



## A House Called Pain

An Autoethnography On Bereavement, Intimacy and Scars

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## Abstract

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### English

The three essays that make up this thesis illustrate the difficulty of portraying the full experience of living with a disability. The first essay makes use of a story of a wild boar to explore how humankind has found different strategies in visualizing bereavement. It then considers the possible negative implications of these strategies for those who experience loss, within a context of disability as well as losing a loved one, mapping their analogies. The second essay is an imaginary encounter about what it means to have an invisible disability, opening a conversation about 'coming out'-discourses, finding companions and the value of disability in understanding pain, relationships and intimacy. The third essay covers the subject of scars and their importance to ideas of community, intimacy and their experienced fluidity. All essays are autoethnographic, allowing inductive and poetic language to underscore the emotionally and bodily lived experiences of these themes.

### Nederlands

Deze drie essays, geschreven als masterproef, tonen de moeilijkheden in het compleet portretteren van mensen met een beperking. Het eerste essay gaat, doorheen een verhaal over een everzwijn, over hoe de mensheid verschillende strategieën vond om verlies te verbeelden en de mogelijke negatieve impact hiervan voor zij die verlies ervaren, zowel binnen de context van een beperking alsook het verlies van een geliefde en de gelijkenissen daartussen. Het tweede essay is een ingebeelde ontmoeting over wat het betekent om een onzichtbare beperking te hebben en opent het gesprek over 'uit de kast komen', lotgenoten vinden en de waarde van mensen met een beperking in het begrijpen van pijn, relaties en intimiteit. Het derde essay gaat over het onderwerp littekens en hun belang voor ideeën betreffende gemeenschap, intimiteit en ervaring-gebaseerde vloeibaarheid. De essays zijn een auto-etnografie die inductieve en poëtische taal toelaten om de emotionele en lichamelijke ervaringen van deze thema's te vergroten.

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## Foreword

I thank my promotor for unconditionally supporting my thoughts, ideas and approaches to this master thesis. I thank my partners Winter and Tine for helping me write this document. It has been a personal journey of bereavement and recovery that would not have been possible without them. I thank friends like Kika and Niekje for keeping me company during my writing and motivating me with their kind words, advice and help.

This thesis is written in honor of Dieter, the partner we lost in September 2019.

## Introduction

This thesis is an example of rarely used methodology in academic research. The motivation for this type of research is a well-balanced mix of a personal need for sharing one's story through the medium of autoethnographic writing, acknowledging the importance of first-person narratives in academic research, and exploring their possibilities. As such, it is an opportunity to find a balance between academic research and creative writing. For me, as a queer and disabled person, working as an artist and art-historian, it opens the opportunity to follow an alternative and more free approach without ignoring academic quality, exploring methods of creative freedom in the academic field. This thesis is a collection of three essays, built up like a sequence but still independent, exploring rather uncommon themes in disability, connecting disability to intersectional theory and critical trauma studies through themes like grief, bereavement, scars and intimacy. This thesis is an autoethnography written in a unique and experimental format. The following paragraphs will explain the justification of this thesis, highlighting its motivation, methodology and shortly introduce two main genres of academic research that informed this thesis.

Before starting further analysis I will address my positionality as a key aspect of this thesis. Especially as I occupy a position of lived experiences, as well as of being a student in academic and artistic education. In every approach of exploring disability narratives, one must be aware of how the distribution and recognition of these narratives is subjected to positions of privilege. There is no guarantee that 'all' voices can be seen or heard. Narrative privilege can also come dangerously close to an ableist position of assuming that narrative capabilities are intrinsic and essential to humanity, to the extent that whoever does not satisfy these requirements of narrativity falls short in the normative category of being human. Furthermore, not all narratives are treated equally, like language, they have a social existence. They are born and composed and they circulate in a social sphere. In language, in discourse, rises power. In relation to self-narratives in particular, one must attend to the socio-political and cultural forces of what could be called power relations that are necessarily operating upon them, giving meaning to narratives, facilitating their understanding and regulating their dissemination. What narratives of disability does power incite, induce, seduce? What narratives of disability does power make easier or more difficult to produce? Which are the more probable narratives of disability and why are certain narratives dissuaded, discouraged or kept in check?<sup>1</sup>

With this I do want to acknowledge that my disability comes with a specific story, like all disabilities do. This introduction vocalizes that every disability is inherently unique and that stories are always individual perspectives that cannot be ignored, also not in an academic context. The field of disability studies is still a widely underacknowledged field of academia, resulting in a critical shortage of diverse narratives and acceptance of those narratives in the collective consciousness of our mainstream (Western) society. As a person with a disability I have the unique position of exploring my

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<sup>1</sup> Kurt Borg, "Narrating Disability, Trauma and Pain: The Doing and Undoing of the Self in Language" *Word and Text: A Journal of Literary Studies and Linguistics* 8 (2018): 172.

own narrative through the gaze of critical disability studies and critical trauma studies, transforming it into an approachable empathic document for academic scholars and others to read.

I am also aware that I take up space from a position of privilege. I am a white, middle class, size-normative person with ability-privileges like walking, hearing and seeing, enjoying the possibility of an academic education, being 'passable' enough to escape specific ableist, structural and institutionalized discrimination.<sup>2</sup> Many others do not have these abilities. I do not wish to talk in generalized terms about people with disabilities. The only thing I can share with authenticity is my own perspective.

The story of my body is a reflection of pain, trauma, and grief in relation to socially stigmatized and/or unrecognized disability, impairment, and the loss of a partner. It is a very specific, almost unique story of how deep concepts of disability intervene in one's life, as a person with a disability, and this should be seen as a very distinct opportunity. This is why the content of my thesis will explore these same themes. It is a personal contribution to the politics of disability throughout its engagement with core notions in disability studies, as well as the disability movement, activism and the social model of disability. It is also a critical work of thought on impairment that draws upon incorporated insights from philosophical works and embodiment of love and loss.<sup>3</sup>

In order to positively contribute to the acceptance of disability in mainstream society, this thesis should use the concept of 'ability', exploring it in content as well as in form. In other words: this thesis is an exploration of the ways narratives can be written down in a way that is of use to difficult subjects in disability. This thesis is an exploration of what non-normative approaches to academic research are efficient and contribute to disability as an auto-narrative.

## 1. Methodology

Originally, this thesis had the intention of supporting a creative process in visual arts, though given how artistic practices evolve they often turn to a different medium and approach. This turn of events, allowing full creativity and associative thinking, resulted in the essays that are presented in my thesis.

This thesis, with its own specific individuality, purposely denies expectations of normativity regarding the form of a thesis. It is a conscious deviation from the normative approach, construction and form. As such, I do explicitly ask the attention of the reader to be open to this alternative approach, recognizing the existing expectation regarding a thesis, and reading this with an open mind.

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<sup>2</sup> I use the term *passable*, borrowed from the queer-vocabulary, implementing a similar use for disability.

<sup>3</sup> Borg, "Narrating Disability, Trauma and Pain," 173.

Any story contains both what is said, the content, and how it is said, the structure. These elements provide ways to analyze a narrative.<sup>4</sup> At first, the process of developing themes and structures started with the collection of memories and anecdotes. This approach is validated in what is called artistic research, focusing on the inductive and the deductive perspective. Methodologically, it does not aim for a purity of approach, like mathematized natural sciences as an explicitly and experimentally proven claim for objectivity, or like a creative practice as a hermetically presented result of an implicit singular process. Deductive perspectives point to the idea of starting from linear constructions which are used to determine dated and scripted settings, while inductive perspectives allow response to experiences, including their bodily, psychological, and mental implication, characterized as always being 'in-between', opening up to more embodied approaches, techniques and media, like creative writing for example.<sup>5</sup> In the process of writing the essays, I aimed for a specific openness to inductive methodology, allowing emotionality and bodily experiences within an autoethnography. It is much like the distinction the Dutch scholar Carolien Hermans makes in talking about a disabled body in contemporary dance, using the German nouns '*Leib*' and '*Körper*'. Where the '*Körper*' is the instrumental and medical framework of referring to a disabled body, in analogy with how often disability is labeled in society, it claims its objectivity as a valid approach to experiences of disability. '*Leib*' is an embodied and lived experience of a '*Körper*'.<sup>6</sup> This thesis uses its content like a '*Körper*': embodied, frail and vulnerable.

Following this argument, it is important to acknowledge the importance of the choice of media regarding telling self-narratives about disability. This thesis uses a lyrical and imaginative method, allowing genres like magical realism to invite empathy for the lived experiences of disability, loss, trauma and pain. An important art-historical reference in this context is the catchphrase 'the medium is the message', like media analyst Marshall McLuhan and graphic designer Quentin Fiore have pointed out. Both state that all media influence us completely. They are pervasive in their personal, political, economic, aesthetic, psychological, moral, ethical and social consequences and leave no part of the viewer or reader untouched, unaffected and unaltered.<sup>7</sup> Their book *The Medium Is the Message: An Inventory of Effects* demonstrates the ways media, in all their variation, are extensions of human senses, expanding capability to how the world is affected. It shows the impossibility of ignoring the relevance of how media influences the viewer or the reader.

There is a need for awareness of how regulations, expectations and the organization of a thesis are an important part of an academic education, and in this way, subjected to a normative script and the possibility of displaying power dynamics. To deconstruct and point out its benevolent normativity, the concept of 'queer use', as explained by scholar Sarah Ahmed, considers the

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<sup>4</sup> Elizabeth McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability: Using Critical Disability Theory to Examine a Disaster Narrative" In *Critical Qualitative Research Reader*, red. Shirley R Steinberg and Gaile S Cannella. (Germany: Peter Lang Inc. 2012), 310.

<sup>5</sup> Volkmar Mühleis and Esther Venrooij (To be published in 2020). "Audio-Topography – some conceptual remarks."

<sup>6</sup> Carolien Hermans, "Differences in Itself: Redefining Disability through Dance", *Social Inclusion*, Nr 4 (2016): 161-163.

<sup>7</sup> Robert McLuhan and Quentin Fiore, *The Medium Is the Message: An Inventory of Effects* (London: Penguin Books, 2008), 26.

possibility of breaking out of its inflicted standard. The understanding of the term queer as odd, strange, unseemly and disturbing, describing anything that is noticeable because it is odd, uses queer and fragility as semantic companions. The term 'queer use' might also be understood as improper use, using queer as perversion, because the word perversion can refer not only to deviant from what is true or right but to the improper use of something. The wear and tear of the academic field, like any other field, is the loss of value on the determination by the extraction of value.<sup>8</sup> To value a different, or queer, use of a thesis as a framework of research shows awareness of different yet equally valid methodologies of proving one's quality as a researcher and academic. Moreover, the idea of 'queer use' is associated with a conscious choice for being used. To value a self-narrative in a thesis is to think of it as a record of the fragility of life, letting oneself willingly be used and subjected to academic methodology. In this case even literally so, as the author identifies as queer and crip. In crip theory, scholars like Petra Kuppers, have also applied more creative and open methods to analysing poetry and fine arts. In this way, within its specific domain and approach, the seemingly different methodology within this thesis is not as uncommon as one would think.

Multiple perspectives in anthropology subvert the idea of a unified 'truth' and advocate for self-examination, due to its potential to describe social context from the margins. The vulnerability of the speaker, of the writer's body, often neglected in academia, is brought forward in various forms of exposing oneself to, for example, readers. Whether the motivation is to critique, disrupt, reclaim or rethink social order, the common phenomenological effect of such writing is to transcend embodied cultivability through intersubjectivity.<sup>9</sup>

Every time one puts forth an image, a word, a sound or even a silence, these are never instruments simply called upon to serve a story or a message. Ideas like this, vocalized by filmmaker and theorist Trinh T. Minh-ha, help us understand that all media have a set of meanings, a function and a rhythm of their own. She explains the notion of 'poetic language', not referring to the poetic as the site for consolidation of subjectivity or as aestheticized practice of language, but referring to the fact that language is fundamentally reflexive and that only in poetic language one can deal with meaning in a revolutionary way. Opening a narrative to more free expressions and descriptions is to offer meaning in such a way that it can never end with what is said or shown, thereby destabilizing the speaking subject and exposing the fiction of all rationalization.<sup>10</sup> It is for this sake that the dialogue between the sources and the autoethnographic anecdotes is implicit, but that does not defy its academic relevance. Minh-ha even points out that the ideology that informs the way 'clarity' and 'accessibility' are understood continues to be largely taken for granted.<sup>11</sup> Keeping in mind that this is a thesis with disability as its main subject, it was a conscious decision to choose a medium like poetic and lyrical essays that is more accessible to other non-academic readers.

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<sup>8</sup> Sarah Ahmed, *What's the Use: On the Uses of Use* (Durham: Duke University Press, 2019), 197.

<sup>9</sup> Ellen Samuels, "Critical Divides: Judith Butler's Body Theory and the Question of Disability" *NWSA Journal* 14, nr. 3 (2002): 2.

<sup>10</sup> Nancy N. Chen, "Speaking Nearby": A Conversation With Trihn T. Minh-Ha", *Visual Anthropology Review* 8, Nr 1 (1992): 83.

<sup>11</sup> N. Chen, "Speaking Nearby," 86.

It is with these arguments in mind that this thesis is a conscious choice of exploring the autoethnographic, embodied narratives, critiquing while simultaneously making a contribution to existing research and theory. It embraces vulnerability and frail recovery as a way of understanding emotions and validation and the importance of relationships. It has the possibilities of disrupting taboos, breaking the silence and reclaiming lost or disregarded voices and makes this story accessible to multiple audiences. Personal stories often convey complex messages. They declare our positions. They publicly acknowledge what is personal to us and a written testimony of that takes responsibility for what happened to us.<sup>12</sup> In this manner as they are brought into public, the other becomes accountable. They can no longer be ignored. Telling stories is how one makes sense of their own experiences.<sup>13</sup>

## 2. Critical disability studies

One of the main themes of this thesis is disability. Within the corpus of this thesis, a number of sources from the field of critical disability studies are referred to, invigorating statements on impairment, loss and pain. Disability studies is the field of research that is concerned with people with disabilities. The conceptualization of the medical and social models in disability theory provides a perspective in which these models are created as a binary dichotomy, and argues that if disability is perceived as personal and embodied, disability is defined as a social issue. They suggest we let go of these models, and instead, focus on disability as an identity.<sup>14</sup>

Every body is subjected to certain limits and to the social consequences of those limits. Between the disabled and the non-disabled body lies a gap that clarifies the social implications and points out its opposites. There is the idea that the disabled body lives in another world, far away from the 'normal' able-bodied people.<sup>15</sup> The lack of representation of those bodies in society shows that they are barely recognized and researched.<sup>16</sup> Repositioning contemporary writers and artists' oeuvre and artworks in a context of able-bodiedness is not common but nevertheless offers a great power and contribution to society. It frames the works of artists and writers in a historical and multidimensional perspective on disability.<sup>17</sup> Bodies interrogate the socially constructed environment and so confirm the expectations determined in the binary dichotomy between disabled and non-

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<sup>12</sup> Slava Greenberg, "Stories Our Bodies Tell: The Phenomenology of Anecdotes, Comings Out and Embodied Autoethnographies" *Review of Disability Studies: An International Journal* 14, nr. 4 (2018): 5.

<sup>13</sup> McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability," 310.

<sup>14</sup> Greenberg, "Stories Our Bodies Tell," 9.

<sup>15</sup> Rosemarie Garland Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 201), 21.

<sup>16</sup> Rosemarie Garland Thomson, *Extraordinary Bodies*, 15.

<sup>17</sup> Sonya Millet- Gallant, *The Disabled Body in Contemporary Art* (New York: Palgrave Macmillan, 2000), 6.

disabled.<sup>18</sup> This socially constructed environment is defined by history. A history that manages the idea that nature and humans are subject to a generalizing idea that everything can be defined and categorized. The reality of the impossibility of this is destabilizing. Everybody embodies the unlimited amalgamation of social and cultural categories, floating in between what should be and what shouldn't.<sup>19</sup> This thesis also uses sources found within crip theory, an specific method of looking at the concept of disability and it's identity, focusing even more on the invalid categorization between the disabled and the able-bodied.

The methodology of subjective experiences as evidence in an academic field is more accepted in the field of disability studies than in any other field of human sciences or academic movement. Disability studies has for a long time been familiar with the transformative powers of autobiographies or autoethnographies focusing on narratives of impairment. First person narratives critique the social constructions of the disabled body and facilitate counter-narratives of survival and empowerment. This redefining, as a countermove to the useless medical and/or social categorizations, is a better approach as it searches for a redefinition of the individual body outside the social stigma of the medical discourse.<sup>20</sup>

In dominant discourse about disabled people that circulate in society, people with disabilities are often portrayed in discourses of dependency. It sets a subtext of representing them as in need of help, instead of portraying them as independent and autonomous. It is a very rigid interpretation of the social model of disability. It is a model that focuses on the social structures and organization rather than the individual impairment, as the cause of the disability fails to account the deep experiences of pain and loss. It is at its best a fantastical normality, conforming to the public demand for a story of healing and renewal, suffering and redemption. Such narrative expectations proceed at the expense of disavowing the traumatic dimension that is accompanied with any type of impairment. Notions and phrases like 'living on' or 'moving on' attempt to minimize the never normalizing pain, the trauma and the meaning of disability and intense grief of bodily functions.<sup>21</sup> The same can be said for the loss of a loved one.

### 3. Critical trauma studies

This thesis has not only used sources from critical disability studies, but also critical trauma studies. As a branch of trauma studies, it is a field in which a critical approach is taken towards trauma, considering both those who study trauma and those who experience and narrate it as a personal and embodied event, looking at the way in which these two parties inform each other. Critical

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<sup>18</sup> Rosemarie Garland Thomson, *Extraordinary Bodies*, 7.

<sup>19</sup> Rosemarie Garland Thomson, *Extraordinary Bodies*, 24.

<sup>20</sup> Greenberg, "Stories Our Bodies Tell," 2.

<sup>21</sup> Borg, "Narrating Disability, Trauma and Pain," 171.

trauma studies deal with how social relations and cultural meaning produce trauma in two ways: on one hand through acknowledging socio-demographic identities like class, gender, race, sexuality, social relations... and how it denigrates and oppresses individuals, and trauma as a social construction on the other hand. It introduces an awareness of the fact that trauma has progressively become a key notion in discussions that interrogate the links between social history, subjective experience and cultural representation. I have endeavored to acknowledge important voices in the field in terms of new inter-disciplinary and inter-cultural methodological perspectives.<sup>22</sup>

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<sup>22</sup> Arleen Ionescu and Anne-Marie Callus, "Encounters between Disability Studies and Critical Trauma Studies: Introduction" *Word and Text: A Journal of Literary Studies and Linguistics* 8 (2018): 20-21.

## 1. Essay I – The Wild Boar

Grief is a human experience. It is something we are wired for. It allows us to not be overthrown by what happens to us, or what happens to our loved ones. It is our reaction to trauma, grief is designed to accept, to accommodate and to help.<sup>23</sup> We are made to grieve, to be in pain, in the same way as we are created to heal. Deep, dark sadness makes us feel adrift, but our life eventually finds its ways again. Funnily enough, sometimes this happens more easily than we can imagine. This is the nature of grief. This is human nature.<sup>24</sup> It is similar to our bodies knowing when the sun sets and night falls, without having to see it happen. Our body knows that every night there will be a point at which bright red, orange and the most beautiful yellow will find its ways to the retina of our eyes. It is a rhythm, a circadian rhythm of grief. As human beings we belong to an extremely resilient species. Since time immemorial we have rebounded from our relentless wars, countless disasters, and violence and betrayals in our own lives. But traumatic experiences do leave traces. Whether on a large scale like in our history and culture or close to home, as individuals, dark secrets are imperceptibly passed down through generations.<sup>25</sup>

My partner died in an incredibly sudden, shocking and unexpected way. On Tuesday the 10<sup>th</sup> of September 2019, I had woken up early in the morning to make pancakes. Pancakes I wanted to give to my partner, who at the time was in the hospital after complications following a routine surgery. Before leaving the house, I woke up my neighbor downstairs. She opened the door with eyes still filled with sleep, but the view of my pancakes with some berries and sugar put a smile on her face. I went out of the house, took my bike to the museum where I work as a guide. I felt energized and ready to have a busy day. I was looking forward to it, because the sooner I was done, the sooner I could go to the hospital to visit my partner. I had a meeting at the museum so I could check the local photographic archive for my next artistic project. I had just entered the office when I received a text message. '*Your partner went into cardiac arrest. They're doing CPR. We have to wait for further news.*' I froze, standing outside the museum. I couldn't talk, see, hear, move... Only to be woken up by my neighbor, whom I had called quickly. She put her hands on my shoulders, shaking me: 'you have to go to the hospital, you need to be there'.

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<sup>23</sup> George A. Bonanno, *The Other Side of Sadness: What the New Science of Bereavement Tells Us About Life After Loss* (New York: Basic Books, 2009), 7.

<sup>24</sup> Bonanno, *The Other Side of Sadness*, 24.

<sup>25</sup> Bessel Van Der Kolk, *The Body Keeps the Score: Mind, brain and body in the transformation of trauma* (London: Penguin Books, 2014), n.p.

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The day after the funeral, I packed my backpack and left home. I travelled, against the advice from mental health professionals and that of all my friends. I found a simple, black, wooden cabin in the middle of the countryside in Estonia where I could spend my nights. A place where I could be scared and shattered into a million pieces. The need to leave everything behind cut like an axe through my heart, with an enormous impact I could no longer ignore.

It was grim outside when I arrived at the cabin. I was in the middle of a forest and I could only see a few trees coming forward, out of the darkness. The leaves were wet and crackled underneath my shoes. The rustle of the leaves were a rain shower, performed in the orchestra pit of an incredibly gruesome opera. Next to me was Henri. Henri melted into the forest we stood in. The holes in his wool sweater provided air to the twigs that were growing from his skin. His face rugged as the racket of the leaves that surrounded us, but his blue eyes carried a softness and shone their light onto mine. Henri broke the noise of the leaves.

He told me about Marit, a Latvian woman he had lived with previously.<sup>26</sup> Marit had lost her husband two years ago. The farm Marit had lived in with her husband turned into emptiness. Bereavement dripped like black tar from the walls of the wooden house, dripping to the ground. She could not enter it anymore. During the summer she slept in the grass meadow, under trees where dew drops could pinch her cheeks every morning telling her a new day had started. Marit slept, drowning in tears, and the dew on the grass kissed her awake every morning. When it got colder, she slept in the barn, made merely out of three broken-down walls with a leaking roof on top of it. There she could find shelter that felt somewhat like homeliness in the sense that it's like what many of us would call a roof over our heads, which to her still felt close enough to the outside. Where the rain could pour and still find her body through the cracks of the leaking roof as a replacement of the tears she couldn't cry. She emptied herself. She emptied and hollowed out herself by the loss of the home she had. The home that was only a couple of footsteps away from her but felt impossible to reach and to ever enter again. Marit strayed around her own home living in a fluidity where there was no longer a distinction between what is called the inside and the outside. Where warmth and cold could no longer be differentiated. A rhythm of nature where there was no good or harmony to be found but where timelessness became the frame and irrelevance set the tone. The house was only the remainder of a partnership that once was home and now not more than unattended bricks and cement. She wandered around it, surrounded by the power of the infinite landscape of a grass meadow that swallowed her alive.

Henri told me how he asked her if she ever felt scared sleeping outside. Marit said she did, once. Of all the nights she slept outside, Marit chose to talk about a night during which her sleep was disturbed by an animal. We, home-having people, are used to a good and well-constructed house to

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<sup>26</sup> Marit and Henri are fake names, to protect their privacy.

live in, yet we are scared thinking that animals could have direct contact with us while we are asleep. Even the littlest ones like flies, spiders and other insects are big enough to disturb our illusion of a comfortable, safe house and its lie of controllable security. They have created narrative canons that last for centuries. Stories of hornets drilling their ways into our brains to turn into stones of madness, that in turn result in painted panels, like the one by J. Bosch, for which we lost the iconographical vocabulary necessary to read it properly a long time ago.<sup>27</sup> Or the urban legends about spiders on a kamikaze mission and how they crawl into our mouths at night when we are at the beginning of our unconscious sleep pattern. Marit told Henri about the time she woke up in the middle of the night, sleeping in the barn, only to hear some rustling close to her in the hay that was her mattress. She turned to the other side and right in front of her was a big, black, wild boar. Its fur rusty and stinging, like an old metal comb or an unwelcome touch. An enormous organism filled with unpredictable, flesh-crushing authority, ready to tear her apart in seconds. Small beady eyes, a mucous snout, dripping saliva into the hay. Asymmetric, crooked, pale-white tusks that were well-earned war medals. The wild boar was staring right at her and she stared right back in a completely silent conversation. Time went by, maybe minutes, if not seconds, until the wild boar continued its nightly walk, crossing the grass meadow, right back to its home. "Marit closed her eyes and woke up again the next morning", said Henri, upon which he fell silent. We looked at each other and I could only imagine that, maybe, it felt somewhat similar to the way Marit had stared at her wild boar. Henri said that the carelessness and indifference with which Marit told him about the boar had terrified him. She finished the story confessing to Henri that if the wild boar would have killed her that night, she wouldn't have cared. 'That is how nature works', she told him. Once again, silence fell like a machine in a hospital after the last heartbeat. Dense and uncomfortable. Henri said: "It was only then I realized how fatalistic she was" and I could see how his worries were honest and coming from a place of deep affection for Marit. "I don't know why I'm telling you this", said Henri, yet when we looked at each other we both knew he was lying. He wanted to warn me. This was a warning.

\* \* \*

I went home and for weeks, months... even today, I am still trying to find the words to describe what happened. The massive, abstract, and identity crushing power of bereavement was so dominantly overwhelming I could not grasp it. I couldn't tell anybody how grief had gradually and violently slipped into my life, covering my mind in a veil of the blackest black possible, obliterating all sunlight, swallowing it into negative space. We humans wrap up everything in language. It's like we are always looking for the right shape or body to pour our feelings into. But every time I tried to articulate this, it fell into pieces again. My words weren't worthy enough. The absence of an all-encompassing body of words made it impossible to talk about it with others. The only ones who understood a glimpse of what was going on inside, were others who had also untimely lost somebody

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<sup>27</sup> Hieronymus Bosch, *Cutting the Stone*, ca. 1494, Museo del Prado, Madrid.

they loved very much. Trauma can shatter one's most fundamental assumptions about our world, including the belief surrounding our ability to control what happens to us or to the people we love.

When I had entered the hospital on the day of my partner's cardiac arrest, medical caretakers did not let anybody enter the room for hours. We spent hours in front of a closed door. When I finally entered the room, in between a colossal installation of pumps, white-beige plastic trays and boxes, I could see a human shape that only felt somewhat familiar. This was not the person I had visited two days ago. Surrounded by a halo of tragically big and small cables and tubes lay a face I did not recognize. This was not my partner but a held-together-by-skin organically orchestrated coming-together of mere coincidences and a couple liters of blood to which I had lost my heart. A broken mirror in a hospital bed. My trust in the good and warmth of people and the disbelief of having found it with my partner, was shattered across a hospital bed in the ICU like pieces of glass. The radiating emptiness my partner gleamed was overwhelming but seemed painless. At the end, the heart machine tracking the rhythm of a dying heart changed into the phonetic tinnitus that deafened any vitality.

Pain itself is not only resistant to language, but it also actively destroys language, deconstructing it into the pre-languages of cries and groans. To hear those cries is to witness the shattering of language.<sup>28</sup> It is isolating and paralyzing. The short life I have lived until now is one in which pain, trauma and disability is ever existing. Many times my vocal cords could only thrust out breathed shrieks and weeping pain and I felt an uncanny similarity standing at the deathbed of my partner. I could not tell how inherently different and yet how very familiar the pain felt.

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The thing that kept me awake for so many nights after Henri's story was a question. What is the image of trauma? How do we construct a way to communicate what is going on, on the inside of our skin? I searched for similar stories like mine, like Marit's story and found numerous stories of people who describe grief and pain through metaphors found within the outskirts of our daily lives. Stories by close friends and stories of famous painters and writers. In fields like art, film and humanities, we are not supposed to speak about our subjective perceptions nor the corporeal aspects of the – metaphorical – bodies we use to vocalize what we feel, or at least not in the theoretical field surrounding it. They are bodies to analyze and rationalize, not to use. We may see them as anecdotes, analyze them on screen, paper, or canvas, but directly sharing our bodies' histories is not considered legitimate. We see them as overloaded by enhanced sensory, intellectual, or social stimuli. But there are ways to force us to acknowledge our diverse ways of reaching our writing or creative desks, to defy the admiration of disembodied podiums and the types of bodies they accommodate.<sup>29</sup> How do we disclose our state of being in a way that is relevant and meaningfully perceived by others?

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<sup>28</sup> Borg, "Narrating Disability, Trauma and Pain," 169.

<sup>29</sup> Greenberg, "Stories Our Bodies Tell," 8.

Telling stories is how we make sense of our experience.<sup>30</sup> The performativity of narratives functions as a mark on our identity. We are forever composing impressions of ourselves, protecting a definition of who we are, and making claims about ourselves and the world. In that world, we test them out and negotiate them with others.<sup>31</sup> The performativity of narrativity is not only about telling a that fittingly exposes our internalized thought experiences, but also about finding a strategy of vocalizing the right words and drawing the right image to have the impact that is needed to be felt understood.

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Memories of people and places, as components of our stories, are not just objects in our heads. They are more like clusters of snakelike neurons, arranged in branching pathways throughout the brain.<sup>32</sup> They are not binary in the sense that they are either existing or non-existing, remembered or forgotten. The ones that have an impact on us wander like abstract concepts, shattered throughout our brains. They are difficult to grasp because they fluctuate through the labyrinths of our heads. Yet, at the same time, we all have memories associated with particular people, songs, smells and places that stay with us for a long time, even forever. Most of us still have precise memories of days in which our lives changed violently, but probably remember little of, for example, what happened the day before.<sup>33</sup> Although we can't undo or erase a memory, we can weaken it. If we haven't thought of something for a long time, traces of its neural pathway will still exist, but other memories and associations will obscure it, and interfere with its revival. The gradual obscuring of past events takes years, and for these broadly branched memories, the most powerful ones, even a lifetime would probably not be enough to do the trick. When we intentionally try not to think about something, we usually end up making the memory, that event, that person, easier to find. They gain even more power to simply pop into our minds.<sup>34</sup>

When we try to not think of something, the alternative could be to imagine something else. Imagination is unmistakably critical to the quality of our lives. Our imagination enables us to leave our everyday-routine by fantasizing about other things. We can relieve pressure in our reality by imagining how bad relationships could have been good, how badly ended discussions can be won by imagining having the last word or how we can imaginarily conquer the people that were so cruel to us. Imagination gives us the opportunity to envision new possibilities. It is an essential launchpad for creating hope and healing. It fires up our creativity, relieves our boredom, alleviates our pain, enhances our pleasure, and enriches our most intimate relationships. When people are compulsively and constantly pulled back into the past to the last time they felt intense involvement, deep emotions and pain, they suffer from a failure of imagination. It creates a double loss: the loss of molding and

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<sup>30</sup> McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability," 310.

<sup>31</sup> McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability," 316. (quoting Reissman)

<sup>32</sup> Bonanno, *The Other Side of Sadness*, 17.

<sup>33</sup> Van Der Kolk, *The Body Keeps the Score*, 175.

<sup>34</sup> Bonanno, *The Other Side of Sadness*, 17.

cherishing memories and the loss of the path to recovery.<sup>35</sup> Imagination is a vehicle to do something with our pain. It is the first word of the sentence we pronounce to speak about our pain with others.

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It hasn't only been the privilege of poets, painters and directors to use their imagination to find imagery within trauma. There are endless systems, frameworks and referential vocabularies. The bigger question is, what medium do we, in this society, need to use, in order to be heard? Again, it might not be about what image suits you to explain, but more what narrative construction is approved by society to be understood. There are ways of speaking that society believes to be truer. Often, when thinking about the connection of our minds, bodies and psyches, the medical model is the way to talk about how we feel on the inside, using words like nerves, electric loads, hormones, and neurotransmitters. To track the pen pal conversations in between our stomachs, intestines, hearts, sex-organs, brains..., we see medical technological equipment as the recipe of our complex trains of thoughts on the inside of our skin.

Science has taught us that trauma is not just an event that takes place sometime in the past, it also leaves an imprint of that experience on the mind, the brain, and the body. This imprint has ongoing consequences for how the human organism manages to survive in the present.<sup>36</sup> Positron emission tomography (PET) and later, functional magnetic resonance imaging (fMRI) has enabled scientists to visualize how different parts of the brain are activated when people are engaged in certain tasks or when they remember certain things from the past. For the first time in history we can watch the brain as it processes memories, sensations, and emotions. It's the beginning of a map of the circuits in our minds and consciousnesses.<sup>37</sup> These scans are filled with puzzling dots and colors. When we think of the things that hurt, specks in the right lower center of the brain, the limbic system, also known as the emotional brain, spark bright red.<sup>38</sup> The flashing alarm of a smoke detector, warning danger. Years and years of scientific research have shown how traumatized people, when presented with images, sounds, or thoughts related to a particular experience, fire off their amygdala like an alarm.<sup>39</sup> Our scans clearly show that images of past trauma activate the right hemisphere of the brain and deactivate the left.<sup>40</sup> As much as we can try not to think about them or want to forget them, the neurons and pathways others, lovingly or with violence, etched and carved into our brains will be there forever. They become the houses we might not ever want to enter. They turn into relics, where they are somewhere in between the spectrum of being adored and being cursed. A cacophony of incomprehensible sounds and images presses in on our pristine nervous system. Even after we

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<sup>35</sup> Van Der Kolk, *The Body Keeps the Score*, 17.

<sup>36</sup> Van Der Kolk, *The Body Keeps the Score*, 21.

<sup>37</sup> Van Der Kolk, *The Body Keeps the Score*, 39.

<sup>38</sup> Van Der Kolk, *The Body Keeps the Score*, 42.

<sup>39</sup> Van Der Kolk, *The Body Keeps the Score*, 42.

<sup>40</sup> Van Der Kolk, *The Body Keeps the Score*, 44.

acquire consciousness and language, our bodily sensing system provides crucial feedback on our condition. They communicate in our viscera, in the muscles of our faces, torso and extremities that signal pain and comfort. What we see, hear, feel or smell or when we think about somebody in particular, a certain sound, a piece of music, a siren or a sensing shift in temperature, it all changes our focus of attention and can turn us back to the times we got hurt.<sup>41</sup>

Abandoning those houses makes us feel like it would all have been in vain, so we leave them there, withering. All the imprints, alternations, or scars in our brains will be there forever and turn into a graveyard of broken houses. The ruins will forever be traced by archaeologists, or in this case doctors, long after the first shovel was forced into the ground. It's what Freud said in an essay on trauma in 1895: 'I think this man is suffering from memories.'<sup>42</sup> That trauma that started 'out there' is now played out in the battlefield of our own bodies.<sup>43</sup> What happened to Marit, what happened to me, or to be even more precise, the people that happened to us, are forever in our brains. It is as if you could put my head into a scanner, and when I would look at the result, the doctor turning around their desk screen, I could take my index finger, point it to the red spot and say: 'There you are! Finally, I've found you!' Maybe, if this would happen in twenty years, I might say something like 'Where have you been all that time?'. If I get scared of forgetting, I can make a monthly appointment at the hospital, just to check if my partner is still there. The people we lose are etched into our brain-matter for all eternity. We are often so scared to forget the beautiful details about the people we love, the sparks of brightness in dark times, but that's unnecessary. They live forever, as a physicality, in the grooves of our brains. As ever shape-shifting and sophisticatedly cunning those memories were perceived before, they are actually very clear and well-defined, concentrated by the manifestation of the things and the people we love, made visible in the alarming red stains on an unintended picture. Living in houses in our heads built by sadness and yearning. Technology can make them visible again but these red spots on the blueprints of our mind, do those whom we lost no honor. These methods rarely capture the inner truth of the experience.<sup>44</sup> It is so much easier to talk about the things that have been done to us, than to notice, feel and put into words the reality of our inner-life. Our scans reveal that our dread persisted and can be triggered by any aspect of daily life. They are not integrated in our experience of the ongoing stream of our life. We continue to be 'there' and do not know how to be 'here'.<sup>45</sup> In a way, the dead are still alive, untreated in our brains. Nobody can treat a war, abuse, death or any other horrendous event, for that matter, what has happened cannot be undone.<sup>46</sup>

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<sup>41</sup> Van Der Kolk, *The Body Keeps the Score*, 94.

<sup>42</sup> Van Der Kolk, *The Body Keeps the Score*, 15. (quoting Freud)

<sup>43</sup> Van Der Kolk, *The Body Keeps the Score*, 68.

<sup>44</sup> Van Der Kolk, *The Body Keeps the Score*, 43.

<sup>45</sup> Van Der Kolk, *The Body Keeps the Score*, 47.

<sup>46</sup> Van Der Kolk, *The Body Keeps the Score*, 203.

Every death or loss is unique and our experience of grief is related to numerous factors: the circumstances, like a death that is anticipated, all possibilities of violence, preventability, or if it followed a lengthy illness. Our relationships to the one that died will also influence the depth and gravity of our grief. Closer relationship between the deceased and the bereaved usually yields a more distressing grief experience. The characteristics of the bereaved individual differentiate the experiences of bereavement. As we are all individuals, thus including age, cognitive style, coping strategies, gender, spirituality or religiosity, previous life history and current crises, the availability of help, the type and extent of interpersonal support and whether or not the support is perceived as helpful are merely examples of all the things that will help us understand why we all uniquely grieve our losses. An assortment of sociocultural factors has to be taken into account in the presenting and perceived relevance of customs and traditions. The roles professionals play in facilitating practical and psychological support enable a sense of healing.<sup>47</sup> They are often the new secular rituals we go through, helping us on our way to the realisation that a loved one has died. The impact of a death depends on all the ways people can be different and how our relationships are constructed. They are layers and layers of partial identities creating unique designs of our future time of grieving. death is intersectional. It makes every bereavement unique, but that does not mean we can't tend to look for what is shared in our stories. Death connects us all. We are all one accident, illness, event of bad luck away from our frail lives falling to pieces or just stopping all at once. We are all walking future corpses.

There is a massive canonization, an academic mountain, written about pain and loss. They reveal that our understanding of grief is based on merely just assumptions. The idea that grief follows relatively distinct patterns, the idea that grief is a short-term process and finite. The idea that grief is depicted and characterized by stages or phases and has tasks or processes people have to go through. The idea that grief also seems to be something that needs to be 'worked through'. For people bereaved through illness we expect grief to start at the anticipation of death. We are constrained to find 'meaning' or 'the positives' from the death or loss and it has to culminate in a detachment from the loved one we lost, the idea of 'letting go'. The idea that grief is gruesome, never ending, not anticipated or meaningless scares us.<sup>48</sup> We have trouble in finding a way to vocalize our grief, to even remotely find an understandable translation of our inner thoughts but at the same time we expect grief to present itself ever the same and as consistent and clear matter. Consequently, these fiercely-held beliefs are rarely questioned by those who hold them, despite fervent critique in literature.<sup>49</sup> Our ideas on how one is supposed to grieve is a part of our collective understanding of emotions and the human condition, executed in norms and standards. We have strong cultural norms about emotional expressions following bereavement that we regard as 'natural'. For example, the absence of negative

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<sup>47</sup> Lauren J. Breen and Moiria O'Conner, "The Fundamental Paradox in the Grief Literature: A Critical Reflection" *OMEGA* 55, nr. 3 (2007): 200.

<sup>48</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 200-201.

<sup>49</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 201.

emotions following bereavement is deemed offensive, and the deceased is perceived to be 'owed' and needs to be 'properly' mourned. These myths are pervasive and resistant to anybody who challenges them.<sup>50</sup> It is not that the way we should grieve is wrong. Rather, it may be more likely to capture grief experiences of those on whom the theories were based, 'normative' people, and it might be less able to account for the grief experiences of others, such as parents grieving the loss of a child, bereavement resulting from sudden, violent, preventable, and stigmatizing deaths, or grief experiences outside Western culture. Given the potential lack of transferability of this dominant grief discourse, its uncritical application to all grief experiences might give rise to situations in which the bereaved feels judged or judge themselves. This is especially because of the dominant cultural prescription and it carries potentially harmful consequences along with it.<sup>51</sup> Thus the research, or that medical idea of 'how to grieve,' is too limited, and where it does exist it usually pertains to 'easy' deaths, rather than reflecting the full diversity of experiences.<sup>52</sup> People perceive the way we are going to die as 'easy': at an old age, with a successful life behind us, surrounded by family and painless, with the help of caretakers. Our limited idea of grief, following our limited ideas about our death, makes us forget about all that there is to grieve about and the infinite ways we can feel it.

We wish for a step-by-step-program or a guideline to help us through gut-wrenching times, the need for something to tell us what to do. The prescription of 'what is supposed to happen now' is the clear plan we want to have. It is an answer, the medicine, to the despair and chaos we feel. Those scientific stages of grief become an illusion of a simple plan to get back on our productive feet, as we hope it takes us back to how things were before. Because we expect what is broken must be fixed and who is ill must be cured. The truth is that there is no guideline, there is nobody to tell you what to do and we are all broken, ill and cursed with pain and loss. The horror lies within the fact that nobody can help you or tell you what is going to happen next and it is terrifying. It leaves us in this stagnated present tense with the impossibility of predicting even the slightest occurrence of the future tears we are going to shed. The provision of support following a loss is complicated by people's discomfort with the existential anxiety concerning loss.<sup>53</sup> Even more so when it concerns a 'complicated' death, all deaths that are not 'easy', those sudden, violent, preventable, stigmatized losses. Loss outside the hospital, outside care settings, lost outside our expectations. These bereaved are not easily known and seen.<sup>54</sup> We don't see all the loss, the grief of society. Pain is hidden by a normative discourse. One can mourn about everything. One can mourn with every aspect of our identity. I can mourn as a woman. I mourn as a queer person. I mourn as a disabled person. I mourn in every adjective or label I could make my own.

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<sup>50</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 201.

<sup>51</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 202.

<sup>52</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 206.

<sup>53</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 207.

<sup>54</sup> Idem.

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The discourse concerning the recognition and pathologizing of grief relies on the differentiation between what medics see as 'normal' and 'complicated' grief. It remains a fundamental paradox in thanatological literature.<sup>55</sup> It's a paradox of grief. We treat it the same way as a disability. There is a medically constructed guideline that, through what is called a medical model, defines a binary idea of who is legitimately in pain and who is not. This results in conventions that are the base for creating organized help and support, to 'cure' pain. But reality is more complicated. The same conventions that are created by medical discourses, executed by health care and governments are the same ground for producing inequality. It results in wrong comparisons and leaves out so many uneasy, complicated, invisible ways one can feel lost and bereaved. It ignores the diversity of ways of feeling bereaved because one doesn't fit into what is expected. Where the goal of the medical model is to legitimize the urgency and necessity of help, it breaks it down to censorship, leaving uneasy and difficult pain and loss isolated, unrecognized and those who encounter it helpless. A greater recognition of the unique nature of grief experiences beyond this rhetoric is required to resolve its incongruence. No form or description of a person experiencing loss should be put as a sample or a prescription for others.<sup>56</sup> While bereavement is a universal phenomenon, grief is not. Grief is a unique experience that occurs within a historical, social, cultural and political context.<sup>57</sup> We can only hope to be so lucky that our own unique experience is an accidental match to the normative discourses. All things affect our individual grief experiences and, as such, must not be omitted or viewed as extraneous variables. Instead, they need to be held in as much regard as the grief experience itself. Despite the wide acceptance of grief experiences, embedded in a context, there remains a tendency in our thinking to examine individual factors in isolation with no, or a minimal, attempt to look at them as the complex interplay between infinite variables and individual experiences.<sup>58</sup> Would it not lead to a body of literature that is more usable to describe and account for the uniqueness, the diversity, of grief experiences that are in existence?<sup>59</sup>

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It's almost comical how we see a medical, scientific, or academic framework as the most correct and objective method to talk about subjects so visually ungraspable. The infinite brain scans, statistics, bibliographies and footnotes do not even slightly come close to a proper translation of pain, loss and bereavement. They are merely clusters of wayfaring enigmas, set up to be criticized and ridiculed by our own lived stories. Trauma, pain and loss, by nature, drive us to the edge of

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<sup>55</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 207-208.

<sup>56</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 208.

<sup>57</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 209.

<sup>58</sup> Idem.

<sup>59</sup> Breen and O'Conner, "The Fundamental Paradox in the Grief Literature," 211.

comprehension, cutting us off from language based on common experiences or an imaginable past.<sup>60</sup> We can try to listen to the groans and cries of others, to that incapability, through the events that hit us and our stereotyped understanding of it, to speak. We can try to reach a different understanding of the pathological PGD (prolonged grief disorder) that 'wrong mourners' are labeled with and see it only as someone who is experiencing a difficult, complicated and intersectional experience of grief. There is no need for medicalization. If we listened without our privileged 'yet-to-be-bereaved' minds, we could look at their brain scans as visual allegories, poems written with a medical vocabulary. These scans are only a different framework away from being looked at like all the thanatological poetry and art humans have created. They all serve the same goal: an image to show that we are suffering. Within every individual story, there is only one collective and returning thing to be found: grief. It is always different yet inevitable, and therefore something that connects all of us. We all want to recreate language for the loss that shattered our bodies, whether it happened yesterday, ten years ago, or even over forty. The very thing that causes us so much pain also becomes a source of meaning. It might just feel like we are only fully alive when we are revisiting the things of the past.<sup>61</sup> They become the start of a different way of understanding the incommunicable and the unpronounced like the deep emotions and memories we are all haunted by.

Out of all the things I have read during the pathway of digging myself through the ruts and grooves of my grief, I chose the story of Marit to alter and use as my own. I like to think that Henri wanted to give me this story as a gift. Now, when I think of the grief, the pain and the impairment I experienced with the loss of my partner, I imagine a wild boar. If trauma is the house we cannot enter, the wild boar is the natural coping-strategy called grief. As authoritarian and violent as it is, the wild boar also embodies the virtues of a warrior. Wild boars are explicitly linked to the month of October, initiating autumn, the month I buried my partner. Their dark colored fur as a symbol of its nocturnal solitary habits, like the grief that comes at the darkest moments of our lives. An often unacknowledged and underestimated, violent predator.<sup>62</sup> A wild boar is the grief that stepped into my life and it'll forever follow me around the house.

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It was the early days of October when I packed my stuff to return home. I was worried. It was only during the six-hour train ride back to the capital of Estonia, Tallinn, that I started to understand how my instinctual urge to be in the woods had not been driven by a need to let go and find tranquility. It was an initiation ritual into months and months of paralyzing pain and shattering, life-threatening feelings of depression. Maybe it was not just closure of a time filled with traumatic experiences, but rather the start of an even bigger challenge. I had survived the death of my partner

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<sup>60</sup> Van Der Kolk, *The Body Keeps the Score*, 43.

<sup>61</sup> Van Der Kolk, *The Body Keeps the Score*, 18.

<sup>62</sup> Massimo Scheggi, *La bestia nera: Caccia al cinghiale fra mito, storia e attualità*, (Ed Olimpia, collana Caccia, 1999), 14-15.

but the skin I wore had been torn open and I needed to sew it back together. I was doing everything I could not to turn into Marit, but in the distance I could hear the tapping of an eerie mammal. I had to force myself to go back, to wherever that was, pick up the pieces and build a new home. With a backpack filled with burdens, I stuck the key into the lock of my home, expecting the tyranny of an empty room. I opened the door and my house was gone. What I saw was a chaotic wreck of pulverized shards and splinters on the floor. Fractured wooden planks that created a pattern like a cubist painting of a deconstructed still life, and I was standing in the middle of it. All the objects broken, the roof partly gone, making holes for bright golden beams of light touching the floor, lighting dancing dust particles in the smoke of an only recently finished demolition. I had opened the door, with my hand still on the doorknob, only to find an enormous wild boar tapping its hooves on my wooden floor. It was staring right at me, snorting moist, unpleasant, vaporized saliva into my face. I turned away my head, squinting my eyes. I was terrified.

## 2. Essay II - Imaginary Table Conversations

I was expecting bad things to happen. As somebody who lived through long-lasting experiences of pain, I am always anticipating its possibility. For years, I have fought through all my surgeries. When broken, you always anticipate the idea that the end of that chapter in your life is only an illusion and that events might repeat. You watch over your own life, suspicious of the possible thunderstorms to come. When going outside, you always wear a raincoat. At a certain point you no longer believe in the idea of luck, except for when it's bad luck and it is waiting to happen to you. I've always thought it was going to be something like a car accident, breaking my body to the point I would end up in the hospital again, with months and months of recovery. Or maybe something like a terrorist attack, physical assault or a natural disaster. Never did I anticipate the danger of the damage that could have been done to others. How selfish of me. Meeting my partner was like a flash of a lightning bolt, shaking me wide awake. Death was the sudden and immediate thunder that followed only seconds after it. In between, you count the seconds, waiting for the disruptive blast of noise.

During the months following the death of my partner, I sat in pure collateral emptiness at my kitchen table with a blank stare. I drank. I smoked. The first two weeks after the death of my partner friends helped me, and my household turned around me with such speed that it felt like fast forward movie effects, making me dizzy. It felt jolted and jarring as though I was holding a camera. People running around buying food, doing dishes, calling other friends to take over their shift. I was at the epicenter of care and empathy, given by people who also lost their friends, mothers, children... Losses I didn't know about. My house was spinning around me and all I could do was hold on tight to my kitchen table. They knew the simple gestures of helping with practical nonsense and they knew that was the thing I needed. I was severely impaired. They knew.

Grief became a fourth dimension, abstract and obscure, completely out of focus. When my friends left, the silence became unbearable.

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A couple of days before my partner's death I remember we talked about one of my partner's favorite books.<sup>63</sup> My partner said that the author believed that all important things happen in our beds. I remember disrupting that conversation for the sake of avoiding my own discomfort with my own awkward and embarrassing anecdote of having to piss in a bedpan. 'Ok, maybe not all things', my partner replied. We laughed and we both understood. Being bedbound is not to be romanticized.

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<sup>63</sup> The book 'Ijstijd' by the Dutch writer Maartje Wortel.

For months my bed was a place of pure pain and torture. My bed turned into a holy site of sadness and became a token of my love and the heartbreak that came with it. For as long as possible, I wanted this to remain *our* bed. Sleeping alone turned into a gesture of how much I missed my partner, as it was almost a habitual mourning performance, a loyalty to my own feelings and a promise to my partner I would not just let go. Just like Tracy Emin did in 1998, I could have taken my bed and put it in a museum. First shown at Tokyo's Sagacho Exhibition Space, she took her wooden bed, with wrinkled sheets, pillows and twisted blankets and left it in the gallery, exactly the way she got up that morning, too depressed to clean the house.<sup>64</sup> Intimate things do happen in a bed, a shrine of grief and loneliness. A cocoon to cry in.

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People who know what it is to be bereaved know that during your time of mourning, however extended and profoundly deep it might be, there will be a moment in which only for the slightest second you'll see somebody on the street or in a café and have the uncanny confrontation of the dead being alive again. I have heard stories from friends seeing their lost loved ones walking the streets or finding out that somebody has died and thinking 'no that's not possible, I saw that person yesterday?'. We see the people we had to leave behind, knowing it's impossible.

That moment presented itself to me in a dream. I had woken up in bed with my partner next to me. The sun was rising outside and the most beautiful oranges and reds filled the bedroom with love and innocence. I woke up surprised and I could feel my excitement. My partner was here with me again and I fell head over heels in love once more. Joy filled my whole body with warmth but I knew something wasn't right. 'Why are you here?' I said. 'What do you mean?', my partner had answered worryingly. 'I buried you last month. You died. Don't you know that?' The disbelief and confusion on my partner's face, made me realize that my partner never knew what had happened. I said 'Don't worry, I'm taking good care of the people you love', and this was answered by a kind and thankful smile. We chatted about the funeral and about what had happened, cuddled and stroked each other's skin. At one point, my partner got cold and needed help. I offered to prepare a heating pad or maybe some tea. My partner got up, politely declined and said: 'No. No, it's fine. I'll do it myself' and with that the white wrinkled sheets uncovered a chest black and blue, lungs severely damaged. I looked at this and lifted my eyes to my partner's face, knowing I saw something that shouldn't be seen. 'Don't look, it's nothing.' I was scared that if my partner would leave for the heating pad, my partner wouldn't return anymore but I was even more scared to say that out loud. Because for the sake that if I did, it might become true, so I bit my tongue and I hoped for a return. I was lucky this time. Our bedroom conversation ended with my partner kissing me on the forehead, telling me it was time to go. I begged, crying out loud, but before I knew it, I woke up again in the reality of an empty bed. I woke up again to that wild boar, tipping its hooves on the wooden boards of my bedroom, counting the days, counting

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<sup>64</sup> Tracy Emin, *My Bed*, 1998, Tate Gallery.

the dreams that occurred a little further away each time from the last time we shared my bed. I looked at the wild boar and nodded, whispered 'I know' and got up to the side of my bed with my feet touching the ground and my face buried and sobbing in my hands.

But what if you did? What if you are still alive somewhere in a parallel universe, having walked millions of lightyears, without even making the effort of knocking on my door before you just walked in? I have been able to imagine you so many times just wandering around in my apartment, reading, sitting up at the table having breakfast or hovering star-like above me wherever I went, during meetings, making little jokes in response to the things I say, trying to cheer me up. Maybe you would be a little different. Maybe your chest would still be black and blue and maybe you'd now know that you've died.

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I could imagine you sitting at the kitchen table. There is a chair in my house I know you adored. 'It's like a cat bed' you said 'I can sit here and have an overview of your whole place.' But really, what if you would be here again, would you sit in that same chair? What if we had the chance to have that last conversation, after the occurrence of death, meeting our loved ones halfway in the middle of our mourning. If it would happen to me, I'd tell nobody, and I'd make you a pot of tea and have you sit at my kitchen table. We'd stare for maybe the first few minutes and I know I'd cry. I'd shed tears quietly but with a generous smile on my face to greet you.

'You were like what a good book does to me, a piece of music, silencing me in full wonder, the feeling of recognition and deep unconditional support. You are extraordinary.' That is the first thing I would want you to know. And I know you wouldn't want to take up space and you'd give me room to take a deep sigh. 'What happened while I was gone?', you'd probably ask.

'I've learned so much' I would answer, 'I've learned the need to flesh out what I mean by grief. At a bare minimum, grief is just a set of experiences that occur in the face of death, whether in anticipation or bereavement. In our perception of grief, it's only ever intended as a heuristic device, a way of speaking about the sort of experiences that generally present similar commodities. And grief, like death itself, is undisciplined, risky and wild.<sup>65</sup> You'd continue, 'We describe the final stage of grief as 'acceptance', which does not entail feeling good about what has occurred but recognizing this new reality and its permanence and therefore to learn to live with it.'<sup>66</sup> I would nod in confirmation. 'I have suffered overwhelming pain, when my head was so confused it couldn't see the difference anymore between mental and physical pain for the deep grief of all I'd lost.'

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<sup>65</sup> Shane Clifton, "Grieving My Broken Body: An Autoethnographic Account of Spinal Cord Injury As an Experience of Grief" *Journal of Disability and Rehabilitation* s.l. (2014): n.p.

<sup>66</sup> Idem

'Grief gathers people, to chant, to sing, to hold on to each other. We cried, we screamed, we clutched hands and sobbed tears.<sup>67</sup> I mean, we might have seen this *'pulmonary lung embolism train wreck'* coming our way and you would expect somebody so perfect like you to survive. You know they say that it takes a tragedy to bring people together, but I'm sure you've found a very thorough way of achieving that.' You would probably giggle and say you're sorry, knowing you'd interrupt me but I'd continue: 'The suffering we are tormented with due to your death glued us together like a fortress. My sadness is my proof of love, for you and for the others you love as well. And my love proves that I am driven by a profound bond to the relationships we've had, past present and the ones to come. And I see this through an anarchist lens. Even as I was convinced that I'd lost all my belief in anarchists, I found myself born again into something that lived outside of the conventions of what it means to love somebody. Because it's true what us anarchists contend, though it is rarely actualized: when people create a new culture together, they turn into better people, in an upward spiral that births a new society and new selves.'<sup>68</sup> We now all live by that idea and that's thanks to your death.'

I would have told you how I slowly re-engaged with my intellectual and artistic life, mostly by reading and how this brought me into new areas within disability studies. I noticed how writing about my experience was a way of connecting my past and present, making sense of the new and overwhelmingly, energy demanding, mind and body I was living in. I had to learn a new way of housing in my own body. I'd tell you about how I think I should be angrier. I should be so fiercely, with unquenchable passion. 'I should be as relentless as the state', I'd joke. 'If I am sad, the state has won. If I'm sad, the fight is over.'<sup>69</sup> You've told me that it doesn't matter what gets you through the night, and half of that would have been a sarcastic remark but you've pointed out to me that there are probably worse ways of coping.

'I've told you not to worry about me when I said my goodbyes at your deathbed.' And I would repeat that again, while taking the pot of tea, filling up your cup again. 'you told me I should write... I did start to write.' and with that the cups would be full again.

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'The pitiful state of having to stay inside for months to regain your strength and protect yourself from further harm is a social death sentence. It is weird how my life's story helped me to understand the cruel and fast forgetting ways of our society, especially when it comes to bereaved people. If you see grief as an impairment or a disability, it's easy to see its parallels. Throughout the history of disability, the conceptualization of disability has accrued different meanings and elected varied responses

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<sup>67</sup> Cindy Milstein, red. *Rebellious Mourning* (California: AK Press, 2017), 60.

<sup>68</sup> Milstein, *Rebellious Mourning*, 393.

<sup>69</sup> Milstein, *Rebellious Mourning*, 20.

across the centuries, ranging from fear to charity to rehabilitation.<sup>70</sup> I look at you for a brief moment. ‘I have imagined myself many times making a mourning-mandala. I’ve had this image of myself having to rearrange an infinite pile of tiny branches and twigs and put them in order again. As though if I would want to heal, I would have to count, register, archive and reevaluate all my little memories of you. I can see myself on the floor laying them out in front of me piece by piece, forgetting to use a proper tactic and ending up completely trapped in this painful mandala of twigs I cannot step on. I get stuck due to all my memories about you and they turn out to be the reason that I feel isolated.’ Your answer would be rational but I know that this is how you sometimes chose to support someone. ‘Representing pain and acknowledging losses that we must grieve will allow for a richer conversation, and a deeper commitment to creating the conditions to sustain fully livable lives for us all.’<sup>71</sup> Those twigs will make you see new patterns, and not only just about me. Indeed, the location of impairment, on your skin, in your bones or an event of the past, in social context makes it mutable and open to interpretation, and the consideration of these different conceptualizations and interpretations is important and should be studied thoroughly. It might very well be that bereavement is nothing more than another idea of thinking about disability.<sup>72</sup> I would continue and fill you in: ‘The way we think of disability, however abstract, has a real impact on people’s lives. When these ideas are negative or deficit-oriented, the impact is devastating. All too often, disabled people have been regarded as missing something and even as not being fully human.’<sup>73</sup> We would both laugh because we know how wrong that prejudice is.

‘What matters is that I am finding the truth and that truth is subjective. It’s a story we write about our bodies, how we tell our bodies, draw our image, so we can give it to others, to society and to our partners. Our efforts flowing from the goals of doing something positive with our past contribute to our understanding of well-being, and thus also of the well-being of people with injuries. All too often broken bodies are metaphorically described as a ‘dead weight’ or a ‘broken down ship’ – indeed they are dead and broken, but there is more to them than those adjectives.’<sup>74</sup> It has to be possible to concede and affirm an array of ‘materialities’ that pertain to the body, that which is signified by scientific domains like biology, anatomy and physiology and talk about them in terms of hormonal, chemical composition, illness, age, weight, metabolism or even life and death. It’s this medical speak that is often used when they are talking about us. Their ways of speaking about is enables and limits our necessary affirmation. We might want to claim that what persists is the materiality of the body. But perhaps we will have fulfilled the same function and opened up some others if we can claim that what

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<sup>70</sup> Ionesco and Callus: “Encounters between Disability Studies and Critical Trauma Studies,” 6.

<sup>71</sup> Christina Crosby, “We are Looking for Positives Here: Seeking Intersection of Pain, Grief and Disability” *JHR Narrative Reflection* (2017), last consulted on 1th of August 2020, [https://www.jhrehab.org/wp-content/uploads/2016/11/JHR\\_Fall\\_2016\\_Crosby-1.pdf](https://www.jhrehab.org/wp-content/uploads/2016/11/JHR_Fall_2016_Crosby-1.pdf), 4.

<sup>72</sup> Crosby, “We are Looking for Positives Here,” 10.

<sup>73</sup> Crosby, “We are Looking for Positives Here,” 10.

<sup>74</sup> Clifton, “Grieving My Broken Body,” n.p.

persists here is a demand in and for a better language.<sup>75</sup> 'Exactly,' you would say, 'you can take your twigs and start making words with them. Doing more than just archiving and start to write.'

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'Have you ever been in pain because of your body? I never had the time to ask you that', I would say with a quiet voice. 'I too have suffered from an ableist environment, apart from the physical pain, which simply had more to do with the way my body works. But often my pain was a fierce refusal, not as in resisting a link with bodies with disability, but instead with the world around them. I reject the view that physical or mental impairment is a necessarily painful deficit. I find this social model both intellectually persuasive and politically necessary, but nonetheless incomplete.<sup>76</sup> I too have grieved all that has happened, to me, to you, to all the people I love. The pain of grief, so vivid, is hard to address in only a context of disability, but it also offers a perspective, because in science it is sometimes thought to play right into the devaluing of anyone's anomalies in mind and body. I think otherwise.<sup>77</sup> I mean... I died, it's the ultimate disability, but my sorrow goes deeper. The difficulties of intensely embodied pleasures, when I was still alive, left me wounded, hurt and very sad. In those moments of desolation, the claim that disability is 'a social and political identity' to be worn as a blazon of pride does not seem helpful.'<sup>78</sup> 'It's difficult to demonstrate and be an activist when you're dead, right?!' My witty reply would make you laugh again. 'Yes, it's pretty unlikely that somebody will hear me now shouting from my grave.' We would laugh and take a sip from our tea. 'The single most important achievement of the disabled people's movement is the recognition of the fact that the difficulties encountered by disabled people in their daily lives are not so much a direct and inevitable result of biological or mental impairment but rather a consequence of barriers created by societies that take little to no account of the impairment-related needs of people like us.'<sup>79</sup> If that is what you mean with being in pain, then yes, I have suffered a lot from that too.'

'It's almost funny that's the one thing we never talked about', only thinking about that idea makes me sad. 'It's not,' you would say 'disabilities are unsharable and uncommunicable, not only is it impossible to convey their intensity, but they can also incorporate and surmount the breakdown brought about by pain. The pain doesn't have to be physical for it not to be spoken about, the pain caused by your disabled identity is enough to feel alone.'<sup>80</sup> Nothing hurts more, nothing is more isolating than a disability that is not recognized. The loneliness resulting from the fact that I will never be able to adequately describe the pain I suffer, is probably the same thing that kept me from talking

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<sup>75</sup> Ellen Samuels, "Critical Divides," 67.

<sup>76</sup> Crosby, "We are Looking for Positives Here," 2.

<sup>77</sup> Crosby, "We are Looking for Positives Here," 3-4.

<sup>78</sup> Crosby, "We are Looking for Positives Here," 3-4.

<sup>79</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 5.

<sup>80</sup> Borg, "Narrating Disability, Trauma and Pain," 177.

about it with you. The pain of a disability shuts us down and leaves us dead. We become the dead weight others have to carry, only for the fact that we can not participate in society. Ignoring our existence is believing society is better off with us dead. So why are disability and death not somewhat the same and why don't we just own that position?'

By this time, you would have stood up to open my window and roll yourself a cigarette. You would have scrambled in your pockets, looking for your tobacco. Taking a small leaf, a portion of tobacco, rolling it up into a cigarette. Maybe I would have done the same. The gesture and ritual of rolling and smoking a cigarette had a deeper meaning to us both. Smoking, to us, was an act of rebellion. If all medical decisions were made over your head, without agency over your body, smoking means reclaiming an affect on your body. If you never had the chance to choose how your body is to be 'cured', then at least let us decide how we want to boycott it. It's a secret act of showing you don't fully agree with 'how healthy' people want you to be. If I cannot decide how my body is built, at least let me decide how I can jeopardize it. Smoking is a rebellious act that, for us, cries out the discomfort of others owning the right to our bodies when it is not theirs.

My partner is right. Disability, in any occurrence, is un-sharable and uncommunicable. It's not only impossible to convey its intensity to another, but it also cannot incorporate and surmount the breakdown brought by pain. Pain brings an immediate reversion to a state of anterior language, to the sound and cries a human makes before language is learned.<sup>81</sup> I too have felt the loneliness of this because I will never be able to adequately share the pain I suffer, nor can anyone accompany me into the realm of pain that is my life. Yet everybody knows what pain is like. That pain is the pain in my legs, but also the pain of not entering a room, in reality and metaphor. The pain of inaccessible rooms is the pain of not sharing a space of being. Invoking disability as a category of critical analysis, at the present time, is still a fairly radical endeavor. Our possible ability to contribute to society is not yet widely recognized as a legitimate or relevant position to address broad subjects such as philosophy, literature and arts, talking about more than disabled people and entering intersections with death, life and the overall human condition.<sup>82</sup>

You close the window again and retake your seat at the table. We breathe in, we breathe out. Fibers tighten and muscles relax. 'You have no idea for how long I dreamed of meeting somebody like you. Up to that point I didn't believe it would ever happen.' I say 'I know,' you say: 'and it hurts me to know what bitterness my death must have caused you. I too have felt very alone in this world. I used to have a cat...' I interrupt, 'Yes, I've heard that story. There's a cat you had, and it had an accident, so it walked with a little limp. You felt less alone at home, because now you weren't the only one with pain in your leg. I wish I could say *I can only imagine how lonely you must have felt* but the thing is... I

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<sup>81</sup> Borg, "Narrating Disability, Trauma and Pain," 177.

<sup>82</sup> Ellen Samuels, "Critical Divides," 58.

don't need to imagine. I was lonely too and there you were, my limping cat. Like a stray you strolled into my house, looking for what a new forever home.'

For many years I struggled with owning the label of disability. I simply didn't know or didn't want to see who I was. The non-disability status provides both a level of privilege but also a profound sense of misrecognition, resulting in a very internalized dissonance. This dilemma was further complicated by a disability whose symptoms and severity fluctuate widely. A variety of nonverbal and verbal gestures means to signal an identity, assuming visibility.<sup>83</sup> I became a master in hiding and with that I also lost my chance to connect with people who were alike. Coming out as *crip* taught me the normal is fluid and not easily addressed and categorized.

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'For the first time I could turn to someone who felt equal. I did not have to come out of the closet with you. Coming out is a process of redefinition of one's personal identity by rejecting the tyranny of the normal. Positive recognition of impairment and embracing disability as a valid social identity is something we all desperately need. Having to come out as a person with a disability entails no longer regarding disability as a reason for self-disgust or as something to be denied or hidden, but rather as an imposed, oppressive, social category to be challenged and broken down. Coming out, from this perspective, involves a political commitment.<sup>84</sup> But really, that requires so much courage. I was ready to be political, but not to throw my own body into the battlefield.' You take a deep and sad sigh 'I know this feeling. The perception that non-visibly disabled people prefer to pass and that passing is a sign and a product of assimilationist longings. Passing as non-disabled minimizes the significance of our impairments within our own personal and social lives. People with hidden impairments, like us, often make an effort to avoid the perceived stigma attached to a disabled identity.'<sup>85</sup> I nod, 'because of my disability, with symptoms varying from day to day, I live in between the world of the disabled and the non-disabled.'<sup>86</sup> In either of those worlds, I felt forced and at the same time assumed to be a liar.<sup>87</sup> I feel like I have no home.' With that said, now it is my turn to take a deep sigh fueled by a heavy heart filled with disappointment. You reply: 'If your body is a part of your identity, and the story of your body is so closely intertwined with trauma, your identity is too. People with disabilities experience past trauma and present pain and almost as if they are colonized, they become their bodies.' I laugh again 'Oh hell yes. The idea of passing and non-passing, and other responses to the stares, the others looking at us, are all embedded in what we allow to be seen. I hide

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<sup>83</sup> Ellen Samuels, "My Body, My Closet: Invisible Disability and the Limits of Coming-Out Discourse" *GLQ: A Journal Of Lesbian and Gay Studies* 9, nr.1-2 (2003): 239.

<sup>84</sup> Ellen Samuels, "My Body, My Closet," 237.

<sup>85</sup> Ellen Samuels, "My Body, My Closet," 240.

<sup>86</sup> *Idem.*

<sup>87</sup> Ellen Samuels, "My Body, My Closet," 242.

a lot because I don't trust others with the knowledge of reading it. It's like that one time somebody wanted to take photos of me, and I was told they would blur the picture so my face would be concealed, they said that no one would know it was me. They did not consider that my legs and scars are so recognizable, it wouldn't have mattered if they did. Everybody would still recognize me, not by my face, but by my scars. They didn't understand that my body couldn't be separated from 'me', that my body is 'me'. We both roll our eyes. We look at each other and by looking at each other we know that we know better.

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'Should I make some more tea?', you say. 'Yes, let's do that.' You stand up and go to my kitchen counter. It takes you some time to boil water by filling up the kettle and putting the fire on. While you're at it, you say: 'But it's true, indeed, when we consider 'theories of practices of identity and subject formation in Western culture', they are largely structured around the logic of visibility, even outside the service of science. It becomes apparent that the speculative or 'invisible' has generally functioned as the subordinate term in analogical equations to this date.<sup>88</sup> And I don't only mean this literally. Someone's disability can be visible and still others might not see it, as in the anecdote you shared. People can see our legs and without considering our label of 'disabled'. You pause, stand still and look up, thinking about your words. 'We have to refocus our endeavors from the visible signs of these identities to their visible manifestations.<sup>89</sup> As in, we need to rethink what we call visible. It's a whole new idea of 'there's more than meets the eye'. The lens of that photographer, as it focuses, enhances the cultural invisibility of your disability. It's the same thing for love. Finding a partner is more than finding somebody you love, sometimes it's also about somebody seeing a very specific pain of oppression that only few would understand or validate, because that person is one of the few who can see it. Someone who sees what is already visible. And others don't see, because they don't know it and because they don't educate themselves to see.' You go on. I notice this starts to turn in a rant, but you are interrupted by the whistle of the kettle. 'Oh, damn, I'm sorry, forgot the tea.'

When you have taken your seat again, I continue: 'I've thought a lot lately about what is called 'embodied coming out'.<sup>90</sup> It's an idea that offers transformative responses and engagements. I think that these experiences of the body inter-subjectively touch other bodies beyond cognitive perception. In other words, our bodies communicate with our bodies beyond our awareness. I have this very close friend and we have a catchphrase we often laugh about. Very often when ranting about stories of gender- and body-dysphoria, which we both experience, we just look at each other and say, 'bodies get bodies'. 'That's a good one', you say while you take a seat at the table again. 'I think I would get along very well with that person.' 'I'm sure you would.' I take a sip of my tea but notice it's still too hot.

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<sup>88</sup> Ellen Samuels, "My Body, My Closet," 236.

<sup>89</sup> Ellen Samuels, "My Body, My Closet," 236.

<sup>90</sup> Greenberg, "Stories Our Bodies Tell," 1.

While waiting for it to cool down I say: 'Rather than being seen as an abnormal occurrence, impairment, and so also illness or grief, are considered a part of the human condition. Moreover, they are considered as an integral part of our selfhood.<sup>91</sup> So why don't we acknowledge this as a healthy ground to connect? There are critics of postmodern body theories, like Sandahl observing Butler's theory of performativity and concluding that performativity relies on a metaphorical association between the gender 'freakishness' of queerness and 'deformed' disabled bodies. Butler uses disability as a metaphor for gender and sex differences.<sup>92</sup> What our bodies can or cannot do, is based on a mutual understanding of the idea that all our bodies are limited by the flesh it is presented in. Even more, the body becomes a ground for negotiating social relationships and addressing experiences of any sort of violence like shame and abjections in the public world.<sup>93</sup> So why can't we do that with pain, and also grief. Since they claim a sameness not of experience but of resistance. We resist our losses whether it is the deaths of a body part or of a person, and we do so with our bodies. It's quite logical when you think about it. However, though it has a certain logic, it does not address the deeper issue of presumptions of sameness that produces oversimplified mapping analogies.<sup>94</sup> As much as I can relate to stories of bodies not being the way they should be, I am still always looking for someone with a body analogous to mine. So I try to connect with knowing that all bodies are limited within their flesh and that causes grief. This uneasiness, often self-destructing tension between appearances and identity, this social scrutiny that refuses to accept statements of identity without proof...<sup>95</sup> Oh, I'm sorry. I'm ranting.' I lean back and look outside. Your gaze follows mine and we see how it has started to rain.

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Your eyes are casting down and I see how you are becoming sad. You're thinking of something, but I can't seem to see what's on your mind. I reach out my hand across the kitchen table, and I make it reach yours. Fingers intertwine and with my thumb I try to stroke the palm of your hand, trying to soothe and bring some comfort. 'What are you thinking about?'. It takes you a while before you can answer. 'As much as we can try to rationalize this and swathe this in academic vocabulary, the pain is just always there. We can learn that in the medical model, pain is theorized as an experience that isolates and individualizes, that pain is assumed to cut the sufferer off from others, it just leaves you with the knowledge that no one else can feel what you're feeling. All too often, pain represents disability as an individual burden.<sup>96</sup> And as much as I have left you alone, I too didn't have the chance to experience a relationship with someone that understood this part of my identity in an

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<sup>91</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 9.

<sup>92</sup> Ellen Samuels, "Critical Divides," 72.

<sup>93</sup> Heather Hewett, "At The Crossroads: Disability and Trauma in *The Farming Bones*" *MELIUS* 31, nr. 3 (2006): n.p.

<sup>94</sup> Ellen Samuels, "My Body, My Closet," 236.

<sup>95</sup> Ellen Samuels, "My Body, My Closet," 233.

<sup>96</sup> Crosby, "We are Looking for Positives Here," 2.

embodied sense. All of us got hurt here, that includes me too.’ A silence falls and the rhythm of raindrops on the roof and windows is the only thing we hear, as almost it is trying to soothe us. I try to help, ‘You could argue that so-called disabled bodies actually understand the world in a new and valuable way unavailable to so-called normal people.’<sup>97</sup> We know something not many people know, that vulnerability, forgiveness and acceptance are privileges. So many others just make the assumptions that they are readily available to all, like fresh products at the grocery store.<sup>98</sup> It’s the reason that I do what I do. I got into disability studies because of the same need of recasting disability as something more than inherently traumatic and traumatizing. There has to be a way to create the possibility of looking at disability through a lens in spite of the fear of a refocus on ‘acts of disabling’. Those moments of bodily breach and psychic tear, moments of wounding and their aftermath, turn human bodies into the real corporeal screen upon which are inscribed notions of the normal and the pathological.<sup>99</sup> There is a way to see disabling effects, which is not only something to be treated as a naïve trigger warning or unthoughtful call for safe spaces, but also something powerful and connecting.<sup>100</sup> That is what we have in common, that is how we can understand and find connection.’ You look at me and I see the tears in your eyes. ‘You see, this is what I wanted. And now it’s gone.’

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In reading I found the confirmation that disability is an identity created by oppression and injustice that activists and intellectuals have politicized and recast as what is called *crip pride*.<sup>101</sup> Our short story was hidden in our bodies, and so it embodied our love. It is our body as much as it is the body we share. Our scars, the way we walk, the difficulties of our scarred skin enduring physical touch. Movies tend to privilege the seen over the heard and it is the same with bodily senses. Experienced as spectators we know that when we watch a movie, we do so with all our senses mobilized.<sup>102</sup> The same can be said about our bodies, we speak with all of our body and there is no canon, no mainstream of bringing these stories to a general public without the easy trap of falling into generalizations and stereotypes. Often because they are written by able-bodied people, often because they are only looked at by able-bodied people. They speak about bodies that are not theirs. There is a lack of care and insight on how much disabilities can add to common themes in what makes us human. The result is a neglect of the enrichment in conversations about trauma, pain, vulnerability, frailty and what it means to heal and connect. This meeting of a person who, for the first time, has a body I knew, was a bitter realization of ‘once in a lifetime’.

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<sup>97</sup> Crosby, “We are Looking for Positives Here,” 2.

<sup>98</sup> Milstein, *Rebellious Mourning*, 68.

<sup>99</sup> Ionesco and Callus: “Encounters between Disability Studies and Critical Trauma Studies,” 22.

<sup>100</sup> Ionesco and Callus: “Encounters between Disability Studies and Critical Trauma Studies,” 24.

<sup>101</sup> Crosby, “We are Looking for Positives Here,” 4.

<sup>102</sup> Greenberg, “Stories Our Bodies Tell,” 6.

Our bodies teach us that they possess the knowledge beyond our cognitive or intellectual comprehension. Few people know the depth of relief of finding somebody who's like you. A rhythm, a cadence, like no other, held in between the very ordinary fact that legs just work the way they work and the recognition that they are the way you are. Your right leg and your left leg have found their own way of carrying through this world, with its limb as natural as can be. Footsteps, like seconds, indicating the passing of your time here on earth. Going foot by foot, one in front of the other. The way my footsteps of the past were built, like the ticking of time, the ticking of losing base and isolation. A limp that has a unique rhythm, which if outcast by society, mismatches the choreography of all others. With my partner, I had found the counterpoint in rhythm. Together, by the simple act of walking, we built a dancing routine of a very specific vulnerable kindness. A ballroom waltz of frailty, acceptance and intimacy. Like *Clapping Music*, made in 1972 by Steve Reich, which illustrated that if one is not as good a guitarist or singer, you turn to the things you know that work: your body.<sup>103</sup> An act of resilience to the contemporary ideas in music can be as small as clapping your hands, and in analogy, the resilience of people with disabilities is within not hiding their limp. We cannot phase the rhythms of the able-bodied walk, but in variations of a 12/8 time maybe, only shifting one eighth of a note to the right, we are performers of pain, continuing into a canonization of rhythmicity by crooked walks, broken legs, crutches and canes. Contributing to the world of syncopations as it progresses in time.

Ableism reinforces what society thinks of as beauty in sometimes the most perversely subtle ways. The normatively beautiful body, we are taught, has two well-functioning arms and legs. It is proportioned, balanced, and if anything, hyper-nondisabled in its appearances and mannerisms.<sup>104</sup> We must commit ourselves to rewriting what true beauty means and we can do that with our disabilities. Our disabilities fracture the assumption that beauty is reserved for those who appear in the perfect bodymind. It urges that there is pleasure and eroticism in bearing witness to the things that are broken, in cultivating a space where bodies and minds that are traditionally forced into invisibility can gather together.<sup>105</sup>

When I met my partner, I was so excited. And scared. But I needn't have been, for no one was ever kinder to me. With my partner I found a story and a body that completed mine for the first time. I felt as though I looked at my own reflection through my partner's eyes. I wasn't alone anymore. But that stray limping cat, by a turn of events, mutated into a wild boar. The limb at first was a funny walk to be romanticized and to fall in love with, but turned into heavy hooves.

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<sup>103</sup> Justin Colannino, Francisco Gomez and Godfried T. Toussaint, "Analysis of emergent beat-class sets in Steve Reich's *Clapping Music* and the *Yoruba* bell timeline," *Perspectives of New Music*, s.n. (2009): n.p.

<sup>104</sup> Shayda Kafai, "Reclaiming and Honoring: Sins Invalid's Cultivation of Crip Beauty" *WSQ: Women's Studies Quarterly* 46, nr. 1-2 (2018): 231.

<sup>105</sup> Kafai, "Reclaiming and Honoring," 232.

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There is a new depth to what it means to feel something in your bones. I could see the stones in my partner's pocket. The warmth and softening of another one's body heat, in this case, became the creation of another, alternative kinship. One in which I wouldn't have to first teach others how to behave around me. In the very stability of our disabled identity, we recognize the pervasive agency over all that is different.

The joy of a life not spent having to worry about whether you are understood or seen, but where instead there is space to begin the next chapter: where we are able to direct our lives to a larger meaning and purpose. Affirming and even celebrating one's identity as a disabled person also finds its expression in where our impairment and what it is based on is not more than a socially-oriented understanding of disability.<sup>106</sup> The act of creating, like scholar Judith Butler asserts, means that a disability by itself is performative in the sense that it constitutes as an effect the very subject that it appears to express. Disability secures its self-identity and shores up onto ontological boundaries by protecting itself from what it sees as the continual predatory encroachments of its contaminated other 'ability'.<sup>107</sup> We can do unique things with our unique bodies, regardless of how violently others may look at us. That is, if that chance is given to us.

The construction of a body constitutes the fact that we cannot operate without it, that without it there would be no 'I' and thus also no 'we'.<sup>108</sup> But if that body is considered broken, perhaps it is also a metaphor for the disconnect of interpersonal relationships, of any kind. A broken body is much more than an identity category. It is the impossibility to connect deeper because of what is broken. It is the knowledge that the one with the broken body can never fully merge with others, it can only touch. I will never be alike; I will be an ally of the able-bodied but never a partner.

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One can see us sitting at my kitchen table, crying over how we never had the chance to properly feel how deeply we needed each other. How our partnership had unique characteristics impossible for some others to see. Death made all that clear for us. Maybe I could have gotten up to my drawer and taken out a handkerchief, sitting right back in the same position I left. A mirror of your body. My hands concealing yours, holding them.

'There is no need to be sad about the things that never happened. It's useless. We had the time we had, and the impact of it changed my life. There is no need to be sad about that,' I say.

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<sup>106</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 10.

<sup>107</sup> Ellen Samuels, "Critical Divides," 64.

<sup>108</sup> Ellen Samuels, "Critical Divides," 62.

'Maybe in some way, you were the breaking point I desperately needed.' I look at my partner and I smile. 'In a way, you never died. Your values and your kindness are still here. Maybe it is only because of your death, that our relationship shows true meaning of the value of my life and so our short existence here on earth. It will be forever symbolized in how kind I try to be to others.' I see that I can grab your attention again. My words are soothing, it's working. 'Really, these memories I have, reminded by my body, of all the possible pleasures... Your body is a site of pain but also of desire and it is of a perpetually unquenchable nature. Even with all its compromised strength and its difficult tactile perceptions, what we had was magic. With you I have found the meaning of what people call 'the power in my disability.' 'How do you mean?' You say and I can see the spark of curiosity again. 'A body comes with a way of life. I have started seeing everything that happened, your death and all my previous life stories, as things that have happened on my body. My body is a site of loss, no bodily existence is perpetual and thus a reminder of vulnerability. Bodies are sites of illnesses, of violence, of debilitation. My body is a social site, it marks me as it is attached to others. My body is not something private, it is a social phenomenon that has a public dimension. My body is a site of agency, yet it also exposes me to the other and to a potential injury. It can be an accident, very physical like a car running me over, or something very abstract, like losing somebody that loved my body in all its appearances. A body is yours and it isn't yours.'<sup>109</sup>

I take a sip of my tea and say: 'You see, in losing somebody you lose yourself. Claiming that the loss of a significant other cannot be understood, starts with seeing that one is never just fully only oneself. It's the constant recurring question 'who am I without you?'. I have lost what I thought was 'you', only to discover that 'I' had gone missing as well. Or perhaps what I have lost 'in' you, that for which I have no ready vocabulary, is a relationality.'<sup>110</sup> You lean back and sigh: 'It's a beautiful way to look at bodies. I can almost see it. I see a body that is like a landscape, as wide as the horizon. There are trees, hills, a small lake and maybe only a little treehouse. We could take endless walks in it. And this bodily landscape of all the feelings it could have visualizes the flood of disaster-prone areas, where people subsequently will have limited defenses against disasters. Exposing pre-existing inequalities, leading to disproportionate damages, loss of property and even death. The social vulnerability perspective is one in which societies collectively determine who they're going to let live in those possible disaster areas'.<sup>111</sup> I smile, and take the kettle again to fill up our tea. 'That's so beautifully phrased. As a result of that metaphor, vulnerability to disasters is not seen as situated within individuals, but rather it is presented as the result of choices that societies make about what populations have access to protection from disasters and their aftermath. There is a question society needs to ask itself: 'Who deserves protection? Who owns what sadness and who takes care of who? For what people do we want to avoid disasters?'<sup>112</sup> You fill me in: 'Even better, you need to ask

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<sup>109</sup> Borg, "Narrating Disability, Trauma and Pain," 175.

<sup>110</sup> Idem.

<sup>111</sup> McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability," 307.

<sup>112</sup> McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability," 308.

yourself 'what is that trauma' because in that wild and big landscape, it's impossible just to see an overview of how it all works. It is the Anthropocene.' I throw something back at you. It starts to make me happy again, I like discussions like this: 'It's so much more than just this body that we become; it's using it as a method. Engaging with these borderline standpoints, arguing that an engagement with trauma is the impossibility to distinguish knowing and feeling. Bringing the idea of 'belatedness' at the center of our existence and arguing that a trauma is an experience so intensely painful that the mind of the survivor who has been exposed to trauma is unable to process the event under normal circumstances. We need the flood in our landscape. The narration written by the witness of a trauma is both amnesic and 'unspeakable', thus demonstrating that the speaking of trauma is an unsolvable problem of the unconscious and illuminating the inherent contradictions of experience and language.'<sup>113</sup> 'We are not the landscape you say, we are the flood.' As I try to follow you, I think I understand. 'Yes! The tendency of authors to use disabled characters in narratives and quota-reaching representation, 'making them human,' doesn't do us any good. Making us human beings in their own right, and doing justice to us is not the same as making a representation for the lived experiences of disability. If we are seen as the flood, disability is an aspect of the human condition that is inevitable but navigable. The autobiographical is merged with the theoretical, we are both.'<sup>114</sup>

I don't know how that conversation would have ended. Maybe a little bell would ring, heaven calling you, saying it's time to go back. Maybe we could have just gone to bed together, and I would have woken up alone again. For all I know you might just have stood up and turned into a cat, galloping out of my apartment. I don't know, in my head this imaginary conversation is still happening.

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Having finished writing this chapter, I fell asleep, alone in my bed. When I woke up in the morning, the light was very bright outside and the first warm days of summer had just started. I opened the window, drank a cup of coffee as I felt how the sun warmed my cheeks. I looked up at the sky and there was an ease in my breathing that had been gone forever. I washed my face, had breakfast and went out into the air.

I went out to have coffee with the people you love. By now we are not only crying anymore, but there are moments like this one when we chatter and giggle about the little things that happen in our lives. It's in those moments I realize I don't even remember I had an old life. I am somebody completely new. I have found a very deep sense of rest within myself. I close my eyes. Tranquility. The trauma of death, and the impossibility to describe it, have made it easier to see that there is no more need for turmoil of past trauma and pain. Not that it isn't there, but it found its way embroidered within me and it is no longer smothering me.

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<sup>113</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 18.

<sup>114</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 11.

Therapy helped me to construct and reconstruct narratives and life stories, which helped me mourn my loss and make sense of my new life.<sup>115</sup> I had turned into my own dark self, merely a shadow of who I was before, with dull pale skin, severe weight loss, losing my hair. I stayed inside, not ready to return to the community, waiting ahead for a very long time of in-house rehabilitation. Therapy helped me to recognize the complex and ambiguous nature of recovery and I soon understood the question 'what am I to do?' can only be answered prior to 'what stories am I part of?'<sup>116</sup> Recognizing my story of disability and grief intersecting was the tipping point, finding my way within mourning. My unique experience has relevance beyond myself. The story of a person within the context of all stories, all experiences: every person is like every other person but is like no other person.<sup>117</sup> My story captures the various performative dimensions of self-narration.<sup>118</sup> The dreams I have written at night are the start of the brink of dawn, as I find my way within grief. My disability gave me the key to understanding a bereaved life and bereavement taught me, for the first time, to grieve about my disability.

I should be angry about what has happened, but I'm not. I'm thankful. One of the last things my partner sent me was a quote by Emma Goldman:

*'They are two human beings, of different temperament, feelings and emotions. Each is a small cosmos in himself, engrossed in his own thoughts and ideas. It is glorious and poetic if these two worlds meet in the freedom and equality... Even if this lasts but a short time it is already worthwhile. But, the moment the two worlds are forced together, all the beauty and fragrance ceases and nothing but death leaves remain.'*<sup>119</sup>

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<sup>115</sup> Clifton, "Grieving My Broken Body," n.p.

<sup>116</sup> Idem.

<sup>117</sup> Idem.

<sup>118</sup> Borg, "Narrating Disability, Trauma and Pain," 174.

<sup>119</sup> Emma Goldman, *Anarchy and the Sex-Question, Essays on Woman and Emancipation 1896-1926*. (California: PM Press, 2016): 28.

### 3. Essay III - The Scar Manifest

Underneath my clothes, I carry a story with me. I carry a burden of a leg, covered from top to toe in scars. They are scars from precious puncture wounds that were a part of the surgical treatment I underwent to 'correct' my disability. Elliptical dimples as souvenirs of a time when metal bolts and pins held a skinny flesh-less leg together. Dimples and bumps alternate like craters and rocks. My leg is a deep-sea mountain of unpleasant bone and thin, flimsy skin, zipped up with long lines of surgical scars. I like to think of them as star constellations. It is trauma that stung like a needle, a puncture that slowly drains you empty, pain survived, but poorly healed. Scars, unnatural birthmarks, project like a phantasmagoria the story of our bodies on the walls in the room. I often fantasize about how that magic lantern lights up the bedroom like a children's night light of the universe. Lying on our backs, we can point out specific star constellations and tell their mythical stories.

Memories emerge in the form of flashbacks, like the wallpaper of a broken childhood bedroom, on our body. A body feels the events of the past and the memories of its being, so real it's comparable to its broken flesh.<sup>120</sup> Flesh feeling raw and fragile, emotional wounds so deep they feel like unhealed burns and fallen scabs. There are infinite descriptions of bodily marks and disfigurements and I'll tell you about mine.

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The word 'trauma', coming from the Greek word for 'wound' and derived from the word 'to pierce' is a term that has long been used in medicine and surgery and that generally designates 'any injury where the skin is broken as a consequence of external violence and the effects of such an injury upon an organism as a whole' and whose implications were extended to other types of injuries.<sup>121</sup> Perhaps the scars that I carry are the clearest example, clearly translated puncture wounds on the skin affecting my organism as a whole. They are the barely healed wounds from an un-consensual piercing of the flesh justified as necessary in its external normative violence. My scars look like a chaotic universe, random and unpredictable, yet they are symmetrical and correlated.<sup>122</sup>

Through scars we see the pain of the other one's body. We gaze upon them and those bodies become the site for continual modification and regulation. They are routinely othered by 'a

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<sup>120</sup> Hewett, "At The Crossroads," n.p.

<sup>121</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 13.

<sup>122</sup> Maybe I'm showing too much of a personal experience here. Maybe I'm being too much of an exhibitionist, but that's how my disability taught me to enforce understanding. It's often funny to see what straying coping-strategies people develop when dealing with potential violence. Mine is to tell my story, provide information, the way I'm telling you in this thesis. I have multiple childhood memories of doctors and medical staff asking me if it's okay to take photos, video-footage of my crooked and limping body. Example-footage to use as teaching tools. I remember well this occasion when I was in the hospital, I must have been around the age of eleven, when my doctor asked me if some students could take a look at my leg. This happened often. Once I counted 20 youngsters from Japan, who came inside my hospital room to take a look at my legs, for educational reasons. I have the narrative of being exposed, exoticized; I don't mind.

tangle of eyes'. Eyes raising, eyes meeting, eyes sliding away, eyes widening, eyes locking and eyes casting down.<sup>123</sup> Our body stumbles over itself by the trauma it radiates and grows bigger than us, aroused by the gazing others, casted and moulded by society. It is created through a process of discipline, as we act upon the body including a calculated manipulation of its elements, its gestures, its behavior.<sup>124</sup> This discipline is the cast to heal our bones, the crutches we walk with and the scalpel cutting our skin. Our bodies are hospitalized, institutionalized, rehabilitated and normalized and often our minds just have to endure. Our beings subjugated and our bodies obedient, utilized as an excuse to be subjected and used, transformed and improved. This carousel of medics swirls like a panopticon around itself. Relationships within Foucauldian prisons, medical complexes and our own violent un-adapted domestic space.<sup>125</sup> The same Western colonial modernity that labeled us turned us into disabled monsters, gendered, sexualized, radicalized figures threatening the 'other body'. Whether we perceive it in gaping awe, delighted terror or in absent knowledge, the monstrous emerges from culture-bound expectations even as it violates them.<sup>126</sup> Through bonds of numerous occasions of violence, actively engaging with stories of systemic, or accidental, collateral violence, there is the possibility of eschewing the clichéd narratives of victimization and individual psychological recovery.<sup>127</sup>

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The meaning of the word trauma was carried into a deeper psychological level, into psychoanalysis: the idea of a violent shock, the idea of a wound and the idea of consequences affecting the whole organization of our inner thoughts.<sup>128</sup> To be scarred is the unbearable heaviness of remembering something forever.<sup>129</sup> It is overwhelming and the terror that follows leads to helplessness. A body that has been traumatized recoils. It freezes to protect itself for nothing will ever be light again. Scars tell us something about how the limited elasticity of our defiled skin fails us, and pulls us ever back to the hour zero that defined us. That wild boar stroked us with its dark fur leaving behind a distorted relief in the skin. We are now forever changed. Trauma is the ultimate experience of 'this will last forever'.<sup>130</sup>

To be scarred is to lose the agency, for our bodies tell our story before we had the chance. Accidental or indented words are written without our permission as our own intentions and mouths are sewn shut.

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<sup>123</sup> Karen Hammer, "A Scar is More than a Wound," 159.

<sup>124</sup> Robyn Long, "Sexual subjectivities within neoliberalism: Can queer and crip engagements offer an alternative praxis?" *Journal of International Women's Studies*, 19, Nr.1 (2018): 2.

<sup>125</sup> Karen Hammer, "A Scar is More than a Wound," 160.

<sup>126</sup> Robyn Long, "Sexual subjectivities within neoliberalism," 5.

<sup>127</sup> Karen Hammer, "A Scar is More than a Wound: Rethinking Community and Intimacy through Queer and Disability Theory" *Rocky Mountain Review* 68, nr. 2 (2014): 173.

<sup>128</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 13.

<sup>129</sup> Van Der Kolk, *The Body Keeps the Score*, 184.

<sup>130</sup> Van Der Kolk, *The Body Keeps the Score*, 70.

The scars embody how badly we own our trauma. All trauma highlights a common theme, namely that such experience is perceived as shattering on various levels. It destroys our body, our psyche and our language.<sup>131</sup> The shattering that trauma brings with it, and on the other hand the use of language to connect the broken pieces, serves as the aftermath of dissolution.<sup>132</sup> When one has eventually regained the ability to speak, they are permanently changed. The marred statement of an altered body provides a continual reminder of all that was lost.<sup>133</sup> A yellow sticky-note on the leg, arm, torso, breasts or brain, telling us that today is a different time.

Being traumatized is not just an issue of being stuck in the past, it is just as much a problem of not being fully alive in the present.<sup>134</sup> If scars are the defined residue of the events of the past, they are a lived, poetic experience of a very particular everyday understanding of an impaired person owning their life.<sup>135</sup> The scar is an embodied sign that traces ambivalences, shifting meanings, and transformations of personal material into poetic labor.<sup>136</sup> A scar is an edge. It is often what drives us to the edge. It is the transgression from what is now to what once was before, from who we are today to who we were the time before we got scarred. When I read Ali Smith's novel *Artful*, I found a description of scars written in words better than I could:

*Edges involve extremes. Edges are borders. Edges are very much about identity, about who you are. Crossing a border is not simply a thing. Geopolitically, getting anywhere round the world in which we live now requires a constant producing of proof of identity. Who are you? You can't cross till we're sure. When we know, then we'll decide whether you can or not. Edge is the difference between one thing and another. It's the brink... It can wound. It can cut. It's the blade – but it's the blunt part of the knife too. It's the place where two sides of a solid thing come together. It means bitterness and it means irritability, edginess, and it means having the edge, having the advantage... There's always an edge, in any dialogue, in any exchange. There's even an edge in monologue, between the speaker and the silent listener. In fact, there's an edge in every meeting, between every thing about to come together with something and beyond it. Edges are magic, too; there's a kind of forbidden magic on the borders of things, always a ceremony of crossing over, even if we ignore it or are unaware of it. In medieval times weddings didn't take place inside churches but at their doors – thresholds as markers of the edge of things and places are loaded, framed spaces through which we pass from one state to another...*<sup>137</sup>

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<sup>131</sup> Borg, "Narrating Disability, Trauma and Pain," 170.

<sup>132</sup> Idem.

<sup>133</sup> Hewett, "At The Crossroads," n.p.

<sup>134</sup> Van Der Kolk, *The Body Keeps the Score*, 221.

<sup>135</sup> Petra Koppers, "Scars in disability culture poetry: towards connection" *Disability & Society* 23, nr.2 (2008): 148.

<sup>136</sup> Koppers, "Scars in disability culture poetry," 141.

<sup>137</sup> Ali Smith, *Artful* (London: Penguin Books, 2013), 125-127.

Where it might be our words that dance, or our knees, amputee legs, spastic arms or difficult tongues, the creation of language is our inner thoughts having to fit into words, dancing in a way, to shape bodies to words and words to bodies.<sup>138</sup> The resulting critical vocabulary tends not to describe the effects of trauma with words such as 'disability', but tells us more about the conditions our bodies have endured.<sup>139</sup> They leave us to the idea that bodies are anomalous. Anomalous embodiment, a term that creates a common ground between all who have gotten hurt. It is the unlabeled and very personal scrambling of semiotics that broken skin gave new meaning to.<sup>140</sup>

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Showing and sharing the grieving body, the broken body, is a narrator's attempt to articulate bodily changes, often painful and unwanted, laying far outside of our control. When seen and no longer hidden, we become subjected to the gaze of those others, and its consequential lack of narrative agency. It shows our frailty in the overwhelming anxiety of the hope of being understood. And for those who had surgery after surgery, wounds pierced bit by bit, 'a death by a million cuts' might feel more like the analogies in every puncture poorly translated in a judgement or stereotype. We, people with scars, are hoping for a way to connect across bodies, independent of their labels. It is the hope of saying 'here are our worlds of pain'. Here are the crisscrossed trails of furrowed scars, our maps of traumatic stars, a powerful symbol of the pain we are rooted in.<sup>141</sup> It is as if our scars want to speak our own native tongue.

We, disabled people, can be anarchists showing that the normal is non-existing and that there is no such thing as a body that is not in pain. The rebellious body denies standards of the 'perfect': coping without help from others, returning to the unwritten body after surgery, or finishing a mourning process. As we lift up our skirts, roll up our sleeves, the undressing of scars is almost exclusively for those who have experienced impairment, pain or loss and some of us have done it numerous times uncomfortably, in full shame, in front of docile doctors. Their meaning is defined in their minoritized identity. As I show that I am different by telling you how we are the same, embarking the journey of a new start, getting to know each other all over again.

Scars present ways to keep the body's world within its specificity safe, its creatures, its strength of emotions, its unbalanced singularity, and to make them resonate with others. The scars we have, their shared pain, everybody's body, honors the best thing we have: our corporal beings,

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<sup>138</sup> Koppers, "Scars in disability culture poetry," 142.

<sup>139</sup> Hewett, "At The Crossroads," n.p.

<sup>140</sup> Let me be clear: this is not a story about how scars are erotic, beribboned honor, or gnarly strength. This is not a story about a scar as a site of masculinity, as battle memento, an amazon's prize, scars as evidence of lives lived on the edge, heroine tracks of the smarting cut of a dueling lash. Nor the exoticized scars; speaking of rituals and desires for difference by modern primitives and other western flower children and fairies. These are all eroticized, fetishized scars. Scars are sexy, surely, until they appear on your own skin, itching, pulling, reminding you of boundaries. To see the power of the scar as a visual object and enticing bodily opening, is to transform its semiotic meaning. (Koppers, "Scars in disability culture poetry," 143.)

<sup>141</sup> Hewett, "At The Crossroads," n.p.

changing in time and connection.<sup>142</sup> The open wound, the mark of pain and living with labels, living with painful bodies, with aching brains, within the pain caused by those same labels and practices on bodies and minds. But once closed, those scars evolve into connections to so much more. They open like a can filled with magic.<sup>143</sup>

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Disability, impairment, trauma, loss, and the rebirth from it give more power to our words and, as a consequence, give more power to our wounds. It is the ability to see beyond the everyday world. Those scars, if turned into words, grow deeper than the surgeon's scalpel or the accidental happening to us.<sup>144</sup> They echo more strongly than their medical origin. They reach both inside and out. Layer on layer the twisted connective tissue finds a way to healing, creating a chaotic cellular soup instead of long steady lines of cells. They enable us to perform as a mediator, carrying messages back and forth between the human world and the divine.<sup>145</sup> That what impairs turns into a source for understanding that the world is layered around the distracting mundane. It is stepping from the daily lives into the enchanting world of misery and pain, to what is beyond our daily routine, and to the existential idea of what it means to get hurt. When knowing what power lies in scars, the disabled become the usable again. We, the impaired, are embodied contradictions, tricksters and mediators, in whose bodily figures their powers are highlighted by the gaps and negative spaces, to deny the 'perfect' body.<sup>146</sup> Like Kharon, the ferryman on the river Styx, we come with the ability to carry words from the living to the dead, stories from the past to the present. We have done it so many times already because we know the bodies that were given to us. With scars the body is the present with a well-written past. We give knowledge and receive golden coins to soothe the pain of our own scars, the thankful gift of validation in society. When sailing out of the cave, those golden coins reflect sunlight and our anomalies become a halo of strength.

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The need of an actual implied listener is knowing that I 'need you' in order to 'be able to see me'.<sup>147</sup> If one is not seen, one falls into loneliness, isolation and disconnection. Aside from a call for recognition and self-restoration, there is an implicit and darker thing in operating in the bodies we share. Whenever you offer an account of yourself to others, you labor to present yourself as coherent and worthy of recognition and attention, like I'm doing now. I tell you how it is and I twirl myself around into a posture that you would like to read. This characterization captures how the disability-narrative,

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<sup>142</sup> Kuppens, "Scars in disability culture poetry," 142.

<sup>143</sup> Kuppens, "Scars in disability culture poetry," 145.

<sup>144</sup> Kuppens, "Scars in disability culture poetry," 144.

<sup>145</sup> Hewett, "At The Crossroads," n.p.

<sup>146</sup> Idem.

<sup>147</sup> Borg, "Narrating Disability, Trauma and Pain," 175.

which essentially revolves around corporeal damages, is shaped by intense affective states, particularly pain, physical and psychological, and grief.<sup>148</sup> Disability is the constant reminder of all that is lost. It is the negative space of what is supposed to be there: a limb, a toe, functioning muscles, an able brain or even a companion or a partner. The scars on our bodies are the memories of our loved ones slowly being buried into the earth, whether it was our previous selves or whether it was another we have loved deeply, they are all the same funerals. That impairment, those funerals of loss, demand a story.<sup>149</sup>

Disability and scars show a potential danger: the danger of possibility.<sup>150</sup> We are the visual reminder to the world that every body is always one sickness, one accident or one unlucky event away from being hurt. The scarred body is the rebellious carrier of all potential bereavement. Grieving the events that happened, grieving the events yet to come. In these real and imagined sites, *queer* and *crip* desire is expressed in small acts of solidarity, in the accumulation of ordinary gestures. Desire and love are expressed in the offering of a cigarette through the bars of a Foucauldian prison cell, the hanging of hand-sewed curtains, or in simple non-verbal gestures that speak to a mutual recognition of shared oppression and pain.<sup>151</sup> Thus scars themselves become not only evidence of wounding, but also a new surface on which to form community and intimacy.<sup>152</sup>

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My disability reminds me every day of the partner I lost, and here I speak in double terms. My partner is my body and my partner is my lost lover. Both of them died in a hospital bed. Both of them die over and over again in my nightmares. It is a double layered dying embodiment in which disability is the intersection connected on my skin. It is the cellular soup on my leg with cells duplicating, changing form into symmetrical bubbling mitosis. Cells of trauma split into different cells, with the same content, yet now there is not one, but two or four, eight... They multiply with membranes, so frail and transparent, they create the infinite beginning of a small human being, that scared child crying, breathing out shrieks and weeping pain.

These cells are interlocking chains of trauma. In this context it is clear that mourning, grief and bereavement are not processes, not on the account of bereavement of a disability, nor for the loss of a

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<sup>148</sup> Idem.

<sup>149</sup> Borg, "Narrating Disability, Trauma and Pain," 171.

<sup>150</sup> Hewett, "At The Crossroads," n.p.

<sup>151</sup> "Conveying the complicity of forming relationships is clear to see in marginalized communities. Through engagement with queer and disability theory, we can make more visible the reality of our collective contingency, in that messy terrain across the identity categories of queer and crip. This awareness often emerges in local queer communities. An essential part of theorizing pain, trauma and disjuncture in queer and crip experiences is to allow memories to surface, and to use this knowledge to achieve an understanding of how bonds are constituted. We should strive for a community built on tenderness, care and connection and avoid a community being angry, aggressive and traumatized, recoiled in its own existence." (Karen Hammer, "A Scar is More than a Wound," 173-174.)

<sup>152</sup> Karen Hammer, "A Scar is More than a Wound," 160.

loved one. The loss of a partner is the scar in my brain, built by the memories of the house I don't want to enter anymore, and it is the same house I have built for the pain of my disability. There is no other side on the path of grief, of loss, of pain, for the entity of a scar is permanent. Broken people live in broken bodies but its meaning is fluid and ever changeable. Trauma and pain cannot make us recover from our scars until we have become familiar with and befriended the sensations in our bodies again.<sup>153</sup>

The fluidity of wounds is not to be categorized and put into numbers, brain scans or labels, vast entities, but is more like a holistic network of hurtful or painful narratives. If one is added, changing or moving, the others follow, like a choreography or a dance. If one is touched they all start changing like a chemical reaction, all the others follow with all the emotional labor that has been performed on previous occasions of loss. Moreover, all of humanity is performing this enormous, collective mass ornament of bereavement.<sup>154</sup> They are like the spiderweb: when one thread is put under tension, it changes the entire shape of the web. It is ever fluid, fragile and mostly invisible. Until we get trapped within it. It is a genealogy of experiences, the consciousness of a body that dances on the spiderweb, tracing back the leitmotifs of pain and loss, rewriting the spider's web that spelled the word 'bereavement'. We are all just dancing anomalies.

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The disabled body is a nightmare for any discourse that is limited by the very predilection of the dominant, ableist culture. The body is a site of jouissance, a native ground of pleasure, the scene of an excess that defies reason, that takes dominant ideas and its rigid, power-laden vision and becomes more than just 'body as a tool'.<sup>155</sup> Our experience of our ailing, aching, aging body provides an important window to what is, at its core, an existential dilemma.<sup>156</sup> Scars offer a perspective on the meaning of disability and its relationships to trauma.<sup>157</sup> By thinking within the discourse of disability studies, discussions about testimony and memory often emerge and it is the same for trauma studies and thanatological literature. They even use a similar vocabulary. However, they all remain elusive, disconnected into two theoretical discussions denying the frequently overlapping phenomena.<sup>158</sup> If these scarred beings and bereaved people are understood as disabled figures, it characterizes and encompasses the seemingly contradictory qualities of frailty and strength, of highlighting the centrality of the body and its dissociation at the same time, and of the experiences of ability and disability during any physical, psychological and emotional journey.<sup>159</sup> There is a constant attempt to transform

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<sup>153</sup> Van Der Kolk, *The Body Keeps the Score*, 100.

<sup>154</sup> This is a reference to the concept of 'the mass ornament' by Siegfried Kracauer. (Siegfried Kracauer, *The Mass Ornament* (London: Harvard University Press, 1963): 77.)

<sup>155</sup> Ellen Samuels, "Critical Divides," 68.

<sup>156</sup> The notion of 'youth' has a double layer here. Where it has a component of criticizing the discrimination based on age, ageism, it is as much as about recognizing vibrancy and liveliness. It is bigger than one's actual age.

<sup>157</sup> Hewett, "At The Crossroads," n.p.

<sup>158</sup> Idem.

<sup>159</sup> Idem.

disability and trauma into a homogenous thing that means the same to us always and everywhere.<sup>160</sup> We must look to refocus on the body as a link between categories like disability and trauma, on the larger social forces that produce trauma and damage people, and on how they continue to shape the traumatized body or the disabled body, how it is read and what it can do.<sup>161</sup> Voicing bodily experiences reveals an essential ingredient to our testimonies.<sup>162</sup> It is the dilemma of being one's own individual and also the wish to be connected to a lover, or a society.

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Evoking the past memories of which the body is a reminder also offers possible pleasures: the body as a site of desire and its perpetually unquenchable nature. However, in the present desire it remains unquenchable because of its 'profoundly' compromised strength and tactile perception. To go back to the words in Ali Smith's novel *Artful*:

*"You can't step into the same story twice, or maybe it's that stories, books, art can't step into the same person twice, maybe it's that they allow our mutability, are ready for us at all times, and maybe it's the adaptability, regardless of time, that makes them art, because real art will hold us at all our different ages like it held all the people before us and will hold all the people after us, in an elasticity and with a generosity that allow for all of our comings and goings. Because come then go we will and in that order."*<sup>163</sup>

Whether it is a body, an art piece, a story, or a letter that is constructed around the stories of our lives, once heard they are put into existence and every next confrontation with them will be different. They are correlated in the sense that our first encounter with them is everlasting and all following meetings with them will always be different. Their often-attributed invisibility and hypervisibility offer the gazer an inter-subjectively oriented awareness of the body.<sup>164</sup>

Take my body for example: it had to be broken, and with it also my mind, to create new rhythms, new patterns of thinking, cubist brush strokes of feeling and moving through the world. It insists that I listen to it so closely, so attentively, in a culture that tells me to divide the two and push my body away from myself while also pushing it beyond its limits. A way of thinking about a disabled identity is to listen to the broken languages of our bodies, translating them, honoring their words<sup>165</sup>

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<sup>160</sup> Borg, "Narrating Disability, Trauma and Pain," 171.

<sup>161</sup> Ionesco and Callus: "Encounters between Disability Studies and Critical Trauma Studies," 23.

<sup>162</sup> Hewett, "At The Crossroads," n.p.

<sup>163</sup> Smith, *Artful*, 31-32.

<sup>164</sup> Greenberg, "Stories Our Bodies Tell," 10.

<sup>165</sup> Greenberg, "Stories Our Bodies Tell," 10. (quoting Samuels)

The way a kaleidoscope works to allow fragmentary or disconnected things to become their own harmony.<sup>166</sup>

We see the ways in which constructions of gender and sexuality also depend on our ability, or able-bodiedness, and youth.<sup>167</sup> From the emptiness of our bones and the breath in our blood we learn how to trust our bodies again, to trust our words again, knowing them better than ever before. Ideas like this are closely related to what Audre Lorde articulates in the power of the erotic: the erotic as a source of power and information within lives.<sup>168</sup>

As for women and as for disabled people, we have come to distrust the power that rises from our deepest and non-rational knowledge, just like Audre Lorde. We are taught to be ashamed and scared of our own anomalous bodies and the pain and trauma that comes with them. We have been warned against it all our lives.<sup>169</sup> The value of this depth of feeling is kept disabled in service of the able-bodied. The erotic is a measure in the beginnings of our sense of self, and the chaos of our strongest feelings. It is an eternal sense of satisfaction to which, once we have experienced it, we can strive to aspire.<sup>170</sup> Aspire to go beyond the encouraged excellence and to go beyond the encouraged mediocrity of society.<sup>171</sup> There is so much more to what has been written on our disabled bodies. The fear that we cannot grow beyond whatever distortions we may find within ourselves keeps us docile, loyal and obedient, externally defined and leads us to accept many facets of our oppression as disabled.<sup>172</sup> To share the power of each other's feelings is different from using one another's feelings as we would use a Kleenex. When we look the other way from our experience, erotic or otherwise, we share feelings with the others who participate in the experience with us. And use without consent of the used is abuse.<sup>173</sup> We, disabled people, used to being subjected to the medical complex, know very well how that feels. And out of all the scars we carry, sometimes those are the worst.

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Trauma has the possibility of destruction, which may offer in itself a new start. There may be new stories to write when medical rehabilitation is completed and our bodies no longer need to be touched by medical speak. Bodily memories of medicalization offer the chance of rewritten memories of intimacy and care, like grief offers the opportunity to connection. If that new touch is provided by people we love deeply, the double meaning of 'to be touched by someone' emerges. The unwanted touch, however, is almost always characterized by simultaneous looking away, a pretense of calling

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<sup>166</sup> Smith, *Artful*, 186.

<sup>167</sup> Hewett, "At The Crossroads," n.p.

<sup>168</sup> Hewett, "At The Crossroads," n.p.

<sup>169</sup> Audre Lorde, *Your Silence Will Not Protect You* (Madrid: Silver Press, 2017), 88.

<sup>170</sup> Idem.

<sup>171</sup> Idem.

<sup>172</sup> Lorde, *Your Silence Will Not Protect You*, 90.

<sup>173</sup> Idem.

them something else, whether a religion, a fit, mob violence, or even playing doctor.<sup>174</sup> It is a comfort to be met confidently, deeply, firmly, gently and responsibly. Mindful touch and movement grounds people and allows them to discover tensions that they may have held for so long they were no longer aware of it. We spend enormous amounts of energy on holding back tears, any sound or movement that might betray our inner state.<sup>175</sup>

The shattering of our language that coincides with the shattering of our bodies also offers us the possibility to connect the broken pieces in the aftermath of dissolution.<sup>176</sup> The anomalous body doesn't always have to be a tempting spectacle of the medical complex, or wrongly addressed sexual appeal. It doesn't have to find itself categorized as an oddity by others.<sup>177</sup> Intimacy has no place in a relationship that is based on fetishization.<sup>178</sup> Touch, cultivated in the context of disability, is the knowledge of what it is to be touched in different ways. Trauma and intimacy become intertwined with the joys and labors involved in the creation of a new home, co-existing with the bitter disappointment of loss.<sup>179</sup> The house we don't want to enter is the possible fundament of a more caring and loving home, built on new ideas of intimacy. They mean more than pain only. In the diverse assortment of attributes that scars offer, we can perhaps discern a complete understanding of the shifting nature of physicality, one that challenges simplified concepts of disability and trauma and even the body itself.<sup>180</sup>

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Those re-written scars are not only shallow places of celebration, nor are they solely signs of negativity and loss, reminders of victimhood. These scars shimmer in different lights, marking time on bodies as the scars speak of the magic of making a connection, whatever the cost.<sup>181</sup> The children's night light of the universe I often fantasize about might not be a night light that is helping me through the anxiety of anticipated nightmares. It is more like the veil of the blackest black possible that is my bereaved head. But that veil has holes for beams of bright golden light, turning it into a bedroom pillow castle with the most beautiful, intimate patterns, a new sanctuary. That new home, in mind and body, becomes beautifully imperfect, contingent, and full of erotic moments, questioning the idea that only dependence and self-sufficiency can signify beauty. Every body's awkwardness becomes an opportunity for new intimacy and eroticism.<sup>182</sup>

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<sup>174</sup> Lorde, *Your Silence Will Not Protect You*, 90.

<sup>175</sup> Van Der Kolk, *The Body Keeps the Score*, 216.

<sup>176</sup> Kurt Borg, "Narrating Disability, Trauma and Pain," 170.

<sup>177</sup> Hewett, "At The Crossroads," n.p.

<sup>178</sup> Idem.

<sup>179</sup> Karen Hammer, "A Scar is More than a Wound," 171.

<sup>180</sup> Hewett, "At The Crossroads," n.p.

<sup>181</sup> Koppers, "Scars in disability culture poetry," 148.

<sup>182</sup> Karen Hammer, "A Scar is More than a Wound," 172.

Our body, our beauty as we know it, our bodies as we have known it, at one point scarred, become a different experience of intense pleasure and ecstasy.<sup>183</sup> They mimic the abrupt and searing pain of loss, not only in our disabilities but also in our youth, and show our vibrancy, liveliness and resilience. A place where love might be invented beyond the roles of gender, race, sexual orientation and ability, leaving behind inherited and failed mimicries of intimacy.<sup>184</sup>

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The death of somebody I loved deeply is written on my body and will never fade away. The new narrative I have written about my scars, or should I say our scars, changed my view of my own history of violence, connected and multiplied. My scars have expanded from my own to the scars of my partner. In other words, I do not only carry my own scars anymore, but from the day of my partner's death I also started carrying the scars of my lost partner.

We both experienced our bodies as medicalized anomalies, constantly having the sense that our bodies and minds are inadequate and in need of intervention. However, it is within and not despite the medical narratives that our love for each other formed, broken and sutured in a pattern that deviates from the normative reflecting contingency and interdependence at the heart of rationality.<sup>185</sup> It is within our medical dependency that we found each other on a level no un-scarred person could understand. It is a surgeon sewing intimacy, stitching with collateral damage, creating possibilities of exceptional and extraordinary love. There is a healing acceptance that ironically recalled a medical intervention.<sup>186</sup> Almost as though it was the surgeon's sadist intention.

That is what we could have had, a lifetime of remarkable, uncommon bodies dancing, crooked legs tapping a choreography of loving heart rhythms. With my partner I found a sanctuary and with its loss I was left orphaned again. The only remainder of it is the loving house built by grief in my brain and the knowledge of the potential that it might happen again. I will no longer accept powerlessness, or those other supplied states of being, which are not native to me, such as resignation, despair, self-effacement, depression and self-denial.<sup>187</sup> I will no longer accept impairment in grief. Recognizing the power of the erotic within all our lives can give us the energy to pursue genuine change within our world, rather than merely settling for a group of characters in the same weary drama. For not only do we touch our most profoundly creative source, but we do so with ability and self-affirmation in the face of an ableist patriarchal and fetishizing society.<sup>188</sup> I am scarred but maybe no longer scared.

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<sup>183</sup> Hewett, "At The Crossroads," n.p.

<sup>184</sup> Karen Hammer, "A Scar is More than a Wound," 160.

<sup>185</sup> Karen Hammer, "A Scar is More than a Wound," 167-168.

<sup>186</sup> Karen Hammer, "A Scar is More than a Wound," 167-168.

<sup>187</sup> Lorde, *Your Silence Will Not Protect You*, 90.

<sup>188</sup> Idem.

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The person that I loved had crawled underneath my skin in a way that I thought would never be possible. My partner's death left me ripped apart. The pain of disconnection that was already written on my leg by the metal rods turned into a new puncture wound, a new memory of deep love. I carry my partner under my skin. It shows how firmly close I hold and mourn the death of my partner every single day. I do so with my whole body, for it is the same grief of my own disability. There is not even a need for scientific evidence of a parallel universe to prove that maybe my partner is still alive somewhere and I'm the one who died. Death left behind a distorted relief because for all I know, my partner's touch tore open my skin and the most treasured warmth got underneath it.

## Conclusion

The effort in writing these essays was immense. It takes a traumatic experience to bring people together and it takes an ocean of tears to pin it down on paper.

The three essays, written as the corpus of this thesis, show the difficulty of portraying the full experience of living with a disability. The first essay makes use of a story of a wild boar to explore how humankind has found different strategies in visualizing bereavement. It then considers and explores the possible negative implications of these strategies for those who experience loss, within a context of disability as well as losing a loved one, mapping their analogies. The second essay is an imaginary encounter about what it means to have an invisible disability, opening a conversation about 'coming out', finding companions and the value of disability in understanding pain, relationships and intimacy. The third essay covers the subject of scars and what their importance is to ideas of community, intimacy and their experienced fluidity. All essays are autoethnographic, allowing inductive and poetic language to underscore the emotionally and bodily lived experiences of these themes.

It shows the lack and limitation of specific domains such as critical disability studies and critical trauma studies, as long as they continue to work as singular and well-defined fields of research. The daily lives of people with disabilities, often heavily inflicted by motifs of pain, trauma and loss, are strongly underestimated within their power and possibilities. Often themes like this are not well researched because of a lack of information and testimonies and a continued ableist-gaze, functioning even within the field of critical disability studies. As such, the potential knowledge people with disabilities have in relation to subjects and struggles connected to the overall human condition is neglected and unseen.

This thesis is an example of a need for carefulness in choosing labels of performed identity, like for example the terminology *super crip*. Critical disability scholars and members of the disability community have adapted the term *super crip* in reference to individuals with disabilities that have accomplished tremendous feats or have achieved extreme advancements in their professions. The concept of a *super crip* reflects societal tendencies to praise such heroic acts and can lead to the expectation that all individuals with disabilities should overcome their abilities. It warrants pointing out that the narrative of the *hero* is not meant to reinforce a stereotype of the *super crip* but instead reflects a chosen narrative as an act of agency.<sup>189</sup> These essays show how the problematic but often used approach in the representation of people with disabilities is harmful for people with disabilities themselves. In portraying people with disabilities as 'heroic', their pain and struggles are often generalized, or even worse, ignored. The portrayal and expectation that one has to 'overcome' something is toxic and ableist in the sense that it ignores the pain that comes with a disabled identity.

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<sup>189</sup> McAdams Ducey et al., "Choosing Agency in the Midst of Vulnerability," 316.

There is an existing potential to connect disability with the loss of a loved one. This can be seen in semantic analogies, as well as similarities in coping and grieving with both subjects. The conclusion to this is that grief, as a general concept, counts for a lot more than just the loss of a partner, but can also cover feelings of sadness concerning the loss of bodily abilities. The prevailing literature has lost sight of the fact that disability constitutes a loss that is analogously equivalent to the loss of a loved one, precisely because losing one's body is to lose an intimate companion.<sup>190</sup> This can be put the other way around: disability studies can offer a new perspective on the experiences of the loss of a loved one, with or without an interpersonally shared disability-narrative. In exploring this explicit overlap, a critique can be made towards trauma studies, as well as towards disability studies. The stories that are told show how specific expectations and imposed normativity is harmful to the healing and/or grieving process of a person, with or without disability. The overwhelming influence of the medical complex as a categorization tool and point of guidance is very closely intertwined with the problematic experiences of people with disabilities.

The methodology of an autoethnography as a form of self-narrative places the self within a social context.<sup>191</sup> Instead of reading a thesis conventionally from the point of view of content and subject matter, one reads it in terms of language plurality, comparing the diverse speeches, retrieving them authentically. The play effected between literal and non-literal languages can be infinite and the two should not be mutually exclusive of each other.<sup>192</sup> As a conclusion of this thesis, a concept can be used that Minh-ha addresses as 'speaking nearby'. It is an aspect of indirect language, in other words, a speaking that does not objectify, does not point to an object as if it is distant from the speaking subject or absent from the speaking place. A speaking, or in this case writing, that reflects on itself and can come very close to a subject without seizing or claiming it. A briefly speaking, whose closures are only moments of transition opening up to other possible moments of transitions, within poetic language.<sup>193</sup>

Finally, I quote Minh-ha one last time as she gives a remark on a famous quote by philosopher Walter Benjamin namely 'Nothing is poorer than a truth expressed as it was thought':

*"Truth can only be approached indirectly if one does not want to lose it and find oneself hanging on to a dead, empty skin. A body needs to be alive and inhabited."*<sup>194</sup>

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<sup>190</sup> Clifton, "Grieving My Broken Body," n.p.

<sup>191</sup> Greenberg, "Stories Our Bodies Tell," 5.

<sup>192</sup> N. Chen, "Speaking Nearby," 87.

<sup>193</sup> Idem.

<sup>194</sup> Idem.

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