously. She wakes me in the night, but perhaps less often; she is exhausting in her demands, but also more inclined to rest. She remains prone to big emotions, to public tantrums, her continued presence reminding me regularly that I have little or no control over anything she does (Ojala et al., 2015). She fatigues and infuriates me. She teaches me patience.

One might call the patience a gift, but I think it more necessity; I have no faith in silver linings. (*On a scale of 1-10, how much does it hurt? 55 shames, 179 futilities, 63 despondent wailings*). This pain, she is without consciousness, she lacks any awareness of the consequences that her errant nerve signalling has on our communal embodied experience. While I might be assigned some level of agency in how I deal with my pain (Broom et al., 2015), she cannot. It's simply easier to be patient with my physical limitations when I think of her this way.

I have been mostly left to my own devices to make sense of this chronic pain (Thomas, 2000), to reorient myself in time and place (Caldas & Bertero, 2012), to redesign my days (Persson et al., 2011), but I find an unexpected ally in this shifting, changing, (Jackson, 2005) three year old child. Her unpredictability demands new ways of seeing (Tamas, 2011), of sensing, of viewing the world. Where before I have scribbled and doodled to help calm her (more cacophonous incarnation) down, now I invite her out to the garden, show her dew on a leaf, pick some daisies to marvel at. We dig for worms, take photos of roses, plant raspberry canes and harvest lettuce leaves for our lunch. Inside my shrunken world, I find an enlarged appreciation of these small things (Persson et al., 2011), and blessed relief in the unpressured play.

She does more for me than this, and I understand that she is not a she at all, that we are me (Kugelmann, 2017). But that's also not important, not here, because I don't live my life as a philosophical position, I live it as a collection of experience and memory and story. This story of a three year old gives me permission and inspiration to live with a body in pain more openly and kindly, and with greater understanding, than the drugs, the meditations, or the prescriptive set of exercises I have yet been able to do. Pain resists treatment (Ojala et al., 2015), but I find for me, for now, it opens to imagination (Ratzan, 2014), which offers me some small level of control. And some small level is better than no control at all (Broom et al., 2015).

Ratzan (2014) says that we need this creativity to connect, and I think this is right, or at least we can use it to connect, and the connection matters. To quote the poet Geoffrey Hill (2012), if we meet each other in hell, it's no longer hell.

* * *

Survival is insufficient. – Emily St John Mendel

Pain is disturbingly normal. I adapt. We all do (or don't do) (Charmaz, 1995), and in any case, life, it goes on (Frost, n.d.). They fool me sometimes, though, these increasing moments of relative peace and relief; I mistake not feeling pain with being pain free (Leder, 2016). It's a misjudgement. I do too much, rouse the pain too soon, and so it wakes louder and more upset than it otherwise might. It's no way to treat a long-term companion, which is what we have become.

If I must continue this relationship with a body in pain, then I must, I suppose, decide what that relationship might be. Decide what I believe it could be.

Here is one thing I believe: I believe that this pain was not avoidable, it is not unnatural, and nor is it abnormal. Pain is common (Persson et al., 2011), it is one way among many that an acceptable, appreciated, loved and beloved, body can be. (*On a scale of 1-10, how much does it hurt? 1 beating heart, 2 healthy lungs, miles and miles of functioning intestinal tract*). Everyone suffers in one way or another, to greater and lesser extents, and the pressures of normative compliance (Soley-Beltran, 2004) are also visited on us all. I believe that if I could, I would choose a body free of pain, and I believe that in an entropic universe I have never been, nor will I ever be, more entitled than any other person to have one. I believe I am unique, but most definitely not unusual. I believe that pain, yes, affects the whole person (Ojala et al., 2015) but so does love and rejection, joy and oppression, and all the myriad ways humanity has discovered to act cruelly, to behave considerately. I believe all experience affects the whole person, and I believe we are all, always, whole people, in sickness and in health. I believe that wholeness is a conviction, not a goal.

I believe that this is who I am now; a slower, more patient, more isolated, whole and wholly imperfect woman. I believe that if I cannot remove the pain, then I can add to it; not with more pain, but with other internal sensory conversations, a balance of merry to the burden of sorrow. My shoulder hurts, I listen to music; my arm aches, I knit a lace scarf. My fingers burn, I write fragments of poetry. I write this fragment of poetry:

I pass the time by looking
inside forests, tunnels, ruins and caves,
hidden in shadows and waiting
for one wild moment
of available light

I believe that if the world has no natural home for a body in pain (Thomas, 2000), then I will build one for myself, and I will build it out of a vast collection of these (small and) wild moments of available light. Perhaps slowly, perhaps erratically, perhaps the whole flimsy structure will one day surely crumble. Even so. I believe the building matters more than the falling.

I shall have to change to a bird or a fish. – Janet Frame

I would like to follow the King's advice (Carroll, 2009) and carry on until I come to the end, but there is no end. There is no critical moment of transformation (Svenaeus, 2015), no catharsis, no conquering heroine living happy ever after. Pain is persistent (van Alfen et al., 2009), hard to make sense of (Svenaeus 2015), it is variable (Hunhammar et al., 2009), and ambiguous (Leder., 2016), it moves and shifts in uncertain status (Jackson, 2005). What use to anyone is a story like that? (Ellis et al., 2011).

Rather than story, perhaps it could be thought of more as an embodied palimpsest, with each wave of pain, each set of experiences, partially overwriting the last. These traces of the past body, past bodies, remain discernible and palpable, and also increasingly erased by the next wave, by the next layer (*On a scale of 1 – 10, how much did it hurt? 68 ~~I~~ can't remember, 13 ~~I~~ can't ~~remember~~, 4 ~~I can't remember~~*). If I have learned to live with pain today, perhaps this knowledge would not have helped me with pain yesterday, perhaps will not help me with pain tomorrow. This jumbled, non-linear, and very personal struggle (Thomas, 2000) remains largely without meaning (Leder, 2016), and a thing less to be transformed by (Svenaeus, 2015), than repeatedly adjusted to (Biguet et al., 2015).

Everything I have learned, have become, now believe in, could momentarily be overtaken by yet another unexpected oncoming storm.

Pain is so many very different things (Angheluta & Lee, 2011). Pain is loud and pain is a secret, it is a bully and it is a friend. It is vulnerability, it is strength, it is unexpected, it is familiar. Pain is outside of time, it is ruled by time (Rickles & Kon, 2014). It is resistant, and an onslaught, it is child and it is demon; pain is a fiery, flaming existential storm. It is home, and it is without a home; pain is boring, it is ordinary, something to accept, and something entirely unacceptable.

Pain is a paradox (Leder, 2016), and pain is always new.

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CHAPTER 4

An Introduction to Witches Dance Backwards: Fatigue, Shame and the Valence of Desire

If pain is the hell of a brachial neuritis diagnosis, then fatigue is the purgatory, a place of waiting, of limbo, where the chronically fatigued are somehow lacking in soul, without life's energising vitality (Ryan & Frederick, 1997).

The lived experience of fatigue related to chronic illness is a common one (Passik & Kirsh, 2011), and correlated with a sense of embodied shame (Whitehead et al., 2016), a shame that is often associated with a lack of social connectedness (Jaime-Lara et al., 2020) and loss of productivity (Hay, 2010). Research on fatigue commonly targets the individual sufferer as the locus of the problem, conceiving of fatigue as a condition to be self-managed (Pearson et al., 2022), and the chronically fatigued a societal burden (Harmsen et al., 2022), dysfunctional (Whitehead et al., 2016), and lacking agency (Hay, 2010).

This derogatory gaze (Stage, 2022) is problematic in many ways, not least because it neglects to consider that the expectations of cure (Folkmarson Käll, 2013), of productivity and agency (Hay, 2010), are cultural expectations, and that shame is always a negotiation between the personal and the communal (Richards, 2019). To this end, *Witches Dance Backwards* looks at the roots of western medical culture as historical context to the phenomenon of shame and fatigue, birthed as it was in an era where the physical body was an active detriment to the eternal soul and illness a spiritual test (Grosz, 2005), where women's bodies were inferior to men's (Greenaway-Clarke, 2021). This context is important to understanding the shame of fatigue because “history is a social process” (Carr, 2008, p. 55) and without a collective reckoning of these foundational myths, their influence persists.

Though not a pleasurable emotion, Uebel (2019) suggests that shame can be positively valent in a reflexive sense by challenging self-conceptions and constructed limits. The personal narratives included in *Witches Dance Backwards* aim to interrogate and reflect on those conceptions and constructions, but unlike the layers between anecdote and analysis in *Crafting Autoethnography,* or the synthesised stories of pain in *Circles of Hell*, these narratives are looser and explore a wider, seemingly unrelated, series of anecdotes, memories, and metaphor. This narrative technique is called the braided essay (Christian, 2018) and it is not used to obscure my experiences of fatigue and shame, but rather to create, as Bancroft (2018) writes, “spaces between narrative threads [that] become apertures through which we can apprehend that which we cannot usually see” (p. 263). That is, this weaving of seemingly unrelated storylines together is done to stimulate the creative imagination.

Kirmayer (2006) says that since the enlightenment, the use of imagination as a cognitive tool has been overshadowed by the empirical precision of scientific reason, yet imagination can be invaluable in constructing meaning and uncovering hidden connections. In an autoethnographic sense, constructing meaning and uncovering hidden connections between the personal and the social are both important research goals, so an imaginative structure such as the braided essay can be a useful methodological tool. Walker (2017) suggests as much when she writes “perhaps the braided form is most effective when the political and the personal are trying to explain and understand each other” (para. 19).

Beyond this methodological justification, however, is a personal one. The stories we tell ourselves are powerful, they can affect wellbeing (Kirmayer, 2006) and alleviate distress (Clark, 2013). My experience of ongoing fatigue has been a socially painful one, and as discussed in *Crafting Autoethnography*, the embodied shame became somewhat embedded in my identity as a moral and personal failure of character. Though I don't believe this on a rational level, I had also accepted it on another, more figurative level, and I hoped that my choice of the braided essay, with its emphasis on imaginative exploration, would allow me to write myself out of hiding and "back into visibility" (Richards, 2019, p. 279).

Relational ethics (Ellis, 2007) and the ethics of self (Edwards, 2021) would suggest there is a risk of harm to such a personally vulnerable disclosure, and this risk was considered carefully in deciding to write a personal story of fatigue: academia does have a tendency to prefer disembodied knowledge over embodied knowing (Richards, 2019) and there is always a cost to the emotional labour of personal disclosure (Brown & Leigh, 2020). However, there is an equally important cost to the emotional labour of staying quiet because silence can be protective, but it can also reinforce shame (Richards, 2019).

In the end, I believed that writing about fatigue was a more authentic representation of my lived experience, which in turn was a more truthful autoethnographic story. All bodies are morally neutral, and I don't accept mine as more deserving of shame than any other. To paraphrase Titchkosky (2007), we exclude the groups that we find excludable, so if fatigue is indeed a type of purgatory, then it is purgatory of our own making.

Witches Dance Backwards:

Fatigue, Shame, and the Valence of Desire

Megan Young

Massey University

Albany Village, Albany, N.Z.

Witches Dance Backwards: Fatigue, Shame and the Valence of Desire.

Abstract.

It is common to describe chronic fatigue as a burden to sufferers and society, a problem that must necessarily be in need of a fix. What these narratives can miss is the harm this focus on cure can cause those with chronic fatigue, the shame and alienation it can sometimes provoke. *Witches Dance Backward* utilises the creative non-fiction technique of braided narrative to investigate this intersection between social judgement and individual shame, asking the question of who we exclude, and how we can reframe burden to embodiment.

This is a story about fatigue. It is my story, and one I have the conflicting desires to both publicly scrutinise and remain completely silent about. The desire to investigate is rooted in an appreciation of the mundane and the quotidian as useful sites of knowledge, combined with the privilege of access to both the intimate details of a lived experience and the scholarly resources with which to examine it. I want to tell the story, because I can tell the story.

The desire to remain silent is more ambiguous. It is a vulnerable thing to discuss personal fragility in a professional space, to expose the details of a functional limitation that could be used to exclude and denigrate, but trust that it will not be. There is also a shame implicit in staying silent too, however, a tacit acknowledgement of deficiency, or wrongness (Titchkosky, 2007). I don’t want to tell the story, because it embarrasses me to tell the story.

I might counter this reticence with an argument that autoethnography is an empowering methodology (Patrycja, 2012), that it can build an empathetic bridge between researcher and reader (Denshire, 2014), highlighting our shared humanity (Boylorn & Orbe, 2014). I could contend that autoethnographic research contains useful tools for reflecting on some of the hidden (Muller, 2016) and poorly understood (Birk, 2013) aspects of living with fatigue that would help give them context, illuminating the past in order to better understand the present (Cotter, 2017), to explain ourselves to ourselves (Ellis, 2014).

I believe in all of these, and more, but none have proven motivation enough to resolve the tensions I have felt between scrutiny and silence. Instead, what impells me to risk this plunge into my own fatigued depths (Lacocque, 1984) is, quite simply, a belief in writing as an act of creation, and an acknowledgement that underneath the conflicting desires to tell my story and to remain silent, is a much deeper, stronger desire to write myself into a different one (Davies, 1990).

This is a story about fatigue.

Introducing our protagonist, a middle-aged woman of European descent, average height, above-average weight, and with a biological tendency toward multi-morbid disease. She is neither fictional, nor entirely substantive, but fabricated from scraps of memory tied together with a few strong threads of verifiable fact.

Recurrent brachial neuritis, arthritis, thyroiditis. Cluster headaches. Urticarial vasculitis. These are her headline diagnoses, her medically valued and verifiable passports into the land of the chronically fatigued. Autoimmune flavoured, as her neurologist once called her, a description she can only imagine tastes of bitterness and ash.

The persistent fatigue is as much out of her control as it is out of medicine's reach, but still, the sheer complicated daily monotony of it feels like it must somehow be her fault. To paraphrase Oscar Wilde, having one chronic illness is a misfortune, but five starts to look like carelessness.

It was a recent addition to the pile, a diagnosis of recurrent brachial neuritis, that caused a shift from the intermittently tired to the permanently fatigued. There is nerve damage in her shoulders that has caused muscle wastage and atrophy. It's embarrassing saying such a sentence out loud. She doesn't think you'll believe her, that it will be at all obvious why weak and painful shoulders are the source of unrelenting weariness. It isn't obvious. She wouldn't believe her either.

What is meant by the term “fatigue” as a symptom of chronic illness? It has been described variously in the literature as experientially ubiquitous (Passik & Kirsh, 2011), debilitating (Menting et al., 2018), unpredictable (Primdahl et al., 2019), complex (Cramp, 2019), across diagnoses (Menting et al., 2018), multidimensional (Nikolaus et al., 2012 ; Cramp, 2019), hard to define (Desmond & Hancock, 2001; Passik & Kirsh, 2011), and a “fundamental phenomena of existence” (Wardley, 2016, p. 117). It has been said to be an indicator of illness (Norelli & Harju, 2008), an ordeal (Blum, 2014) and a dysfunction (Whitehead et al., 2016) that affects everything (Primdahl et al., 2019).

So many descriptions, so much research, so overwhelming. How to understand such a phenomenon if we are unable even to succinctly define it? (Margulies, 2020).

Witches dance backwards (Oldridge, 2012). This is known. Sometimes they wear striped stockings while doing so, or a pointy hat, and occasionally, if they are good witches, there may be a beautiful dress and a sparkling wand involved, though this is likely to be a glamour. Witches are ugly. In any case, and in all situations, you will know that it’s a witch if they like to dance backwards.

If there is no occasion to observe the directional frolicking of your target occultist, there are other ways to know if such a person is servant to the devil. Or a devil. Evil in general. They might enjoy killing babies, and hailstorms in their vicinity, or unexplained cattle deaths are both a certain giveaway. They melt in the rain and are known to cackle. Sometimes they eat babies too. They like to tempt young women into the sins of carnality, they like to shrivel young men’s progenitory desires.

It’s not an exhaustive list, certainly, but collected as it is from memory, books (Oldridge, 2012; Kramer & Sprenger, 2009), and the pure figments of so many vengeful imaginations, it is an entirely fantastical one. Ludicrous nonsense, a fictional laugh. Or it would be were it not for the countless non-imaginary women who died under its weight.

A collective myth is a powerful thing. Amazing then, that any witch would ever choose to dance.

She hates to shower. This may seem like a trivial fact until you imagine how unsociable her already narrow world would become were she to stop the practice entirely, and how many times she must repeatedly do it. It’s not the shower that is the problem per se, as utilitarian as she finds that particular human activity, but the undressing, the redressing, the lifting arms over head to wash her hair. She hates feeling incompetent every time she struggles with the pulling of her head through the head holes, the arms through the arm holes. She wears loose clothing to help, but still. Her daily struggle with something so fundamentally simple makes her feel like a very young child yet to learn the basics of daily living.

Also her atrophied muscles look weird.

It’s infantalising, it’s embarrassing, it's exhausting, and it's often quite painful.

Also, and this is the bit she would probably never tell you, it can make her terribly sad. There is a small round spot on her upper left back that can’t feel the heat and pressure of the water like all the other bits of skin can, a minor but permanent sensory loss. When she visited her rheumatologist just days after the nerve damage in her shoulder first became apparent (a temporary paralysis after weeks of searing pain), he checked the skin on her upper back for numbness. It was odd to feel the gap, the missing few inches of sensory input, a skip in the record, a ghost in the machine. It made it all real somehow, more real than her then-paralysed shoulder, which was such a ridiculously improbable thing that she never could quite take it entirely seriously. And unlike her paralysis, it never improved, and every time she stands under that shower head, the water somehow both too hot and too cold, and weirdly not entirely there at all, she viscerally and immediately remembers the shock and fear of being diagnosed with this stupid disease no-one had ever heard.

Displaced grief for a handful of unimportant motor neurons. It’s not something from which epic life stories are made.

Here is an idea, can we understand fatigue better if we know what its opposite experience of vitality might be (Ryan & Deci, 2008)? Titchkosky (2007) contends that society defines a disabled body by all the things it is not, so perhaps this logic works for fatigue too.

> ***vitality (n.)***
>
> 1590s, from Latin vitalitatem (nominative vitalitas) "vital force, life," from vitalis "pertaining to life" (see vital). (*"Vitality", n.d.a).*
>
> Figurative. Active force or power; mental or physical vigour; activity, animation, liveliness. *("Vitality", n.d.b).*

In health research, vitality has been called the amount of energy we have available (Ryan & Deci, 2008), a feeling of aliveness and invigoration (Ryan & Frederick, 1997), of being energetic (Rozanski, 2023), having mastery, well-being, and an "interest in life" (Barbic et al., 2013, p. 1547). Agentic definitions, every one, equating vitality with life, inferring fatigue brings us closer to, or associates us with death; at the very least moving us closer toward it via ill health (Rozanski, 2023). Indeed, Deng et al. (2015) state that vitality is an "important domain for a health-related quality of life" (p. 81), and Rozanski (2023) even suggests vitality as the one single most important signifier of good health.

It is a small example of a much larger body of research, but representative of the problematic nature of the assumptions that fatigue is antagonistic to vitality. If fatigue is described as the ubiquitous experience of chronic illness (Passik & Kirsh, 2011) and vitality the ultimate expression of the best of good health (Rozanski, 2023), then they are necessarily oppositional and incompatible. In their work on the assumptions embedded in the research on fatigue, Paterson et al. (2003), note that it is common for researchers in this area to assume fatigue is always caused by disease, that it is a singular phenomenon, unquestionably problematic, and exists independently of the sufferer's broader lived experience. In other words, researchers embed into their research the idea that the people who experience chronic fatigue are the sole embodied source of a problem that stands in opposition to a fully alive and vital experience of life.

This problematic lack of aliveness sounds like a form of purgatory, maybe. Certainly Rozanski's (2023) suggestion that healthcare professionals advocate exercise as a promoter and restorer of embodied vitality does seem reminiscent of Dante's (Alighieri, 2012) punishment for the slothful who are made to run around and around their terrace in purgatory until they learn to appreciate the value of making an effort. This also resonates with Bombak and Monaghan's (2017) concept of a healthy body as a necessary credential for the good life. Either way, learning to love physical effort is the fatigued's only hope to move back into the land of the living.

Every woman has the potential to be a witch (Bovenschen et al., 1978), this too is known, and evidenced by the preponderance of this gender to be discovered as such and sentenced to death (Ehrenreich & English, 2010). Which is not to say that men can't also swear fealty to the prince of darkness, many sadly have, but simply that their higher nature, closer to the divine heavens than the primal earth, makes it unlikely for them to do so (Kramer & Sprenger, 2009). Indeed, male public justice officials, Catholic priests who are experienced in exorcism, and men "blessed by the holy angels" are the only creatures in God's good universe incapable of falling prey to such deception by witchcraft (Kramer and Sprenger, 2009, p. 55).

Women, however, are more carnal (Bovenschen et al., 1978; Ehrenreich & English, 2010; Kramer & Sprenger, 2009). They are blood polluters (Blumenfeld-Kosinski, 2004), wilful and wonton (Nichols, 1987); they cannot undo their wrongs, and “when a woman thinks alone, she thinks evil” (Kramer & Sprenger, 2009, p. 17).

This is not their fault; it is just their nature. Or so the story goes.

* * *

How tiring is an entire day without a shoulder? Well, she *has* a shoulder, of course, two shoulders, with all the bones and joints, ligaments and tendons, more or less intact. It’s a complicated joint, prone to injury at the best of times and with the best of intentions, and without the binding strength of a series of muscles which evolved to hold the whole thing in place, it is hard *not* to injure it. This is her problem: some of those muscles have atrophied into uselessness, some weakened into poor supports.

Fatigability is what this particular form of exhaustion is called (Van Eijk et al., 2016), an inability of the muscles to keep their strength up over repeated effort. She can lift something heavy once, maybe twice, and then everything fails. This makes the aforementioned showering difficult, also the washing and vacuuming and carrying loads and making the bed. Anything that uses a shoulder, which is mostly everything, becomes tiring after a while.

That’s a very abbreviated description, a broad strokes story she is used to telling, and it’s true enough, as far as it goes. What it doesn’t tell you is how she doesn’t really know how tiring an entire day without a shoulder is if she stays at home, where there is comfort, and familiarity. What she doesn’t tell you is that she forgets this, and thinks her life is not so bad and she is just a little bit lazy, actually.

How tiring is an entire day without a shoulder? It is staying home, perpetually.

There is no fix for damaged nerves, but she did read somewhere that nerve transplants can sometimes be performed if shoulder functionality never returns. She’s never been offered it, and it’s probably too late to mitigate any damage now.

Here’s something she didn’t mention before: brachial neuritis is much more common in men than women; often active men, regularly manual labourers. She is none and neither. She wonders sometimes if she was never offered surgical help because it is not a well-known procedure in her small corner of the much bigger world, or if it was because she does not “need” her shoulder to earn an income or play a sport. She thinks about that, sometimes. She’ll never know, but it seems important somehow. She’d like to think she would be worthy too.

The lack of stability in the joints can cause swelling in the shoulder sometimes, and it can hurt too much to sleep. A surgeon did offer to drain the extra joint fluid once, usually a cure for this kind of inflammation. He also said, *the thing is, without the muscles to hold that joint in place, it will only happen again. But you’ll have six months of feeling better, if you want it*.

She declined. She couldn't keep having surgery every six months. Might as well learn to live with the lack of sleep sooner rather than later.

So, how tiring *is* an entire day without a shoulder? It's a constant negotiation with these kinds of unwanted limitations.

Grosz (2005) accuses medicine of an embedded somatophobia for which we can blame Aristotle, maybe, or perhaps Descartes. One or other of the ancient archaics. What is meant by somatophobia in this context is a privileging of the idea of spirit, as the pure and eternal form of ideal humanity, the soul as the animating force. This puts the body in the realm of the decaying and the mortal, a temple, or a carrier, a house for the soul. A *tool*, and if a tool then something to be wielded and shaped and disciplined (Grosz, 2005). Fixed when broken.

This was the cultural belief system at the time the formal institutes of western medical knowledge were being created, and it has had a profound effect on the way bodies and health have been viewed (Ehrenreich & English, 2010). As Ryan and Frederick (1997) note, "... generations of thinkers have assumed that health and spirit are inexorably intertwined" (p. 561) and although this is not how we might describe it now, we still conceive of a difference between the body and psyche, at an experiential level if nothing else. It is hard, as Benoist and Cathebras (1993) suggest, to move away from this.

But there are also other problematic areas that such a dichotomy has encouraged, such as the phrasing of chronically ill bodies as a burden (Harmsen et al., 2022), as if the measure of an individual is solely their economic value, how productively they function. This positions the fatigued body as a faulty economic unit in need of fixing, an unhelpful position when you are, in this context, unfixable. Again, this idea of fatigue and vitality as incompatible in the same body models a binary of strength *or* weakness, health *or* illness. This might possibly meet the needs of a capitalist economy, but it does nothing except act as a judge and exile for the individual sufferers themselves (Brown, 2002). This perspective is itself a burden.

The medical profession has a lot to offer the immediate and treatable physiological symptoms of many kinds of disease, but have little in their medical or cultural toolbox to meet the more holistic sociocultural challenges of a chronically fatigued body. Perhaps we expect too much of one profession, and perhaps the philosophers and scholars who constructed the foundations of our entire medical culture got some of these important aspects fundamentally and horribly, but not irrevocably, wrong.

Here is another interesting fact about witches: they have no shame.

A non-exhaustive list of things she thinks you should know, but does not want to tell you:

1. she finds it hard to concentrate sometimes and this makes her feel stupid.
2. she is afraid the latter has become factually true.
3. at the very least she gets confused/doubtful about her own knowledge
4. despite her diagnosis, and the pain, the muscle atrophy, she sometimes wonders if she’s just faking this perpetual fatigability.
5. or if not faking it, then perhaps she has just made feeling fatigued a habit, or takes the feeling too seriously, when she could just ignore it if she wants to.
6. maybe she doesn’t actually feel fatigued at all and this is how everyone feels actually?
7. that is, she doesn’t trust her own judgement.
8. perhaps there is something truly, deeply, *wrong* with her as a competent human being, like she’s failed at it on some fundamental level and would rather stay silent than ever let anyone see how battered, worn out, addled, riddled, fetid, ragged, putrid her tiny little soul has become.

Which is a bit much, a bit ridiculous. And she doesn’t even believe in the reality of a soul as something separate from the body, is rather biology-centric about the whole idea. At the same time, she also does believe. As a story, as a metaphor, as a symbol, she does believe in having a soul, a little bit. She finds it difficult to translate what being conscious and having agency might mean in any other succinct way, and what are words after all, if not an expression of the human imagination? So, yes. What she secretly believes, and what she doesn’t want you to ever know, is that living in a state of chronic fatigue for so many years can sometimes feel like living with the tattered remnants of a broken battered soul.

The body bears witness to our shame (Folkmarson Käll, 2013), our stigma bears witness to culture's negative judgements (Creel & Tillman, 2011). The chronically fatigued body is in a sense monstrous, associated with the unpredictable, with entropic change (Dixon & Ruddick, 2013). Such a body can never be healed, so it can never be whole and in this sense it remains part of the grotesque. This too a harmful artifact of our Descartian heritage.

But also? The incomplete body, that instance of the grotesque, the monstrous body is what Canguilhem & Jaeger (1962) call an example of the wondrous, the marvelous. An example in reverse, they say, but marvelous nonetheless.

Like witches dancing backwards.

She hasn't danced in a long time. Well, sometimes a move or two in the kitchen when she's making dinner and no-one is watching. Maybe just on the inside. Everything outside seems like an effort, always, and she feels guilty about that. She should be a better mother, sister, wife, and friend.

The isolation is dreary. She'd rather not discuss it.

What she would like to discuss is how fatigue can feel sometimes. The broken, the tattered, those aspects are easy to understand. Fatigue as a wearing out. We all get that.

Sometimes it does feel like purgatory too, a perpetual and everlasting monotone. No matter how much sleep she gets, how many vitamins she takes, how many fingers she crosses, there is never more than an everlasting vista of flat-lined grey.

But also, and it took her a long time to understand this, it can feel like a longing, a sensory desire, a collapse into ease, into rest, into welcome. A call to peace. There are times when she is seated on her couch, her eyes closed, and perhaps it is raining, or perhaps there is just the silence of the early morning, and everything slows down and folds into this one quiet moment. Sometimes she thinks this might be the closest she will ever get to experiencing heaven.

It’s another conceit. But she never does feel shame when she thinks of the sensations of fatigue as a desire, and that seems like an important thing.

A worn out and tattered soul, and a peaceful soul longing for rest. It isn’t contradictory, it’s multiplicity, and isn't this type of “multiple wholeness” (Davies, 1990), the wholeness of vital living?

Desire is a wanting and a wishing (Schroeder, 2004), it goes beyond the dialectic into the ineffable (Davies, 1990). We don’t have to measure it, prove it, justify it. We need only let our soft bodies love what they love (Oliver, 2023).

Witches aren’t real. Not the kind of witches of the Malleus Maleficarum, those lustful, weak, and dangerous deceivers (Kramer & Sprenger, 2009). I tell their stories anyway as a personally resonant illustration of how imagine threats can have real impacts. Disastrous impacts. We cast out precisely the people and groups we agree to cast out (Titchkosky, 2007).

We cast out precisely those bodies and illnesses we agree can be cast out.

But our bodies are not static and finished objects to be labelled and shelved as one particular declarable thing (Greenaway-Clarke, 2021). It is more useful for me to imagine my broken shoulders in my tired body as desirous of a different, more serene temporality, than to believe it broken and unfixable. More helpful to think of it as a contemplative body, a body with the time to stand still and observe, one who seeks the pleasures and joys of a slower pace. To believe it as not a body lacking, but a body longing.

That I have the privilege to indulge in such a belief says a great deal about me, but even more about the expectations of a society for those who don’t have this luxury. That is our shame, and we are wrong. Alive bodies are vital bodies, and the pressure to transform a chronically fatigued one into a more performatively energetic one in order to be accepted and acceptable is harmful and forces people to hide or lie. Aristotle was wrong too; we are not souls who animate our embodied sacks of meat (Grosz, 2005), but bodies who exist in a complicated reciprocity of strength and frailty (Hyland, 2012). We just exist. We just are.

This is my story about fatigue.

Postscript

It is a difficult thing when writing a story like this, a braided and loose narrative that explores interrelated meanings among different stranded threads, to avoid the temptation to weave the strands a little too tightly, to finish on a satisfying narrative closure that acts as a redemptive, or triumphal end point. I'm not sure I avoided this temptation. To write myself a new story, as I suggested in the beginning that I wanted to, there simply had to be some final note, some joining of the strands in a way that created meaning, that made some kind of a sense.

They were true meanings, and it was an honestly created sense.

And also, I think, I am still in the middle of that story, and still at the beginning, and still weaving myself around the edges. Still waiting for a time when my life returns to a non-fatigued normal. Still half sure I'm making most of this all up.

I have a large collection of handwritten notes I made while reading the literature for this project. One of them says:

> "I just can't explain it all. It's too big, messy, complicated".

It is. By which I mean, there is no end to this story at all.

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CHAPTER 5

An Introduction to A Cipher for the Falling

In their editorial on what makes a good autoethnography, Adams and Herrmann (2020) highlight the importance of the ‘graphy’ in autoethnography, the representational portion of the auto-ethno-graphic trio. Though many autoethnographies are structured as written narratives, this methodology is open to alternative presentation forms (Butz & Besio, 2009; Muncey, 2010), including the visual arts (Leavy, 2020). Indeed, Hunter (2020) notes that visual narratives are “ideally suited to autoethnography” (p. 313).

This suitability is supported by the idea that there are some aspects of lived experience which language is unable to express well or fully (Holbrook & Pourchier, 2014), and that art is better suited to narrating in an evocative and visceral manner (Leavy, 2020). This is elaborated further in the exegesis that accompanies *A Cipher for the Falling*, and is a pivotal reason art has been used here as an important narrative element; there were simply some aspects of my story that were better suited to visual representation, aspects that were important to include for a more complete ethnographic narrative of my lived experience.

One of these is the multimorbid illnesses that my diagnosis of brachial neuritis needs to be understood against in order to appreciate the depth and breadth of its impact fully. In both *Circles of Hell* and *Witches Dance Backwards*, where the stories of the pain and fatigue associated with brachial neuritis were told with creative non-fiction techniques, much of the broader embodied contextual elements were edited out by necessity. Those written stories were a snapshot, truthful and evocative, but narrowly focussed by. There was simply too much information to include the full embodied experience as a written narrative, information that would confuse and overwhelm rather than evoke and illuminate.

But it was important information nonetheless. Brachial neuritis was not experienced as separate to the full multimorbid embodied complexity of my daily life. It was central and centrally important as an illness, but it was not *separate.* Given the breadth and complexity of this contextual information, and art's ability to convey a great deal of nuance in a small amount of physical space, utilising the visual arts in *A Cipher for the Falling* was considered the most effective and appropriate narrative tool to use for this purpose. I considered it so because as a form of communication, art is capable of integrating many different "agentic assemblages" (Spry, 2021, p. 168) into a nondialogic, translative whole (Crowley, 2022).

A further reason for the value of embedding this broader narrative in visual artworks, of the importance of telling this broader narrative in the first place, is again one of epistemic justice. The experiences of chronic illness are embodied experiences, the knowledge is embodied knowledge, and where writing stories is an intellectual exercise, making art is an embodied one (Holdsworth, 2022; Shusterman, 2010; van Katwyk & Seko, 2017). To have left out my body's own perceptions, to ignore the sensory insights of "blood, bone [and] bodies" (Spry, 2021, p. 169), would have been to also ignore a wealth of embodied knowing (Mitchell, 2018). This would not have included the fullness of both the 'auto' and the 'ethno' elements of my experience in as much evocative narrative depth as I was able to include it (Minge, 2006). As Guyotte et al. (2018) found, art practice *expands* autoethnographic storytelling.

The visual arts are not the only tools of expressive narrative used in *A Cipher for the Falling,* a twinned series of poetry fragments are also included. This too is further elaborated on in the following exegesis, but the reason they are included here is to serve a similar function that a visual illustration would in a prose narrative: to support, contextualise, and ground the artwork. That is, the art is the focal narrative, the poetry fragments the illustrative feature, and both combine together as evocative pathways into the full autoethnographic story.

Finally, and to circle back to our introduction and the question of ethics of self (Edwards, 2021), telling the broader narrative that is contained in *A Cipher for the Falling* is a personally important one. I call this collection of art and poetry the heart of my research, not because it is the most important element - I believe the whole would be much weaker without any one of its constituent parts - but because the many hours spent drawing and painting and collaging words and pictures were fulfilling, engaging, and even revelatory. I agree with Guyotte et al. (2018) who suggests that this type of creative performativity need not be an aside, an obstacle, to academic work, but can transform it. And though it would be a stretch to say that the art saved me, it did pull those hidden moments (Muncey, 2010) of my embodied experiences back from the hell of pain, out from the purgatory of fatigue, and reconnect them both to the creative vitality of living.

A Cipher for the Falling: Exegesis

A Note to the Falling

In her book *The Sound of a Wild Snail Eating*, author Elisabeth Bailey (2010) writes that "being homebound in the human world is a sort of vanishing" (p. 117). This was a phenomenon we all experienced to some degree during the early years of the Covid-19 pandemic, a social invisibility, a silence, a global stalling. Much of the artwork presented here was made during that period, and I dedicate this book to all of our past homebound selves .

The Academic Context

A Cipher for the Falling is a collection of paired "cut up" poetry fragments (Kleon, 2010), and collaged self-portraits that collectively represent various aspects of a chronically ill body as experienced over the years of researching and writing this Ph.D. thesis. It features brachial neuritis as the central disabling diagnosis but includes other aspects of multimorbid disease that were considered important to the representation and understanding of complex, ordinary, and fragmentary embodied knowing.

The decision to include a curated selection of artworks in an evocative autoethnography is closely linked to this complexity, to the challenging (Donnelly, 2021), messy, and paradoxical lived experience (MacGregor, 2023) of chronic illness and disability. It is sometimes difficult to represent these kinds of experiences well with conventional qualitative methodologies because when we describe an experience, we also inevitably edit some important aspects of that experience out, we focus our narrative on a just a few threads of knowledge at the cost of the many other threads that make up the warp and weft of a larger, more vibrant, complex and paradoxical life. As Donnelly (2021) writes, “those who are truly living the chaos… cannot tell [the] words” (p. 3). If we think of bodies more as sites of *knowing* than of *knowledge*, as an active verb rather than a concrete noun, a temporally layered palimpsest (Maioli, 2009), then it becomes easier to understand how embodied knowing can be difficult to reduce to language (Butler-Kisber & Poldma, 2010).

In addition to this limitation of language, there is also a limitation of culture. We prefer narratives of illness and disability to be inspirational rather than quotidian, insightful instead of muddled (MacGregor, 2023); Frank’s (2013) “restitution” and “quest” narratives, over the difficult non-linearity of “chaos”. While Frank’s narrative categories can be argued to be somewhat simplified and are not necessarily mutually exclusive (Ellis et al., 2011), it is helpful to understand, at the very least, that western storytelling paradigms do favour narrative resolution (Donnelly, 2021).

This is an important consideration, because qualitative research articles are steeped in this same tradition, but the embodied knowing of chronic illness and disability can never be ‘resolved’. There remains, therefore, a lack of representation of stories that reflect the “chaos”, the shadowed complexities of chronically ill and disabled bodies, which adds to the cultural bias against representing these lived experiences accurately and with less erasure (MacGregor, 2023; Patrycja, 2012). Accuracy is an important component of academic criticality, and representation a specific value of autoethnography, and these are two significant contributing reasons for including a muddled and fragmented depiction of my own experience in this thesis. Equally importantly, however, I also believe such representation honours the unspoken stories of the ill and the disabled more authentically (MacGregor, 2023), offering recognition and respect for those without voice who are judged by the values of a culture that prefers either cure or inspiration. Such inclusiveness is an important value for autoethnographic research (Boylorn & Orbe, 2014), but also disability research to which this thesis is also aligned.

If language is a limited tool for expressing embodied complexity, and western storytelling norms are yet to embrace non-linearity, then the creative arts can be argued as tools to communicate these more effectively (Gerber et al., 2020), and with greater potential for dissemination (de Rijke, 2023). The creative arts are neither new nor novel modes of human communication, with the visual arts particularly being part of our species' culture even before the construction of language (Zaidel et al., 2013). As Eisner (2008) says, art evokes empathy, providing emotional and sensorial access to the borders of experience that are not necessarily our own. When we see Munch's "The Scream", for instance, we immediately and viscerally understand something of anxiety, or at least connect something of ourselves to Munch's depiction of it. To put this another way, we can quantify and qualify *knowledge*, but *knowing* must be experienced.

The inclusion of various creative methodologies is well established within autoethnography (Bartleet, 2021), where their evocative and sensorial qualities are welcomed and encouraged (Bochner & Ellis, 2003). Of specific relevance to *A Cipher for the Falling* as an autoethnographic piece is the idea that when we create a piece of art we are engaging a particular sense of self, or a “recalling of self” as Levarage describes it (2023). Creating art does this by providing a focus for such engagement (de Rijke, 2023), and a freedom to do so also (Fenner et al., 2022), in that it allows us to physically express an aspect of experience in place of verbally explaining it.

I believe this also speaks to the potential concern that artistic representation is not a critical analysis (Stahlke Wall, 2016). Certainly, a poem or a painting is not of itself necessarily analytical or research, but in the context of a larger inquiry into the aspects of embodied knowing, it can perhaps be conceived of as a form of intrapersonal analysis. That is, when we create an expressive poem or a piece of visual arts around a specific aspect of our experience, we are engaging in an ongoing conversation with ourselves, with our sense of self, into what is to be represented, how we want it to be represented, whether there are aspects of that representation that are weaker, stronger, or need to be further edited, how to create an entry into the represented knowledge for others. We are asking questions of our own experience and answering those questions with the analytical choices made in crafting a particular piece of artwork with as much depth, nuance, and criticality as one’s technical skill allows. As discussed previously in relation to creative non-fiction writing, this aspect of analysis in creative artworks is largely hidden, or unnoticed, and as such can be too readily dismissed as non-academic and even self-indulgent (Stahlke Wall, 2016).

Autoethnography is not focussed solely on the self, of course, but must also speak to the social, and it could be argued that connecting to a sense of self (Lucas, 2020), or the expression of hidden and shadowy aspects of lived experience, is not enough overt connection to the social to be useful in an academic context. However, the knowledge of self is an inherently social knowledge (Hodgetts et al., 2020), and I cannot express an aspect of my own experience that is not also an expression of the broader cultural constructs and contexts in which I am personally situated. As stated, many of the difficult and shadowed experiences of chronic illness and disability are kept hidden because of the social inhibition as much as the language limitations, and so creating expressive art from these experiences, however intimate and unique to me, is also very much a comment to and of the social.

The Personal Context

As mentioned in earlier chapters of this thesis, shortly after my doctoral studies began I experienced a second and life-altering reoccurrence of brachial neuritis, one that initiated a permanent disability in my left shoulder, and alienated me from my body in a way that no other diagnosis had done before. For a very long time everything I did caused me significant pain, and I couldn't sleep, or focus, or inhabit my life in any kind of a way that I was able to recognise as *my* life.

Except when I created art. When I drew, or doodled, or painted, I could distract myself from pain and focus on the shape of a line, or the subtlety of colour; I could paint myself back into some kind of connection with the world.

I found myself painting bouquets of flowers, often, for their sheer life-affirming vitality I think, in retrospect. Or portraits of imaginary women, sad women, sad women with vibrant clothes and unlikely coloured hair. I gave these women all names, personalities, the occasional abstract personification: this one Endurance, that one Calm, the others Courage, Curiosity, Patience. My personal divine tutelary, my own imaginary garden of Eden.

Over the same period that I was painting these pieces, I would also take self-portrait photographs when I was having a particularly difficult day in any one of my multimorbid illnesses. Sometimes these were to catalogue new symptoms for a medical practitioner, but mostly they were an anchor to the truth of that particular experience on that particular day, a concrete reminder of a state of being that would fade into unreliable foggy memory without such a record. I needed to remind myself that these experiences were real.

These photographic self-portraits also represented my frustration that the fullness, the entirety of my embodied experience, was not being seen or understood by anyone other than myself. The illnesses I lived with were often represented as discrete diagnoses with solid borders to contain each one in the literature I was reading, in the doctors' offices I was visiting, in my conversations with friends, colleagues, family. No-one was fully witness to the messy interconnected inseparable multimorbid experience that I was living. Though brachial neuritis was my most life-altering diagnosis, and the main focus of much of my doctoral research, it could not be understood as an experience of embodied knowing, of *self*, without connecting it to and with the rest of the multimorbid diseases that co-existed in this same body.

This was not because I was not loved, was not paid attention to, did not have a voice. Rather there were simply too many complex, fragmented, chaotic and messy interconnected experiences to be explained adequately with the tools of written and spoken language; I would need to comment on most aspects of most of my days in order for the interconnected complexity of living with multimorbid illness entails. For this reason, including a work of arts-based research was not only a useful means to expand embodied knowledge, it was also, I believed, necessary. Without it, I would be knowingly and purposefully erasing essential aspects of my embodied experience, telling a partial story that would, by omission, erase and mislead.

I could see when looking over all the paintings I had completed up to that point, and the self-portrait photographs, that I had created two dichotomous aspects of the same experience; the imaginary heaven of my painted gardens and my tutelary goddesses, whose job it was to connect me to my future and my hope, In contrast, there was also the more hellish experiences captured in the self-portraits, pictures of my worst experiences in my worst moments, whose job it was to connect me to my body and my despair. Neither were more true, both were better understood in contrast to the other.

In addition to the paintings and the photographs, I had also collected anatomical and medical illustrations from old medical textbooks. I considered these important to the larger social context an autoethnography must connect to as a medical lens on the embodied, and I was inspired to begin to collect them after an MRI scan of my inflamed nerves inspired a friend to see a representation of mythology’s Green Man hidden inside my body. I became interested in the ways that medical illustration reveals and conceals the diseased and disabled body, what is left out, what included, the “clinical authority” that such illustrations represent (Barnett, 2014, p. 22). If my paintings were a relief from suffering, and the portraits represented the depths of suffering, the anatomical drawings were a form of clinical judgement on this same suffering.

I had my raw data, then, representations of my illnesses as experienced over time and through differing but related lenses on self.

The Artistic Context

No work of art is created in isolation, or without the inspiration of other artists, and *A Cipher for the Falling* is no exception. I can cite many artists as influences on the finished paintings, but the main threads of inspiration are Cy Twombly, Frida Kahlo, Fernando Vicente, and the illustrations found in medieval manuscripts.

Cy Twombly is an abstract artist of the 20th century, renowned for large abstract art that often represented mythological figures. He was known to work and rework his canvases, leaving traces of previous marks, creating a visual palimpsest of his artistic process (Bird, 2007). The expressiveness of his mark-marking and the temporal traces he chose to leave in the finished pieces, inspired me to include elements of both of these in my own artwork, not for their own sake (though this personal resonance would be reason enough), but for the evocative emotional connection these techniques often inspire in viewers of Twombly's paintings. As Bird (2007) says, Cy Twombly's work is to be experienced rather than evaluated, and if my goal was to illustrate aspects of shadowed experience that language is unable to express, then expressive mark making and the creation of a temporal palimpsest would be a useful aim towards this end.

The connection between my experiences and Frida Kahlo's work is perhaps more obvious in that she is famous for self-portraits of a body that lived with significant and ongoing pain. However, it is not her paintings that were a direct inspiration here, as beautiful as they are, but my inspiration came, instead, from a reproduction of a diary she once wrote, a diary filled with doodles and poetry and messy unrealised paintings. A particular inspiration from this diary is a haunting vivid self-portrait she doodled of herself on which she scribbled "I am disintegration" (Kahlo, 2005, p. 41). The power of her pain in that moment showed me that fragments and incomplete visual ideas could be useful and even fundamental to convoking "a whole universe out of … [ones's] own self" (Kahlo, 2005, p. 15). It was this kind of raw poignancy that I was inspired to adapt for use within my own work.

I had not known the work of Fernando Vicente before I began my thesis, but discovered his paintings while I was searching for artwork that was medically illustrative without being a medical illustration. I found such pieces in Vincente's work, particularly his collection entitled 'Vanitas', where he paints women in beautiful clothes as if they were on the cover of a magazine. These are no ordinary glamour portraits, however, as Vicente also draws back the skin on a part of his model - her face maybe, her chest - and paints the underlying anatomy in careful visceral detail. I found the juxtaposition of the traditionally beautiful with the somewhat macabre deeply moving, and somehow, in ways I still struggle to articulate, representative of my own embodied experience. They were unexpected, a little disquieting, and truly marvellous in the sense of invoking wonder. As it says in the introduction to his self-titled art book, his work "progresses from vulgarity to poetry, from the prosaic to the poetic" (Vicente & Riano, 2014, p. 8). As with Kahlo's fragments, I found Vicente's combination of the vulgar and the poetic to be a useful way to illustrate the poignancy, and perhaps even grief, of a chronically ill and disabled body.

Medieval illustrations are another important inspiration, and I particularly related to the penchant of Monks during this period to draw ridiculous and imaginative creatures in the margins of the manuscripts: rabbits riding lions, foxes reading books, cats with elaborate crowns on their feline heads (Barber, 1992). Knowledge in medieval communities was not scientific, it was not empirical, reproducible, falsifiable, but commonly imagined (Barber, 1992), and it was this link to human imagination that I was inspired by. Deciding that there be dragons somewhere, does not, of course, mean there *are* dragons anywhere, but it can and did shape how people lived and believed if they *imagined* there to be dragons.

I am also influenced by the humour in many of these medieval doodles; it is my belief that acknowledging levity as part of the fullness of experience, even the experience of illness and diability, is important. I believe that human imagination in all its forms, including the ridiculous, is a powerful tool in the construction of a vital and dynamic lived experience, one that includes and embraces all of one’s self, and does not seek to cure, or judge, or ignore the frailty of entropic flesh that we are all, in some way or another, heir to. Medieval monsters remind me that the imagination is a powerful creative tool for constructing an identity, a worldview, a way of living, and that the ridiculous can be as sublime as the sublime is ridiculous. For these reasons, I was inspired to include humour and fantasy in the finished artworks where they were appropriate to the visual narrative.

It may be noted that a common thread through all of these inspirations is a sense of the grandiose combined with aspects of the banal: Twombly’s mythologies contrasted with his loose abstractions; Kahlo’s universe of self (Kahlo, 2005) contained in an informal, fragmented diary; Vicente’s glamorous women juxtaposed with the decidedly unglamorous depiction of their internal body parts; the strict precision of medieval calligraphy as it sits next to wild portraits of trumpeting rabbits. This was not an intentional connecting thread, but it is a representational one. The gardens and goddesses I painted, the portraits of illness I captured, and the anatomical illustrations I collected, were all contrasting and contrary reflections of a larger, broader, messy and shadowy embodied experience; the next question then became how to craft these various influences and heterogenous data into an expressive and evocative arts-based whole.

The Process

According to Kenower (2021) craft is just a way of asking the right questions, and for reasons already explained, the questions in *A Cipher for the Falling* centre around how to represent the parts of my embodied lived experience that language is inadequate to reach, the parts that are felt but never spoken, and if spoken, rarely understood, in a way that is honest without being overwhelming, that invites participation and empathy rather than antipathy or dissociation.

Collage was an obvious choice to combine the disparate into a coherent whole, and a medium that has deep roots in qualitative methodologies (Lahman et al., 2020), one that works with varied data as “ideas in conversation” (de Rijke, 2023, p. 2). The process of collage is itself a type of analytical process; as Archibald and Blines (2021) describe it, taking notice of the data you have chosen to utilise in the arts-based research process gives one some insight into the thinking and development of the artworks as they progress from inchoate fragments to a fully realised piece of art.

Collage can handle disparity; indeed it embraces it, and has even been described as a form of “wunderkammon”, or “cabinet of curiosities” (Benozzo, 2020, p. 151). As such a metaphorical cabinet, it can be used to highlight meaning of the curated parts of the whole, meaning that is not, perhaps, found in the parts themselves, but in the interpolated relationships (de Rijke, 2023), the connections between (Archibald, 2022). Collage is not a literal representation, but a synecdochic strangeness (de Rijke, 2023), a provocation to societal norms (Richmond, 2022).

The initial plan was to create a straightforward traditional collage, but it became clear that the quality of the finished piece of art did not reach the evocative level I was aiming for. I needed more than a conversation between the paintings and the photographs and the anatomical illustrations, I needed a relationship, a convocation of self (Kahlo, 2005). I wanted the finished work to reflect the disparate fragments of the original data, but also combine into a new cohesive whole, a palimpsest of temporal experience that reflected the temporal and dynamic nature of multimorbid illness. While collage as a medium can absolutely achieve this kind of cohesion, I found that these collages, in this project, did not. The strangeness was simply too strange, too idiosyncratic, and did not allow a way for a viewer to connect to the experiences represented in the resultant art (see Fig. 1).

Fig 1 Early stages of a collaged piece

In contemplating how I could integrate the collaged pieces together without losing the sense of the original artworks, illustrations and photographs, without losing the temporality of the process, or the idea of collage itself, I looked to Rod Judkin's ideas of collaging one's own paintings into a figurative piece that can then be overpainted (in whole or in part) to create a new and evocative whole. He says:

> "Using painting and collage together invigorates the depiction of the human figure because of the unusual associations and dislocated imagery created in the dialogue between the two mediums." (Judkins, 2016, p. 7)

That is, this technique can further the conversation of a collaged piece, rather than erase it, and it was this extra layer of artistic communication that I believe my artwork needed to become the resonant, integrated convocations of otherwise hidden aspects of lived experience (see Fig. 2).

Fig. 2 Resultant figurative painting with collage

Rather than using physical paint as I did with the original pieces of artwork, I integrated these collages with digital paint brushes, as it was easier on my damaged shoulders to overpaint 36 pieces of artwork with these digital tools. Drawing over the collaged pieces with pen on screen in some ways also reflected the original doodling of the early days of extreme brachial neuritis pain where I would sit for hours and simply draw as it was the only thing I was capable of doing at the time, but where that past doodling connected me to a world I felt little part of, this time it was a way to reach back and connect at a sensory embodied level to that past suffering self. It was my aim, and is my hope, that this connection is reflected in the finished pieces of art.

Poetry Fragments

Alongside the 36 figurative collaged painting there is a paired collection of 36 poetry fragments. To understand their place and value in *A Cipher for the Falling* it is important to remember Archibald and Bline's (2021) description of arts-based research as a reiterative experimental process, and to relate this to the tensions felt between embracing this process as an artist, and needing to describe and justify research aims and progress as a doctoral student.

When asked to describe the proposed outcome of my arts-based research, the concrete form it would take, the goals I wished to achieve in creating it, I engaged my academic training and looked analytically at the possible forms *A Cipher for the Falling* could take as it related to the evocative autoethnography research space I had positioned my thesis within. After much reading, debate, and consideration, I decided to utilise the artworks as illustrations in a research version of the children’s “Choose Your Own Adventure” books. In these books, a reader is given various options on each page that change the outcome of the story path they are currently reading; if you decide to do choose one path, you turn to page x, pick the alternate path and you turn to page y, and so on until you meet one of the many and various ends to the many and various possible stories. On coming to such an end, you can return to any place in the narrative you wish and try different choices in pursuit of a more favourable, or at least different, outcome.

These books are an interactive experience designed, as their creator describes, to allow children the opportunity experience danger and failure in a safe learning environment (Karunatilaka, 2023). While I was not aiming my research at children, and neither danger nor failure were part of the imagined storylines I would include, I saw this format as an innovative and interactive way to share the everyday experience of multimorbid illness with a given reader. For example (and overly simplified) *you have a migraine but there is work you must complete by tomorrow: if you choose to carry on and complete the work, go to page 24, if you decide to take pain relief and sleep instead, turn to page 49*. On each of these pages would be a further choice until the story wound back up on itself and you had to start the process all over again. In this way, the unrelenting, complicated and interconnectedness of my own lived experience would, to some small extent, be able to be experienced by anyone who desired to read the resultant book.

I did write this book, made it the same standard 15,000-word length of the original children’s books, placed the artworks in appropriately illustrative places, printed myself a copy to read, and discovered, to my great dismay, it simply didn’t work. The narrative was too directional, it flattened and obscured the art, it told a reader what to think of the pieces of art without leaving room for empathy and connection. The problem was, I believe, that where I had allowed the cyclical and reflective process of arts-based research to lead when I created the figurative collages, I had not done so with the accompanying narrative. In working toward a known end point, this had centered my experience at the expense of connection.

I had three options going forward: I could submit the book as it was; I could leave out the written work altogether and include the artwork as a complete experience in and of itself; or I could accept that this was just one stage in ongoing process and keep working toward a finished product that would more closely reflect the sensory and empathetic outcome I had always intended to aim toward.

I chose the latter, for two reasons: firstly, although the story I had written flattened and sidelined the artworks, when experienced in book form by themselves these same artworks *too* open to interpretation for an academic work, and that the experiences they had been created to represent were still somewhat erased without a form of narrative tether to give them context. Without this tether I could not be sure I was, as Pelias (2019) suggest autoethnographers must, reflecting my experience as authentically as I was able.

Secondly, there were clearly aspects of the abandoned storylines that I had believed important at the time of writing, and thus were now a new set of data that I could work with to create that narrative tether.

I decided to create paired sets of found poetry fragments as a form of linguistic collage to mirror the figurative painting collages. Found poetry has a long history that dates back to the beginning of mass-produced newspapers (Kleon, 2010), and is also not new to autoethnographic research with Faulkner and Ruby's (2015) collaboration of creating found poems from emails as one example of this.

As with visual collage, the unexpected relationships and encounters between ideas that may not have been otherwise uncovered is a strength of found poetry, and to build on this strength, and to further the connections between the poetry collages and the painted collages, I included three sets of data here also. The first and most important was the narrative storylines I had written for each piece of artwork; each work of found poetry was focussed on the specific narrative originally written for it, and this set of data was analogous to the original artwork I included in the painted collages. The second set of data I used for the poetry were medical letters and referrals written to and about me as part of the process of confirming a diagnosis of recurrent brachial neuritis and can be thought of as analogous to the visual information contained in the self-portrait photographs. Thirdly, the same anatomical and medical illustration books that I used in the collaged paintings, I also used in creating the poetry fragments, as a direct link between them, and for the same contributory reasons.

The mirroring of these data sets was satisfying in terms of creative balance and harmony, but of greater importance was the room that they created for the emergence of strangeness (de Rijke, 2023), and non-linear intuition (Archibald, 2022), that is so important to the success of a collaged work. An instance of this can be found on page 140:

"Brachial neuritis

is kind of a boring topic

some mid and lower cervical nerve roots

just large enough to squeeze

a little disenfranchised tenderness through."

The original narrative storyline was on an aspect of brachial neuritis, and the accompanying artwork shows a piece of the shoulder torn out as representative of this, along with a mouth sewn shut in reference to the erasure of experience that comes with having to explain said experience. I included the phrase "some mid and lower cervical nerve roots" from a letter sent to me by my neurologist, and I had also written a note to myself on the original narrative to include a mention of disenfranchised grief in further revisions. The phrase here, however, is 'disenfranchised tenderness' instead of 'disenfranchised grief', because on seeing the word tenderness in the same neurologist's letter, I believed that it captured the sentiment I was wanting to express more precisely than 'grief' did due to its double meaning of something that is both painful to the touch, and also an expression of kindness and affection.

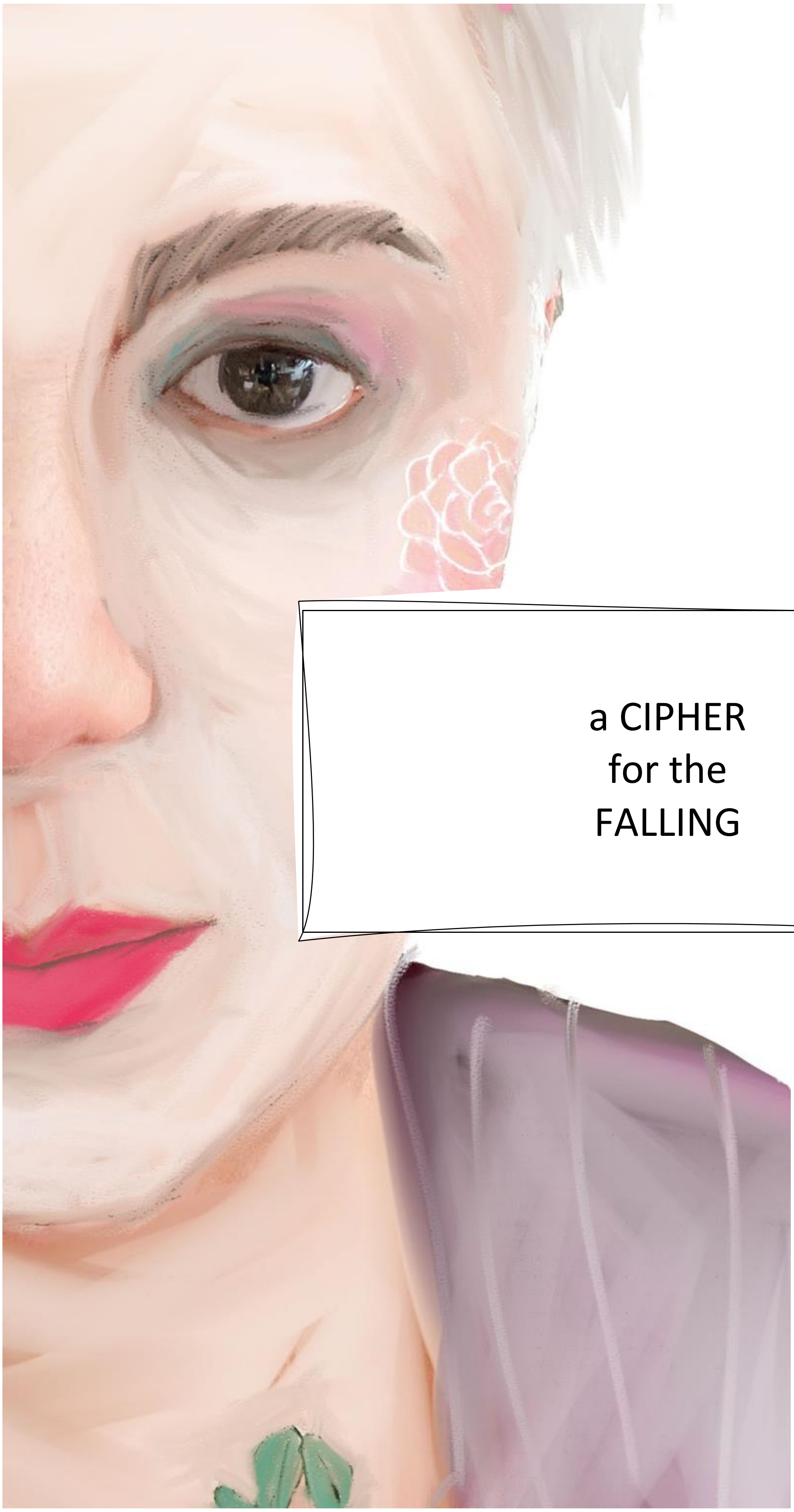
Without the inclusion of the additional letters and anatomical descriptors as useful data, this kind of word play would have been much harder to achieve, and the resultant collaged fragments much less psychologically resonant and poetically lively. While language can erase complicated experience, if treated artistically (Eisner, 2008), it can also provide a useful touchstone as context for the same.

In Conclusion

If chronic illness erodes connection (Brown, 2002), art can become a bridge that reconnects the individual to a lost sense of self (Levarage, 2023), and to a society from whose company the ill and disabled may be said to have fallen (Titchkosky, 2007). As important as connection is, it could be asked what significance this connection holds in the context of academic research, what the difference is between an artwork created for its own self-contained sake, and an artwork created as a piece of arts-based research?

As argued throughout this exegesis, embodied knowing is difficult to explain adequately with the tools of language (Donnelly, 2021). Each piece of fragmented poetry and painted collage included here was created and curated carefully to represent an important aspect of my multimorbid experience, such as a particularly impactful diagnosis, an impactful encounter with medical personnel, a recurrent daily grief, or a memorable quotidian joy. They are fragmented and nonlinear, because my experience is fragmented and nonlinear; they are visceral and embodied, because my experience is visceral and embodied. I decided each piece was finished when it evoked a particularly emotional response in my own viewing experience, as emotions are a key to empathy, and empathetic connection is what I had spent so much time working toward. If art is experience (Minge, 2006), and experience a form of knowing (Eisner, 2008), utilising the twin skills of analysis and craftsmanship to create connection in arts-based research contributes toward human knowledge and understanding. This is a challenging academic space to inhabit (Bartleet, 2021) but it is also this type of mindful and contextual contribution that I believe is key to understanding and sharing the place and value of artwork in arts-based research.

In Ancient Greek mythologies, Chaos was a goddess of possibility, of all the things that could be, of the air between the divine heavens and the mortal underworld (Martin, 2016). She is, therefore, a goddess of the liminal, and it is in this chaotic liminal space that sits between the familiar narratives of resolution and inspiration that my experience of illness and disability is situated, that *A Cipher for the Falling* is placed. While my illnesses and disabilities are often seen by others as a weakness or a flaw, and arts-based research as secondary to my analytical work, I experience both in combination as a powerful lens on aspects of human behaviour, on embodied living, that are often hidden in the shadow of complexity and shame; the erased and erasable ghosts of the academic research machine. It has been my ongoing goal since I began my research career to find and understand these myriad hidden ghosts, to bring them back into the examined company of the full width and depth and breadth of human experience. Children of chaos they may be, unimportant they are most definitely not. If academic research does indeed need more stories of the complexity, mess, unresolved and complicated experiences that is inherent to living with chronic illness and disability, it is my great privilege to offer this small contribution to such a story, this one specific cipher for the falling.



a CIPHER
for the
FALLING

make a note of what you remember

the different types of silence.

repair the holes,

correct the furrows

and

hold weakness as best as you can.

You tried hard,

You'll fool *them next time*.

what about the time you spent ages, years
catching so many Damned gifts of hope

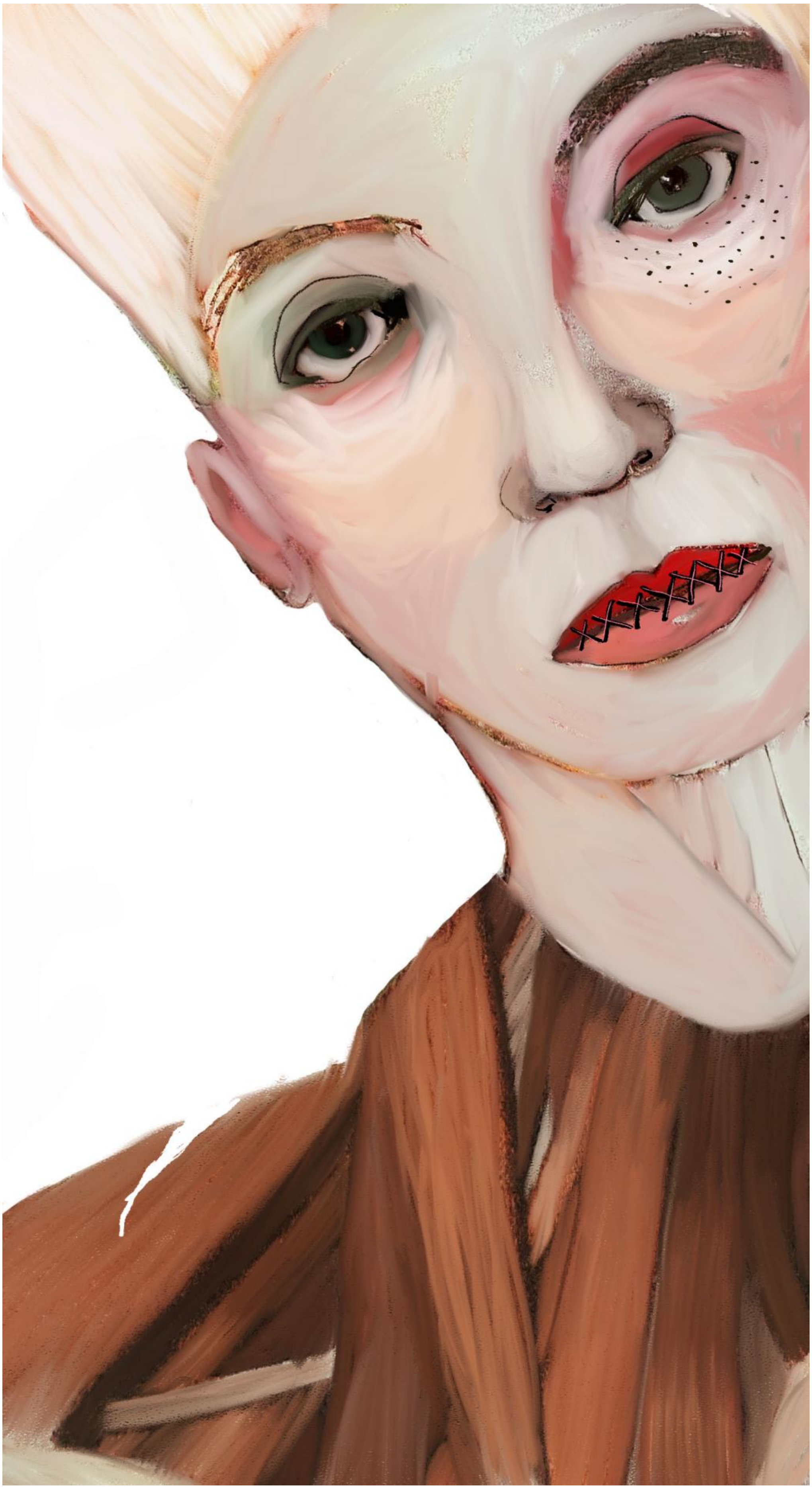
a family pathology of trying.

You don’t bother anymore. You’re no longer afraid of the darkness

You don’t believe desires work quite like sins
nor that the falling needs redeeming.

Brachial Neuritis
is kind of a boring topic,
some mid and lower cervical nerve roots
just large enough to squeeze
a little disenfranchised tenderness through.

You lost your *beautiful* nerve you said
and it kind of likely broke you



The imaging showed multimorbid toadstools
and extradural pockets of swamp shaped sleep

The worst thing about being so tired is you are so tired,
a temporal ghost of unimportant things

Not to worry,
The body is the site of so many mortal stories,
and all hope is a kind of
quotidian **grief**


THINKING

focus on your best smile
and not dying while your most red lipstick
carries on without you

What's the alternative?

life just keeps going on.

you are your own momento mori

and your favourite *lady Fates* appreciate the hell out of
such flippant mortality
They have decided on this rare occasion:

that you can indulge in memory and adventure
And the ancestors own hands

You wear knowledge of the morning well, my friend.

marathon on.

loneliness has a great deal to do with
all the secrets you keep,

It's a bit awkward to talk about
like a slap from the past
like drops of sweat,
and possibly slightly lachrymal

No answers.
That's all.

One day you wake up and you are

a *little bestiary creature*

Unhelpful, discomforting, exclusionary

you're still vulnerable

It's kind of a good warning sign to slow down

and take a breath, actually,

or it would be if

you paid attention to that type of thing.

urticarial vasculitis.

Just another *Shame* to live with.

It's not all sickness and woe all the time

there are gardens and paintings
and blob fish : even Sometimes

fractals of uncertain Sparkles
drawn upwards ; to wonder

, not exactly a triumphal new story
but considerably triumphant anyway

For those days when *the best floral dress*
is *only second best.*
and the petrous lizard
is somehow cracking through

resolve the day
risk the *backwards* plunge

it's not exactly your A-game
but
the functional's beautiful too

Happy Generic Medical Visit™ day!

Remember to get there nice and early because t

their time is precious

and you are not

You are a shoulder, or a head,

or fat

you could weep for the kindness of a caring human touch

but they are professional and no one's been assigned to *it*.

that's ok

you just need to understand

You visit your GP
(though you are too tired),
drive to have blood tests
get dinner on the table

You think you have a lung infection
but Surprise! it's your liver!
in need of a break,
time for a vacation

Okay, but
You're weirdly delighted to be exhausted
by something new.

liver

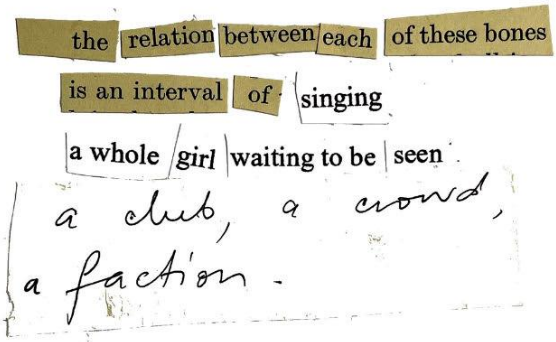
a dedication to the minor but frequent ailments
all flesh seems heir to.

that are not actually minor but
violent and painful *interruptions*

from an inflammatory squamous soul

stop everything and suffer

No choices today



the relation between each of these bones
is an interval of singing
a whole *girl* waiting to be seen
a club, a crowd,
a faction.

You're not Michelangelo.

painting faces. and flowers
doesn't pay your bills.

and You like to work
you have as much right to
stay fed and alive as anyone

don't you?

On methotrexate

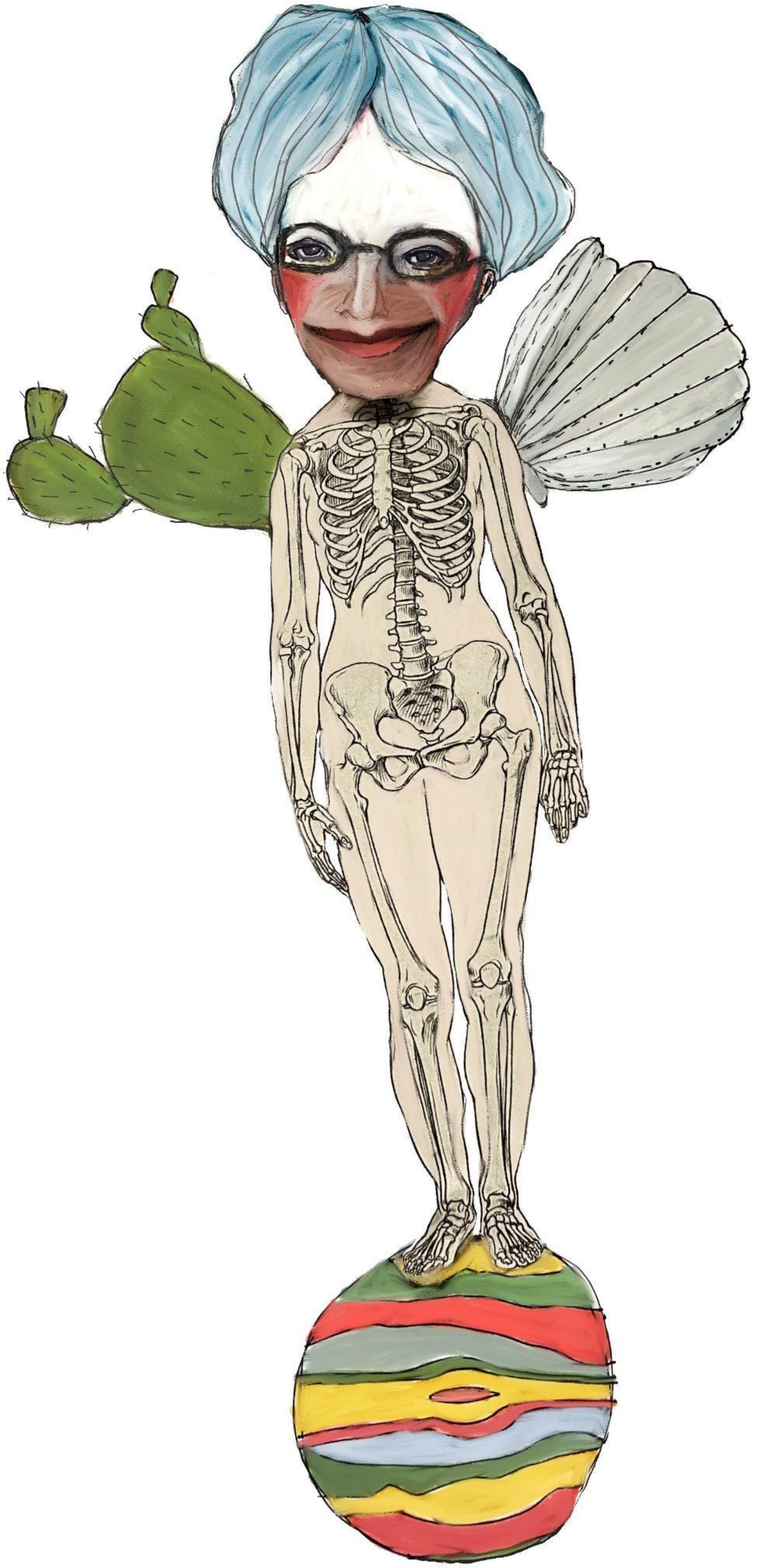
Every single Saturday you take it,
and every single Sunday you feel sick and exhausted,

an endurance effect that just is
why on earth

much of your body works beautifully well.
tonsils *thumbs* pelvis

intestines, appendix a nice wide heart
fingers, , lungs, and pancreas.

they are
fabulous top shelf functional parts
and you should certainly thank them



now *fall* *ahead*
put one foot in front of the other

all you want is for someone
to tuck your heart back into bed

to think about *your* ~~tired~~ skin
and wonder at the choice it took
to keep on limping outward

Well done

bake your self
a time off cake

these doodles are Corrupted
paralysed And disjointed

side-effects of sedation.
and new sensory alteration

perhaps they were a coven of
articulate mistakes
conflicting empty magic.

lines incompletely straight

(That's what you tell everyone

but
maybe
you just couldn't *let*
all those stories *die.*)

you can't bear to witness
your offspring suffer
the same genetic weird
you were born to

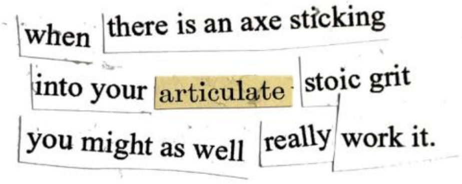
but dear heart,
you shouldn't confuse your self-worth
with their perfect

so its fine.

You never get questions on how a loss of
shoulder affects your every day life
you are not an athlete or a builder
or some being like that

You're left to sort it out for yourself

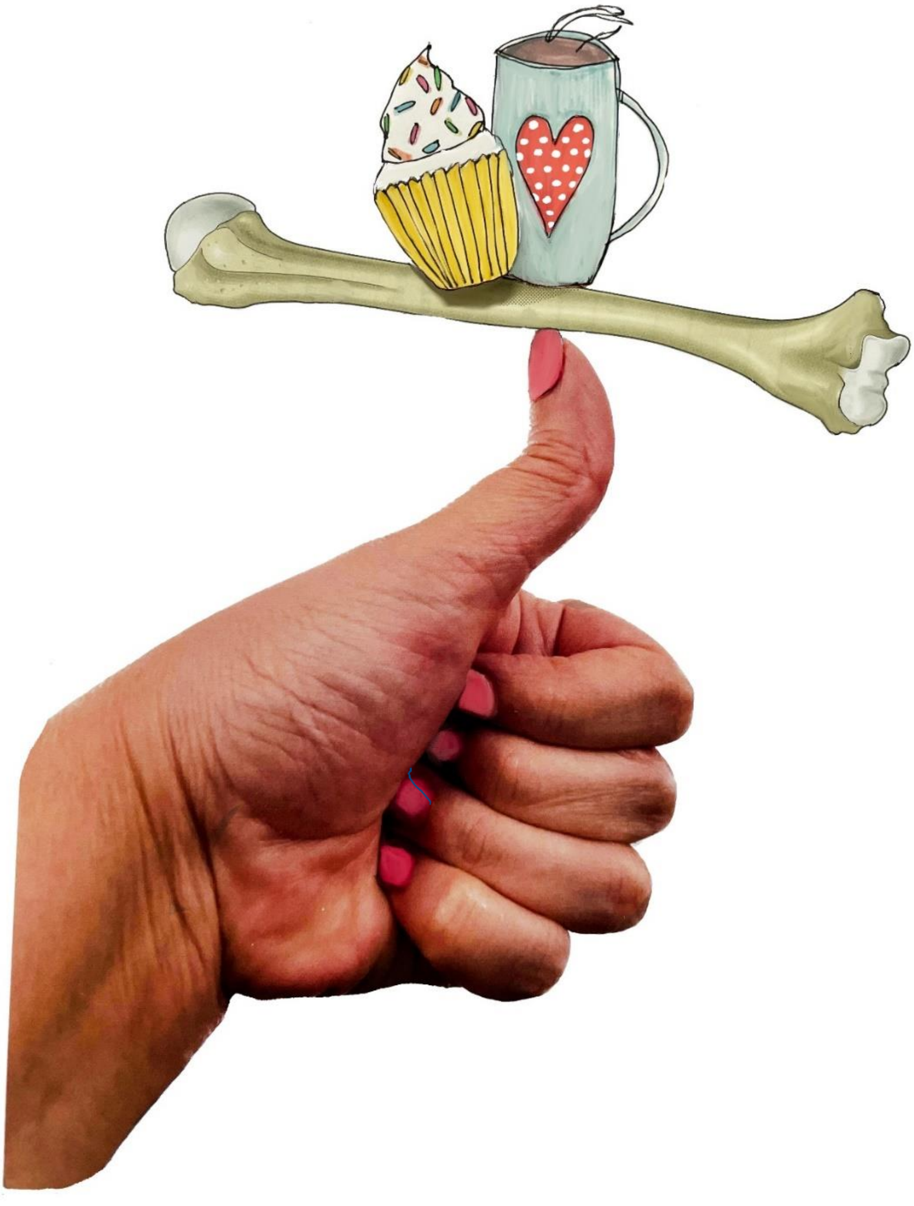
But you do use your shoulder
and
you could re~~a~~lly use some help



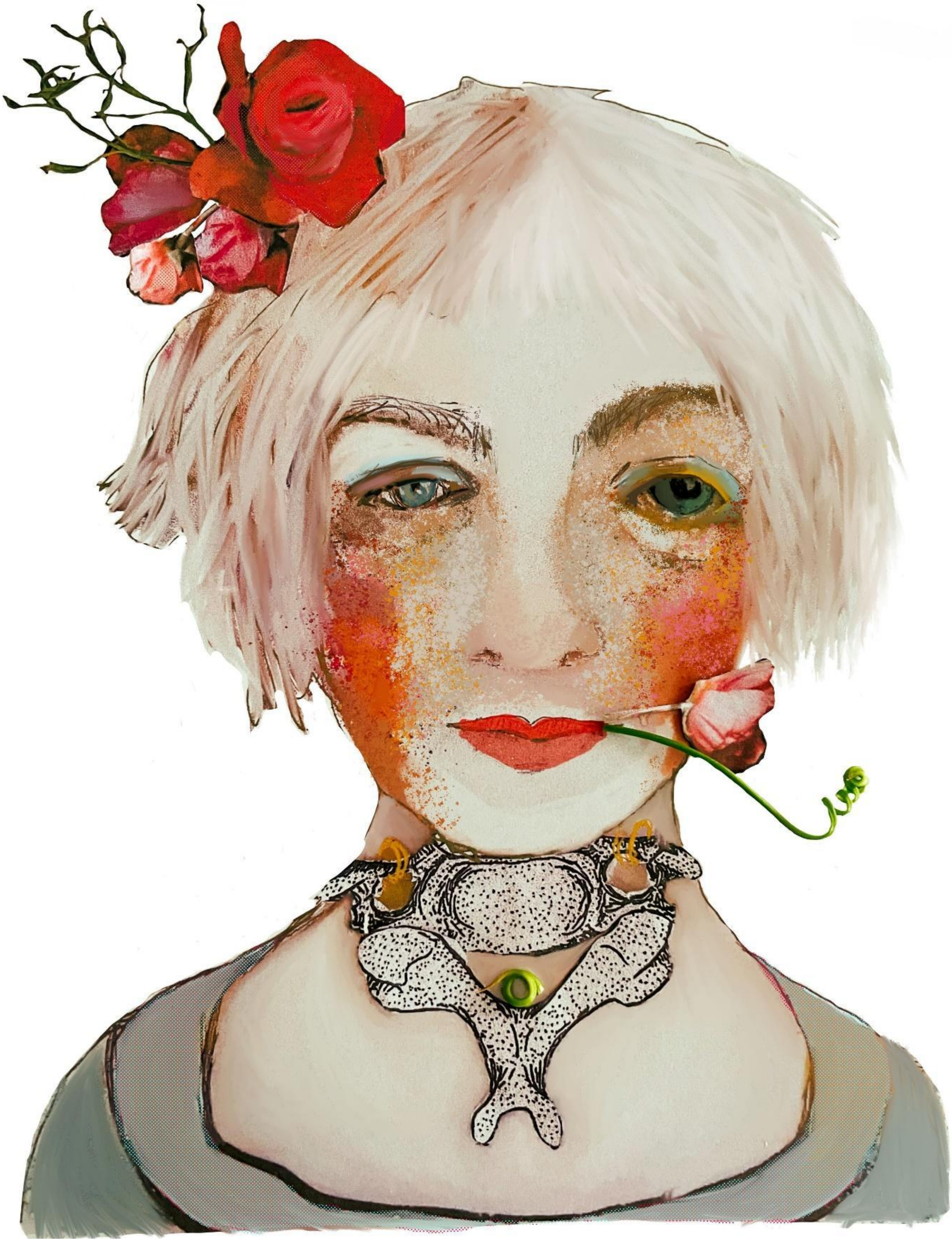
when there is an axe sticking
into your articulate stoic grit
you might as well really work it.

You don't juggle anything.
you're late and slow and lame.
so clamp *your fingers*
where *you can*
and *work* on faking *fancy*

Remember
that no-one is in danger,
but dropped *pride*
just feels 100 worse.



you can’t tame the Green Woman.
a symbol for the devil
wild leitmotif of *burning* Spring
paradox of the living
So,
forget eternity
and honour joy



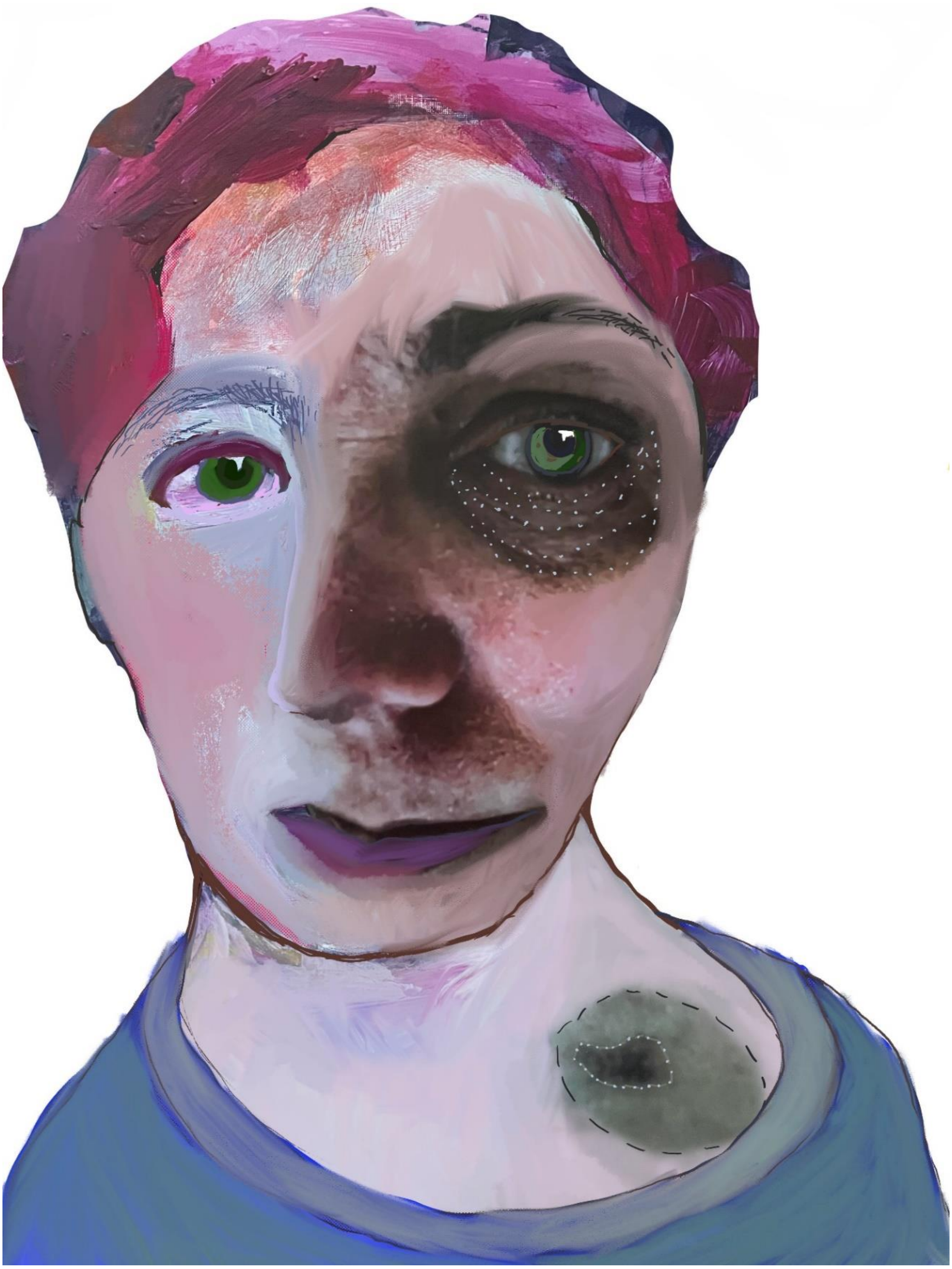
Haemoptysis.
is a word
that has an interesting lyrical ring.
But also

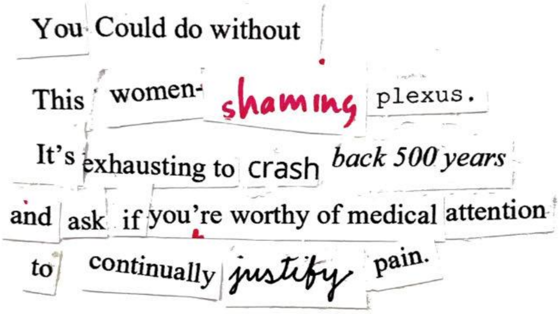
it's
The feeling of a
blood-drowning
relief

sometimes
in the moment
you bust apart
from jealous

How uncomplicated *it* must be.
to have just one diagnosis
to organise yourself around

You could choose
you could compensate
you could *focus*.

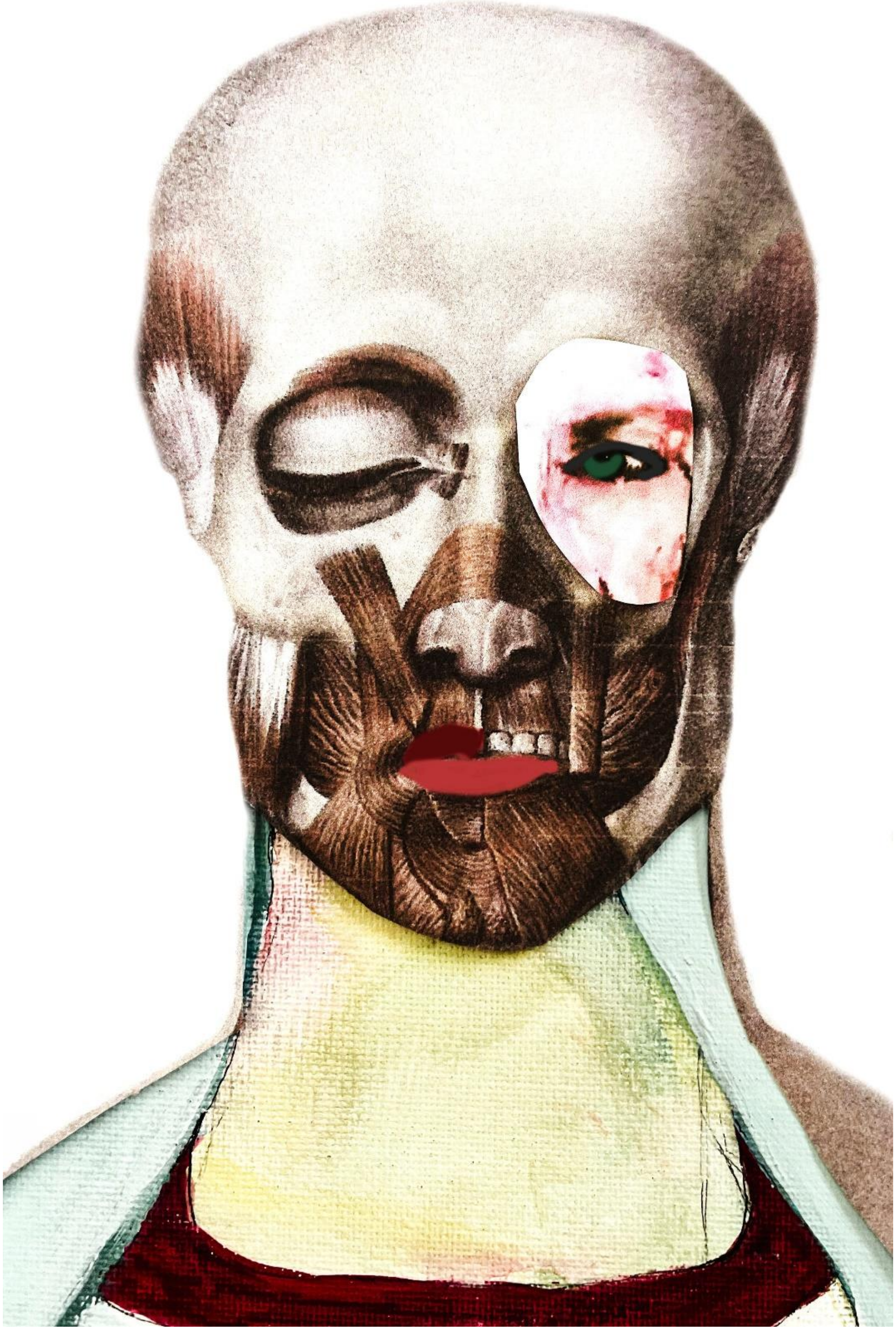




You Could do without
This women-shaming plexus.
It's exhausting to crash *back 500 years*
and ask if you're worthy of medical attention
to continually justify pain.

hold a thought
and build from it space for
the bones
the eyes,
the swelling of less

disjointed,
containing no plot at all
except the occasional fullness
of smorgasbord pain



unsolicited advice *gives you a headache*

Have you ever tried
Can I send you
do you think
Can't they give you
x, y, z.

to endure this
have a sit down
and a relapse *cup of tea*

rest is a luxury
that only the healthy
can afford


BUSY
chores
FRANTIC
working

making light of everything
keeps you from compound fear

you make up a
paralysed shoulder song
and laugh instead of rest

No-one laughs back.

the ‘Rona. Covid-19, SARS-CoV-2.

For a little while we were all suffering
An entire planet shut down

It was nice to feel part of the group again

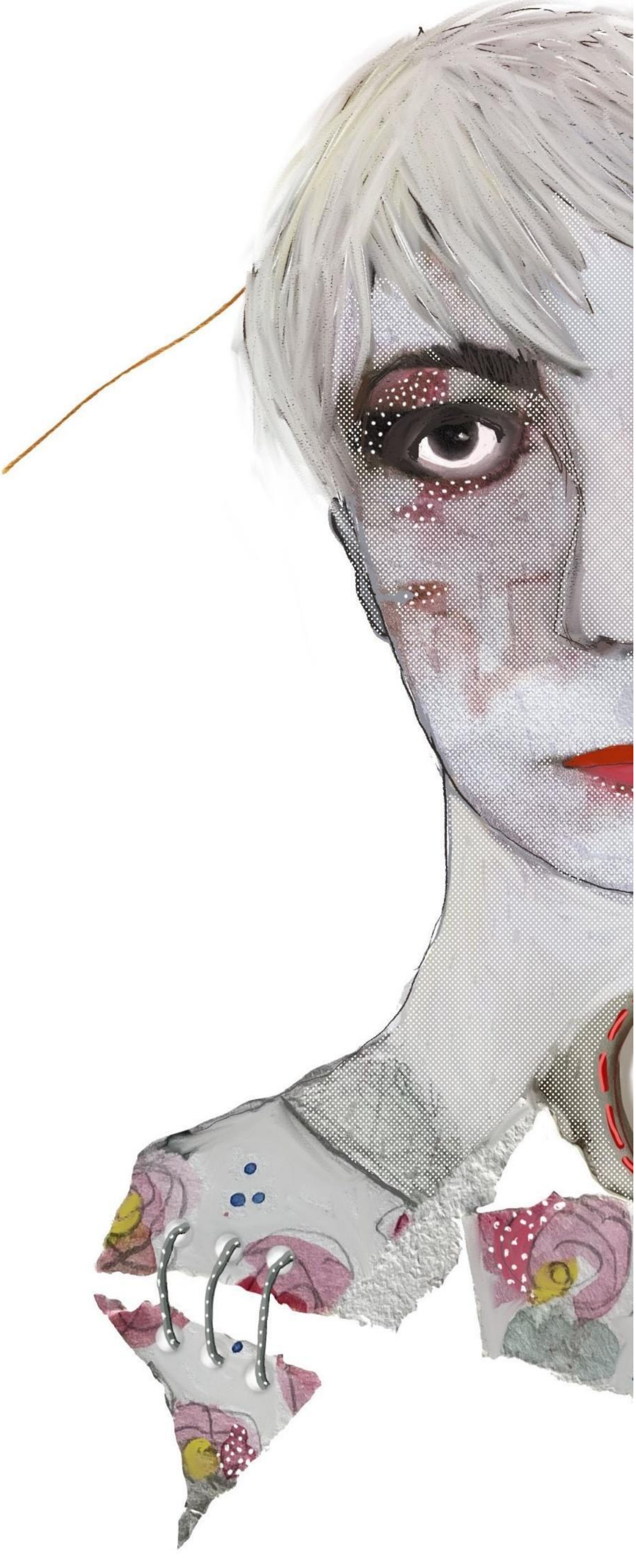
But now everyone is back
and you are *still* small and home

on a particularly bad day,
your life is made of poorly crafted pieces

held precariously together

with duct tape and thread.

The edges are fraying.



the magic of art t is not

a nice quiet nerve

but all of your body

listen*ing* loudly

It's a messy old complicated life,
full of merry covered in sorrow

a paintbrush of possibilities

and you're grateful for a story
that still continues to beat

CHAPTER 6

Conclusion

In the Beginning

Sometimes we write, as Dürig (2017) suggests, because our worlds have fallen apart. As stated in the introduction to this thesis, the stories contained in *Merry-Go-Sorry*: *An Autoethnography of Chronic Illness* were born from such a fall, created out of necessity, frustration, and an underlying unshakeable conviction that, despite the wreckage, my unwell body was a vital body, and my disabled body completely whole.

I was diagnosed with the recurrent form of brachial neuritis just as I began my PhD studies, when I was still in the planning stages of my proposed research. With a Bachelor's degree in English Literature, I had always been drawn to the literary qualities of ethnographic writing - indeed, it was the anthropological book *Comfort of Things* (Miller, 2008) that provoked me to think about a move from literature to the social sciences in the first place - and as I could find no personal stories of the lived experience of brachial neuritis in the literature, I proposed to undertake an autoethnographic study with this disease as the central organising focus.

My plan was a simple one: because I was still in the early stages of this chronic condition, I would follow the progress of the disease as it moved from a more acute stage of experience to a long term chronic one, writing the research stories of what I found as I went. Ellis and Bochner (2006) write that autoethnographic research is more about the journey than it is the destination, and Spry (2021) suggests that “doing autoethnography is what makes it autoethnography” (p. 170), so I was reassured that my exploratory approach was appropriate to the methodology.

Looking back now, I am bemused by my beginner’s naivete. It was indeed a simple plan. It was also a highly complex one.

In Review

Such beginner’s enthusiasm is not, I am sure, unique to me: as Bartleet (2021) suggests, the difficulty of writing an in-depth and rigorous autoethnography can be underestimated by the novice researcher. Having read a great deal of work from other autoethnographers before I started writing my own, I believe I appreciated the depth required as much as I was able to, but I certainly didn’t understand, in a practical sense at least, what was meant by autoethnographic rigour, nor how to achieve the substantial and ongoing reflexivity that characterises it (Koopman et al., 2020).

In many ways, the story of *Merry-Go-Sorry* is also the story of my gradual appreciation of the centrality of reflexivity in autoethnographic research as an analytical tool. It was my initial frustration with the narrow focus of findings in the pain literature that prompted me to step back and look at the research more holistically, recognising the fullness of my personal story within the broader collective. From there, I could see a way to structure a temporally situated, epistemically just, autoethnographic metasynthesis of pain research.

When I began to encounter significant problems writing about my experiences with chronic fatigue, I was prompted to look at the potential psychological obstacles I might be facing in doing so. It became clear that a sense of internalised shame over these experiences was inhibiting my ability to write, which in turn led me to a critical evaluation of the social roots of shame. In these roots I also found a connection to the potential benefits of imaginative knowledge (Kirmayer, 2006), and through these benefits, an unexpected way to write myself into a less problematic understanding of living with chronic fatigue.

With a background in both the literary and the psychological, contemplating the reason that experiencing shame was an obstacle to writing about it suggested I may need to look further into how such a story might be crafted, and if there was a useful methodological lesson to learn by doing so. As autoethnographic writing is connected to the literary (Denshire, 2014), and I had some familiarity with creative non-fiction techniques, I began to look for help to learn to write autoethnography better by learning more of how to write better. Watt (2007) suggests that every autoethnographer needs to write autoethnographies their own way, and this cross-disciplinary approach was how I learned to write mine.

Sergi and Hallin (2011) write that “research is a rich, complex and multi-level experience that mobilizes the whole person” (p. 192). The whole of my person included a multimorbid body, and one that had painted for pleasure and profit for many years. From my very first bout of brachial neuritis, I had coped with the worst of the pain by distracting my body with a paintbrush and canvas. This had become so integral to coping that I needed to include at least portions of these pain-painted pieces into the finished artwork, and from this starting point a process of figurative collage was utilised to build temporal landscapes of embodied pain, fatigue, and disease.

Gabriel (2015) suggests that our success as qualitative researchers is dependent on recognising possibilities, and Pelias (2021) that “digging into the personal is what lets the self unfold” (p. 123). In other words, we need to be reflexive in our inquiries and our critical analysis, and it is important in methodologies of connection and meaning to stay open to the possibilities of imaginative knowledge. Our stories of self are not, and never can be, recordings of experience (Brown, 2010), but are instead reconstructions of memories (Birkerts, 2008) and they require cognitive, embodied, temporal, and methodological introspection to bring authenticity, rigour, and resonance.

This is, I believe, what Spry (2021) meant by saying that autoethnography is defined by the doing of autoethnography. It was certainly by undertaking this ongoing reflexive research practice that I found my confidence and my place among the extensive possibilities of ways to do evocative autoethnography.

The Contributions Made.

An important and obvious contribution to knowledge that *Merry-Go-Sorry* makes are the personal research stories on the lived experience of brachial neuritis. These are the first autoethnographic studies of this disease that I am aware of. Though it is not a rare disease, it is also not a common one (IJspeert et al., 2021), and research approaches to date are very much from the biomedical paradigm. Because of this, adding an insider voice to institutional knowledge would not only be an original research contribution for this disease, but this addition of embodied knowledge to the voices of biomedical knowledge in this disease, is also a matter of epistemic justice.

Furthermore, vaccinations are a known possible trigger for brachial neuritis disease, and the mass vaccinations of the Covid-19 pandemic have increased the recorded incidents in the general population (Ameer et al., 2023). This further underlies the importance of adding experiential knowledge to the literature in this sparsely researched area.

Embodied stories of chronic pain are also underrepresented in the general literature (Birk, 2013), a lack to which *Circles of Hell* is specifically able to speak. This article is also a challenge to the biomedical conceptions of the acute/chronic pain divide as a function of clock time, instead of the way it is experienced by sufferers as embodied time. Written as an evocative and resonant narrative of this experience, *Circle of Hell* contributes to the literature by also representing the commonly dismissed voice of women who experience chronic pain, and in doing so builds what Ratzan (2014) describes as an imaginative link of empathetic listening between physician and patient.

To my knowledge, the concept of synthesising findings from the research on pain to support a timescaped story of lived experience is not a technique that has been used in autoethnographic literature, and as such it adds to the wider discussion of possibility in autoethnographic methodology, particularly ways it can speak to and with other research methods.

Witches Dance Backwards highlights imaginative knowing as a useful cognitive tool to challenge harmful social constructs. As part of this challenge, this article also confronts my unexamined assumptions that some important human emotion I experience in my daily life, such as humour and whimsy, are not serious or intellectual enough for inclusion in an autoethnography of chronic fatigue, even where they are an important part of the more truthful, the more authentic research story.

Hyland (2012) writes that “there is a pervasive tendency in philosophies of the body to explore the body as fully functional in health and as a state of pure incapacity in illness” (p. 93). Both *Circles of Hell* and *Witches Dance Backwards* are written in part as opposition to this tendency, which speaks to Richards’ (2008) concern that stories of the chronically ill and disabled can sometimes be at the expense of their humanity, and more expressive and vulnerable narratives are needed to counter this ‘othering’. To this end, Page (2018) also notes that although agency is commonly thought of only in relation to power, it can also have a dimension of representation, further supporting the value of adding to non-othering representations of the chronically ill and disabled.

This is an area where *A Cipher for the Falling* can contribute also: though it is not an immediately publishable research article, it is a goal to have it published in the future as a stand-alone book of art and poetry fragments. The representational element also contributes to knowledge in research of the lived experiences of chronic illness and disability, as it aims to show the hidden narratives of everyday experience that written explanations are said to erase.

Further, *A Cipher for the Falling* makes a contribution to knowledge with the inclusion of innovative arts-based methods. Arts-based research is an uncommon methodology in psychological research (Chamberlain et al., 2018; Miller, 2018), but it is not unproductive. As the artwork and poetry fragments in this book show, arts-based narratives can be used as an evocative and ethical means to communicate hidden and complex quotidian narratives of illness and disability, as they relate to many areas of the social world.

The artistic techniques utilised here are also of note. Though collage is a well utilised method in arts-based research (Archibald, 2022), the figurative collages developed in *A Cipher for the Falling* are a specific method that layers different art pieces over time, combines and interprets, then paints an integrative final layer to create a rich timescaped palimpsest of narrative and knowledge. Though this is a technique adapted from the artist Rod Judkins (2016), it is not one I have seen used in the same way in arts-based research. Given the potential for iterative deep reflexivity with this method, it may be worth further investigation for its narrative potential.

Denshire and Lee (2013) mention that the written self is an under theorised concept in qualitative research, and the work done in *Crafting Autoethnography* directly adds to the discussion on how the written self can be theorised. It does this by looking at ways the written self is conceived as a character in the creative writing literature, and applying this technique to autoethnographic writing as a useful reflexive technique. It further postulates that in constructing a piece of autoethnographic writing, the ‘ethno’ and ‘graphy’ can be thought of as corollaries for creative writing’s “situation and story” respectively. This is not meant to be a prescriptive theory, or one that is necessarily applicable across every piece of autoethnographic writing, but it is presented as a possible way to find authorial distance, particularly when writing important but difficult stories about the self which a writer may need to gain some authorial distance from.

Finally, and as a thesis overall, *Merry-Go-Sorry* makes explicit and implicit arguments for the value of aesthetic knowledge (Shusterman, 2010), including the concept of craftsmanship, as underutilised but important elements of arts-based and evocative research rigour.

Reflexive Notes

It would be somewhat disingenuous to claim reflexive rigour in this thesis without also acknowledging areas where, in retrospect, aspects of my research could be improved. The most significant of these is a lack of appreciation of the extra emotional labour involved in writing an in-depth inquiry about a newly diagnosed illness, an illness that I didn’t fully understand and hadn’t come to terms with yet. It was difficult to remove myself at times from the immediacy of pain, of grief, of concern for my future, to read and write on these same topics without descending into self-pity, self-indulgence, or overwhelm.

This was, as has been recorded, particularly problematic in the research on fatigue, which I had the misfortune to be writing during a global pandemic. The extra psychic weight of our collective fear and ennui was simply one layer too many to add to an already problematic topic, and for this reason the Covid-19 pandemic was not woven into the story of fatigue. The need for it to be included as significant to the overall experience was clear, however, and instead it became one of the hidden quotidian stories, the narrative moments, that is featured as a collage/poetry duo, catching some important reflexive slippage.

Another area of weakness, and one that is again related to the problematic nature of self-research on an unfolding illness, is perhaps a lack of theorising and reflection on the disability element of chronic illness and disability. How much permanent damage my shoulders would incur was unknown for a long time, and when it became clear that there was a serious long-term impairment (IJspeert et al., 2021), I did not have enough time left in my project to reflect on where I placed myself in the field of disability scholarship in enough reflexive detail. I was concerned at appropriating the language, culture, and identity of a marginalised community without being sure where, or if, I belonged to it.

As a more seasoned autoethnographic researcher, in the same circumstances I would choose to include more arts-based research in this project as way to provide some distance from the heavier emotional labour of cognitive analysis and adjustment to new life circumstances. To reiterate the introduction of *A Cipher for the Falling*, the process of making art is a source of solace and connection, a fruitful method of knowledge production, and an evocative narrative tool.

The view ahead

Over the course of this research project I was introduced to the idea of epistemic justice in health research, and came to be invested in this concept as an ongoing research goal. I believe that there is a lot more work to do in this area, and the aesthetic and artistic methods utilised throughout *Merry-Go-Sorry* can be borrowed, adapted and expanded on to further this goal. Given the paucity of arts-based research in the psychological literature, I believe the epistemic justice element of evocative artwork could be a particularly useful area for future investigation in this academic field.

This is also true of the representative agency that arts-based research is able to promote. It is common for women with chronic illnesses in particular to feel unseen and unheard in medical settings, and future projects that speak to this lack specifically would be a valuable continuation of this research. It would, however, be easy to shift from representation to othering, or to move into overcoming narratives if this was not done as an autoethnography, or with deep reflexive mindfulness.

The use of the imagination as a cognitive tool for holistic wellbeing and for challenging harmful social constructions, such as embodied shame in chronic fatigue, is also an area of psychological research that could be expanded on and explored further. I am particularly interested in the possibilities of literature, storytelling, and collage as a therapeutic tool in this regard, and their potential for challenging the mind/body dichotomy of western medical paradigms.

A gap in the research that I believe would add to the knowledge presented here is a look at what being ‘productive’ might mean in the context of chronic illness and disability from a representational, evocative storytelling point of view. This is, as mentioned in *Witches Dance Backwards,* a commonly cited source of negative self-assessment (Hay, 2010) and I believe more work could be done on the representational stories of the chronically ill and disabled in this regard.

Finally, I believe that creative writing tools as methodological techniques are an underutilised source of innovation and enrichment in qualitative research, and I would like to explore the value of different narrative structures to tell research stories in greater depth in future research.

In Conclusion

Our bodies, as Benoist & Cathebras (1993) write, are worlds. Unique ecologies, vibrant colonies, untamed and untamable entropic worlds. None of these worlds are heaven, or hell, or purgatory; all of them are, in some way or another, a heaven, and a hell, and a purgatory.

If I began my story because a part of my world had fallen apart, I end it not because it is fixed, cured, or overcome; nor because I have made peace, or learned everything I need to know.

I end my story simply because it is time to end my story.

I did my best to breathe into the work (Pelias, 2019), to craft it well, and describe it deeply. I worked hard to “find ways to make the public space of diffusion, where we present the fruits of our work, coincide more with [the] private space of protection” (Sergi & Hallin, 2011, p. 206), both in the written and visual narratives. I did what I could to stay critical, be reflexive, take care with the slippage. It has been an arduous journey, if also a worthy one, and even as my authorial self will close the lid on my laptop and carry on with new and different journeys, I leave this version of my textual self behind so she may tell her story as often and as well to as many people as she is able.

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APPENDIX A

MASSEY UNIVERSITY
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GRADUATE
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STATEMENT OF CONTRIBUTION
DOCTORATE WITH PUBLICATIONS/MANUSCRIPTS

We, the student and the student's main supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the student's contribution as indicated below in the Statement of Originality.

Student name: Megan Young

Name and title of main supervisor: Professor Kerry Chamberlain

In which chapter is the manuscript/published work? Chapter 2

Describe the contribution that the student and members of the supervisory team have made to the manuscript/published work:[1]

Student was sole author, full contribution.

Supervisors provided editing support.

Please select one of the following three options:

○ **The manuscript/published work is published or in press**

Please provide the full reference of the research output:

● **The manuscript is currently under review for publication**

Please provide the name of the journal:
Journal of Autoethnography

○ **It is intended that the manuscript will be published, but it has not yet been submitted to a journal**

Student's signature: MYoung

Main supervisor's signature: Kerry Chamberlain Digitally signed by Kerry Chamberlain Date: 2023.08.29 16:08:29 +10'00'

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We, the student and the student's main supervisor, certify that all co-authors have consented to their work being included in the thesis and they have accepted the student's contribution as indicated below in the Statement of Originality.

Student name:	Megan Young
Name and title of main supervisor:	Professor Kerry Chamberlain
In which chapter is the manuscript/published work?	Chapter 3

Describe the contribution that the student and members of the supervisory team have made to the manuscript/published work:[1]

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Name and title of main supervisor: Professor Kerry Chamberlain

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